

# DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE



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## Maree Todd

Minister for Social Care, Mental Wellbeing and Sport discusses the new 10-year Scottish national dementia strategy



### Alistair Burns

National Clinical Director for Dementia and Older People's Mental Health for NHS England talks about new intercultural dementia care resource



### Florence Lassarade

discusses her role as Senator and rapporteur for the French Parliamentary Offices on the management of neurodegenerative diseases



### Chris Roberts

Chair of the European Working Group of People with Dementia speaks at the 5<sup>th</sup> European Parliament of Persons with Disabilities

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# Welcome



Maria do Rosário Zincke dos Reis, Chairperson, Portugal

I am delighted to welcome you to the 43<sup>rd</sup> edition of our Dementia in Europe magazine, coinciding with the 33<sup>rd</sup> Alzheimer Europe Conference (33AEC) in Helsinki, Finland. This is a busy edition of the magazine and we are excited to share a number of interesting developments at an international, European and national level across policy, research and culture.

To open the Alzheimer Europe section, we revisit the most recent European Parliament lunch debate which focused on environmental risk factors for dementia. I would like to thank Milan Brglez MEP (Slovenia), member of the European Alzheimer’s Alliance, for hosting this most interesting session. Turning to European projects in which Alzheimer Europe is involved, we are pleased to be able to introduce the Multi-Memo project (which aligns experimental molecular, cellular, and animal modelling to human multimodal trials) and the PROMINENT project (focused on precision medicine for the diagnosis of neurodegenerative conditions). We also hear from researchers involved in the RECOGNISED and LETHE projects, on the progress of their respective work on innovative eye tests to identify people with diabetes who may be at risk of dementia, and on early detection and reduction of risk factors for dementia. To conclude this section, the project leaders from PRODEMOS reflect on their work to develop a mobile health application, as the project draws to a close.

Opening the Policy Watch section, we were delighted to speak to Maree Todd, Minister for Social Care, Mental Wellbeing and Sport, on Scotland’s new national dementia strategy; we also hear from Alzheimer Scotland on their views on the strategy. We are pleased to share an article from French Senator, Florence Lassarade, about her authorship of a paper on dementia interventions. Alzheimer Europe was also delighted to speak to Áine Flynn, head of the Decision Support Service, about Ireland’s recent reform of its capacity laws.

Moving to the European level, we then hear from the European Commission on new legislative proposals in relation to cross-border arrangement for adults in need of support, as well as marking what has happened in the two years since the publication of the European Strategy on the Rights of Persons with Disabilities. We then turn to the European Parliament of Persons with Disabilities which took place in May 2023, at which the Chair of the European Working Group of People with Dementia (EWGPWD), Chris Roberts spoke. Addressing international matters, we hear how the World Health Organization (WHO) has supported the development of a network of professionals working on the iSupport resource for dementia carers. Bringing this section to a close, we provide an update on the most recent meeting of the European Group of Governmental Experts on Dementia.

We start our Dementia in Society section by hearing from members of the EWGPWD and European Dementia Carers Working Group (EDCWG) on the importance of involving people with lived experience in advocacy, campaigning, Public Involvement and awareness-raising activities. NHS England then discusses the work they did with our organisation to publish a resource on intercultural dementia care. Continuing on this theme, our next article explores some of the challenges encountered when trying to manage dementia in “dual-heritage” families and couples.

As part of our ongoing work in relation to LGBTQ+ people affected by dementia, we

have two articles focused on this topic. In the first, a carer from the EDCWG shares his experiences supporting his husband, whilst we highlight some of the recommendations from our ethics report on sex, gender and sexuality. We then hear from playwright Jennifer Lunn about her play “Es and Flo”, which explores some of the difficulties experienced by an older lesbian couple when one of them develops dementia. Moving from the stage to the screen, we hear about the Dutch television show “Restaurant Misverstand” and how it has helped build a more inclusive society. Finally, we hear from the authors of a new book “FAQs on Dementia” about how the book came about and how it aims to answer the most common questions readers may have about dementia.

To mark 33AEC, we have a dedicated section, Spotlight on Finland, to learn more about the work being done in the host country. Representatives from the Ministry of Health give us an overview of some of the work that has taken place to date and the priorities of the newly-elected government. Following this, Muistiliitto (Alzheimer Society of Finland) CEO, Katariina Suomu, talks about the importance of moving towards a “memory-friendly” Finland. We then hear from Mauri Laine, who highlights how being open about dementia can help to dispel fear about the condition and in our final article, we hear from researchers from the University of Eastern Finland on their innovative Neuroscience Research Community and some of the key projects underway in the country.

For those joining us in Helsinki for 33AEC, I look forward to meeting many of you and wish you an interesting and enjoyable conference.

I hope you enjoy this edition of the magazine!

*Maria do Rosário Zincke dos Reis*

# Alzheimer Europe hosts lunch debate on “The role of modifiable risk factors for the prevention of dementia”

Alzheimer Europe welcomed attendees to its Lunch Debate on 6 June 2022 in Brussels, Belgium. The session explored the relationship between modifiable risk factors and dementia, with stakeholders representing national member organisations, national ministries, industry partners, policy makers and the European Working Group of People with Dementia (EWGPWD) in attendance.



Milan Brglez MEP (Slovenia)

A total of 85 people attended the lunch debate in person, with a further 148 joining on line. Milan Brglez MEP (Slovenia), a member of the European Alzheimer’s Alliance (EAA) hosted the session and opened by highlighting the importance of modifiable risk factors and primary prevention in relation to dementia – especially in light of the lack of a cure or disease-modifying treatment.

He further noted that as research reveals more about the underlying diseases which cause dementia, the associated risk factors become better understood and have demonstrated that in conditions such as Alzheimer’s disease (AD), physical changes occur in the brain many years before symptoms manifest – interventions therefore need to be targeted at this stage of the condition. Modifiable risk factors cover a number of key social determinants throughout the life course and are often not specific only to dementia, therefore there is a need for greater focus to be placed on primary prevention, identifying how we can minimise risk factors and decrease the risk of developing dementia.

Mr Brglez spoke of the role of decision makers and elected members at a European level, outlining the importance of their role in providing funding for research and interventions through programmes such as Horizon Europe and EU4Health, and support for initiatives to

raise awareness amongst the public about risk factors and adopting a brain health approach across the life course.

## The Lancet Commissions on Dementia

Gill Livingston, Professor of Psychiatry of Older People, University College London, presented on risk factors for dementia, based on the two Lancet Commissions on dementia, noting that a third Commission was under development. Her presentation focused on



Gill Livingston

why dementia can be considered as preventable, what some of the key risk factors are and what should be done in response.

Setting out the context, it was noted that there has been an overall increase in the number of people living with dementia, whilst at the same time there has been a decrease of 20% in the incidence, though in some countries it remains stable or is increasing. Improvements have mostly been in high-income countries and amongst men. Key mechanisms related to this are thought to be cognitive reserve and the ability to tolerate brain changes without developing dementia.

It was noted that there is sufficient evidence to identify 12 risk factors for dementia: less education, peripheral hearing loss, hypertension, obesity, traumatic brain injury, excessive alcohol, smoking, depression, physical inactivity, air pollution, social isolation and diabetes. These risk factors account for 40% of current risk factors (as a population attributable fraction), with the largest single risk factor being hearing loss (8%), followed by lower education (7%) and smoking (5%).

Changing risk factors changes the outcome for developing dementia. It is especially important to target those at risk as trials have tended to take people at lower risk (i.e. those with higher education, higher income).



Based on a follow-up study involving health economists, if interventions in midlife for hearing aids, hypertension and smoking cessation were undertaken in England, it is estimated there would be an 8.5% reduction in prevalence and GBP 1.8 billion saved per year. However, early interventions for diabetes were not cost-effective in relation to dementia prevention alone.

The Lancet Commission's research has been used in the USA and in 2021 a goal was added for the reduction of 10 potential risk factors, with policies developed aiming to reduce prevalence by 15% per decade. The presentation was concluded by calling for stakeholders to be ambitious in prevention, noting that the development of new treatments did not remove the need for prevention and that tackling risk factors provided more years of healthy life and could prevent dementia from occurring, as well as saving money.

### Environmental risk factors for dementia

Tom Russ, Consultant Psychiatrist & Honorary Clinical Reader, University of Edinburgh, presented on environmental risk factors for dementia, covering what causes dementia, why studying environmental factors is important and which matter the most.

Referring to the Lancet Commission, it was noted that in 2020, air pollution was added as a risk factor. The strength of the resource for distinguishing between potentially modifiable factors and unknown risk was highlighted, as was its adoption of a life-course approach, explaining the different risk factors at different stages of life.

He cited a paper which examined Bonavista Bay, Newfoundland, Canada, which showed a north/south divide (based on place of birth) in the number of people who died from dementia, with many more people developing the condition in the north. Additionally, he referred to his own study which examined the north/south divide in Sweden, using data from the twin study, which examined people over 65 who had developed dementia, also showing significantly more people in the north had developed dementia. It was noted that this pattern has been identified in many countries.



Tom Russ

There is a limitation to reviewing scientific literature for risk factors, as there may be risk factors which have not yet been studied. From his review of the existing evidence, some of the key environmental risk factors include: rural living, air pollution, metals (aluminium, fluoride and silicon), vitamin D levels, pesticides and electromagnetic fields. In relation to policy development, it is crucial to bear in mind that some of these risk factors relate to personal choice, whilst others are outwith the control of individuals.

Examining differences between high (HIC) and low & middle income (LMIC) countries, it appears that there is greater risk for developing dementia for those in rural areas in LMICs. For air pollution, there is a useful article "The polluted brain" published in 2017 which explains how pollution affects the brain. The air pollution policy landscape is extremely complicated, however, its potential impact for health policy (not only dementia) is considerable.

In relation to water, using data from Scotland, higher levels of aluminium and fluoride, even in safe levels, are associated with a higher risk of dementia. Additionally, there appears to be an association with lower levels of vitamin D and higher risk of dementia.

### The ADAIR project

Katja Kanninen, Professor, Faculty of Health Sciences, A.I. Virtanen Institute for Molecular Sciences, University of Eastern Finland, introduced the ADAIR (Alzheimer's Disease Air Pollution) project and some of its preliminary findings. The project involves eight countries across Europe and multidisciplinary researchers, aiming to:

1. Identify biomarkers of air pollution
2. Correlate exposure biomarkers to AD risk
3. Assess air pollution exposure-induced health impacts on the molecular and cellular level.

The context of air pollution and adverse health was set out, including World Health Organization (WHO) figures which suggest that 90% of people breathe polluted air, with air pollution linked to 6.7 million premature deaths. It was noted that policies to reduce air pollution offer benefits for both the climate and health. However, cellular and molecular processes altered by air pollution are not well understood, nor is the link to dementia.

Through controlled acute exposure to air pollution, the project was able to identify significant changes to blood plasma, specifically immune cells strongly reacting and, amongst other things, increasing biological processes relating to inflammation.



Katja Kanninen

In relation to long-term exposure, a longer-term study of over 18,000 individuals aged over 40, showed that exposure to air pollution was associated with several metabolites in the blood, including sphinganine which is associated with inflammation and immunity, which may increase the risk of AD.

An impaired sense of smell is known to be an early sign of AD and as part of the research, olfactory mucosa samples (tissue from the top of the rooftop of the nasal cavity which is in direct contact with the brain) were collected and analysed. This tissue is already altered in individuals with AD and additionally, in persons with AD, shows a stronger response when exposed to air pollution.

Concluding, it was highlighted that the project has identified new air pollutant exposure biomarkers in both acute and long-term exposure to air pollution. These are useful in identifying individuals who have been exposed to air pollutants and work is ongoing to understand how these relate to AD.

### Flemish public health campaigns

Jan Steyaert, Scientific Officer of the Flemish Centre of Expertise on Dementia, presented on how to turn research recommendations into practical awareness campaigns and policy actions, based on some of the work taking place in Flanders. The prevalence of dementia in Flanders is approximately 125,000 and is expected to rise to 190,000 by 2040. In Flanders, as elsewhere, there is a demographic challenge. By 2040, the labour market will rise by approximately 3%, whilst the pension population will increase by 25%. In Wallonia, there will be a 3% decrease and 35% increase respectively.

Focusing on prevention is important as there is a potential to lower the number of people with dementia, including the reduced costs in healthcare, as well as the reduction of the number of informal carers. Additionally, as the availability of medicines is still a number of years away, coupled with the ageing demographics, the need to act based on the Lancet Commission findings is evident.



Jan Steyaert

However, there is a low awareness amongst the public of modifiable risk factors and there is a need to translate the findings of such research to a public campaign. There have been two such awareness raising campaigns in recent years in Flanders.

In September 2018, “SaniMemorix” was launched and was also available in Germany, the Netherlands and Norway, which made vaccine boxes, 50,000 of which were distributed, as well as information and resources to pharmacies, plus information for professional bodies about how to talk to people about dementia. This campaign increased awareness about modifiable risk factors from 35% to 44% amongst 40 to 75 year olds.

A second campaign was launched called “Two for the price of one” (2 voor de prijs van 1), which focused on what is good for your heart also being good for your head. Resources and materials included postcards, paper bags distributed to pharmacies and apples with the message printed on them. All of this is open access and people are invited to contact the Expert Centre if they wish to use them.

Key lessons learned during the campaign was not to blame the victim, as there are many environmental factors outwith the person’s control. Additionally, choices people make are social and not necessarily individual. Furthermore, Alzheimer’s organisations need to build relationships with public health

organisations. Reaching out to the public is clearly important but so is reaching and engaging with intermediaries including the press, general practitioners (GPs) and neurologists. Finally, it is essential to reach out to high risk groups, such as people with low education, people with migration backgrounds etc., to work with GPs and health insurance companies.

### Questions and answers

Alzheimer Europe Board Member, Mary Frances Morris, asked about the mechanism in the brain behind hearing loss and dementia, citing her own experience caring for her father. Prof. Livingston explained that the mechanism is complicated, noting that people with uncorrected hearing loss experience atrophy of the temporal lobe of the brain, however, one of the main mechanisms relate to the lack of cognitive stimulation, as well as the social isolation which often comes about as a result of hearing loss. Additionally, where you have to expend energy and focus on listening, it then leaves less capacity for engaging and responding to dementia.

An online question was asked, in relation to the difference in male *versus* female risk factors for developing dementia. Prof. Livingston noted that women were more likely than men to develop dementia, however, that this was not true in some sub populations (e.g. in higher education or higher income



groups). Whilst some think it is related to the menopause, people who take hormone replacement therapy are just as likely or more likely to develop dementia, therefore it is not likely correlated, with socioeconomic status much more likely to explain the differences.

Alzheimer Europe Executive Director, Jean Georges, thanked all the speakers for their excellent presentations and the evidence provided for preventing dementia to be prioritised by decision makers at a European level. He asked Milan Brglez MEP, how to prioritise dementia, given that it was not given significant attention within European Commission work programmes. Mr Brglez noted that this was not an easy question and highlighted that dementia had been included in the Parliament's position on the European Care Strategy (for which he was a co-rapporteur, with Sirpa Pietikäinen MEP). He noted that when committees produce an own initiative report, it is necessary to engage early in the process. He also noted the importance of engaging with candidates who were standing for re-election and to use the opportunity to ask candidates to give their support. Additionally, he noted that the newly-formed sub-committee on health would be a useful place for the issue to be raised, especially as dementia is an issue which is cross party.

Štefanija Zlobec, President of Spomincica – Alzheimer Slovenia added that the run up to the European Parliament elections in 2024 was an important opportunity for associations to raise awareness, engage with the media and to work to prioritise dementia.

Chris Roberts, Chair of the EWGPWD, noted the disparities in access to medicines and support across European countries, noting that dementia is used as an umbrella term for more than 200 different distinct conditions. He suggested that potentially there would be greater access to services and supports if the specific kinds of dementia were identified and talked about, instead of using “dementia”.

### Closing remarks

Alzheimer Europe Vice-Chair, Charles Scerri, thanked the four speakers for their presentations, noting that the presentations clearly set out the science and knowledge of these

risk factors, as well as examples of how these messages can translate into public messages to promote prevention.

He further highlighted that it is up to governments and our organisations to clearly articulate this message to the public and to shift the paradigm of prevention to younger populations. This brain health approach across the life course must become an integral part of our work.

### Presentation to Helen Rochford-Brennan

A presentation was made, marking Helen Rochford-Brennan's time as a member of the EWGPWD (from 2014-2022), including serving as its Vice-Chair from 2014-2016 and Chair from 2016-2022.

Charles noted that Helen had been an active and passionate campaigner both in her home country and at a European level for many years highlighting her tireless work over the years, sharing her personal experience of living with dementia, her professional experience and her many talents for the benefit of Alzheimer Europe, the EWGPWD and numerous researchers and policy makers. He noted that anyone who has had the privilege of working with her would attest to her insight and thoughtful contributions, which has unquestionably strengthened Alzheimer Europe's work.

Helen gave a short speech recounting her time as part of the EWGPWD, noting that it had been an honour and a privilege to be part of the group, and highlighting some of the key research projects in which she had been able to participate. She also spoke of her immense pride in being able to discuss and raise the issue of human rights during her time with the group, including delivering speeches in the European Parliament.

She also spoke of the early meetings of the EWGPWD and her friendship with Agnes Houston, Helga Rohra and Hillary Doxford. She extended thanks to the Alzheimer Europe team for their help and support, as well as the board for their ongoing support and for fostering an inclusive environment, allowing her to thrive. She also thanked the European Parliament and Commission for their support,



*Charles Scerri and Helen Rochford-Brennan*

as well of that of the sponsors, which make Alzheimer Europe's work possible. In particular, Helen acknowledged the support of EAA member Deirdre Clune MEP (Ireland) who has long supported making dementia a priority. Finally, she thanked the Alzheimer Society of Ireland for nominating her and providing the support to allow her to take part in the group.

She concluded by describing her time with the EWGPWD as one of the most enriching of her life and reflected on the progress that had been made and the knowledge that had been shared. She paid tribute to past members of the group, including those who are no longer with us, and their invaluable contributions. She stated that the best way to honour their legacy was by continuing to strive for advancement in dementia research, care and support.

Her final thanks were to her supporter Carmel Geoghegan. She praised her dedication and compassion despite her own challenges and noted how it had been greatly appreciated by her, her late husband Sean and her son Martin.

The videos of the presentations from the lunch debate can be watched here: <https://www.youtube.com/playlist?list=PLO-PgQH1iWOUx6AhLko7ffp4OSBkXzO>

## Snapshots from the lunch debate





# Alzheimer Europe partners in two new EU-funded research projects

Alzheimer Europe is pleased to partner in two new projects. In this article, we present a brief overview of PROMINENT (IHI funded) and Multi-MeMo (JPND funded). The perspective of each project's coordinator is presented, regarding the rationale behind the projects and the concrete actions being undertaken.

## Multi-MeMo

Multi-MeMo stands for “Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia”. The European project officially started in May 2023 and has a duration of three years. The project has a budget of 1.6 million from the EU Joint Programme – Neurodegenerative Disease Research (JPND), distributed across a total of six partners: University of Eastern Finland (Finland), Saarland University (Germany), VU University Medical Center (Netherlands), IIS Institute Hospital del Mar d’Investigacions Mèdiques, Clinical (Spain), Slovak Academy of Sciences, Institute of Neuroimmunology (Slovakia) and Alzheimer Europe (Luxembourg). In this project, Alzheimer Europe co-leads the work packages dedicated to Public Involvement and communication/dissemination.

## Interview with Project Coordinator Alina Solomon, University of Eastern Finland

### What is the problem you are aiming to address with Multi-MeMo?

The main scope of the Multi-MeMo project is to identify better and more effective ways to prevent and/or delay the development of Alzheimer’s disease (AD) and related dementia. These are complex conditions, where multiple risk factors and related biological mechanisms likely play a synergistic role to the development of the disease and the onset of clinical symptoms. Additionally, different combinations of risk factors and biological mechanisms may affect different people in different ways, depending, for example, on their specific lifestyle, health status, and

genetic characteristics. As a consequence, it is unlikely that one prevention strategy can work for all people (a concept known as “one size does not fit all”). Instead, preventive interventions that are tailored to the specific characteristics of individual persons or specific at-risk groups (based, for example, on age, health status, disease stage), and that target multiple factors at the same time (that is, multimodal interventions) should have the highest chance of success.

Multi-MeMo aims to improve our knowledge of the different biological mechanisms that may play a role in the development of AD and the onset of dementia, the way these may interact with each other, and how they affect people’s overall AD/dementia risk. We then aim to use this knowledge to identify the most effective preventive interventions for different types of people based on their specific AD/dementia risk profile.

### What are the objectives and actions taken when implementing the Multi-MeMo project?

Multi-MeMo focuses on studying more in-depth lifestyle-based multimodal interventions that were already successfully tested in clinical trials in at-risk older adults. To this purpose we will combine the study of molecular, cellular, and animal models with investigations in humans.

For example, to investigate intervention mechanisms that cannot be clarified from human trials alone, we will use three different rodent models of neurodegeneration to test multimodal preventive interventions mirroring those tested in human trials.

Once we have identified promising biological mechanisms, we will investigate how they apply to humans. To do so, we will use data from previous or ongoing clinical trials conducted by members of the Multi-MeMo consortium. Data from these trials will be also used to identify the individual characteristics that can predict most accurately the at-risk groups that will benefit the most from different intervention.

Also, it is now clear that research related to AD and dementia cannot progress effectively and its findings be optimally implemented without involving all the stakeholders and including their experiences. For that reason, one of the most important activities of the Multi-MeMo project will be the so called “Public and Patient Involvement”. As part of this activity, we will form an Advisory Board, constituted of lay people who are, for example, people with AD/dementia, carers, older people at risk, which will regularly meet to collect opinions and feedback on specific topics relevant to the project.

Based on the results of this project, we aim to develop an improved multimodal intervention model compatible for combining lifestyle and pharmacological interventions that could enhance each other’s effects. Ultimately, this is expected to lead to timely, personalised interventions to effectively prevent or delay dementia onset.



Alina Solomon

### Acknowledgement

Multi-MeMo is an EU Joint Programme – Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - [www.jpnd.eu](http://www.jpnd.eu): Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Luxembourg, National Research Fund; Netherlands, The Netherlands Organisation for Health Research and Development; Slovakia, Ministry of Education, Science, Research and Sport of the Slovak Republic; Spain, National Institute of Health Carlos III.



## PROMINENT

PROMINENT, a collaborative pan-European public-private partnership funded through the Innovative Health Initiative (IHI) for a duration of five years, aims to establish a digital platform for precision medicine, significantly enhancing the diagnosis and treatment of neurodegenerative diseases and their co-morbidities.

The PROMINENT consortium brings together a diverse range of experts, including renowned professionals in the fields of neurodegenerative diseases, clinical neuroscience, artificial intelligence (AI), health economics, and patient advocacy. Additionally, the consortium includes leading medical centres across Europe that specialise in the diagnosis and treatment of cognitive disorders.

Alzheimer Europe assumes a crucial role in PROMINENT, leading communication, stakeholder engagement, and public involvement activities to ensure widespread awareness and engagement.

Initially, PROMINENT focusses primarily on Alzheimer's disease, encompassing the entire Alzheimer's disease continuum, which currently affects more than 20 million individuals in Europe. Moreover, the prevalence of Alzheimer's disease is projected to double over the next three decades.

In the past, the terms "Alzheimer's disease" and "Alzheimer's dementia" were often used interchangeably. However, contemporary understanding identifies Alzheimer's

dementia as a stage within the broader spectrum of Alzheimer's disease.

It is essential to recognise that Alzheimer's disease initiates years before noticeable symptoms manifest and progresses gradually over time. The advancement from presymptomatic Alzheimer's disease, characterised by abnormal brain changes, to symptomatic Alzheimer's dementia, marked by cognitive and functional impairments, typically occurs slowly and subtly.

It is crucial to acknowledge that the progression along the Alzheimer's disease continuum varies significantly from person to person, making each individual's experience with the disease unique.

### Interview with Project Coordinator Linus Jönsson, Karolinska Institutet

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

Today, the diagnosis of Alzheimer's disease (AD) and other neurodegenerative disorders is often made quite late in the disease, when the disease has already caused irreversible brain damage. In the future we hope that these diseases will be identified early enough to allow new treatments to stop the disease process and to give each patient the most effective treatment for their specific disease, this is sometimes called *precision medicine*. Already today there are several new methods being introduced for diagnosing and treating AD. These however often take a long time to

be implemented in routine care, and there is still important knowledge missing about how these new methods work, and how we should use them. With PROMINENT we are developing tools to help doctors use these new methods for diagnosing and treating neurodegenerative disease, starting with AD with focus on new disease-modifying therapies targeted against a type of protein called amyloid that accumulates in the brain with AD.

#### What are the concrete objectives and actions which will be undertaken in PROMINENT?

Our technology partner in PROMINENT, a company called Combinostics, has developed a decision support system for neurodegenerative disorders that is currently used in several hospitals across Europe and worldwide. The system helps doctors make the



Linus Jönsson



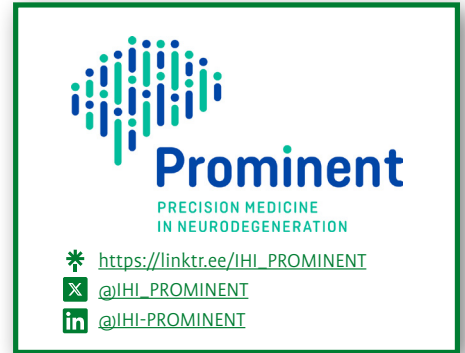
correct diagnosis and makes predictions about how the disease may progress in the future. In PROMINENT we will develop new functions for this system and study how well it works in practice. For example, a new blood test for a protein called phosphorylated Tau is being developed for diagnosis of AD. The system will help doctors decide in which patients to use this test, and how to act on the results. An important application of the system will also be to support doctors using

new disease-modifying therapies for AD. The drug lecanemab was recently fully approved by the FDA for treatment of early AD, and it is right now being evaluated by the European Medicines Agency. If approved, it may become available in Europe as soon as next year. The PROMINENT platform will help doctors determine whether a patient would be eligible for treatment with this drug, and to assess the balance between the potential benefits of the treatment and the risk of side-effects. The

system will also give doctors the opportunity to follow up which effects patients treated with this drug have of the treatment, and for us to learn more about how to best use these new drugs.

**Acknowledgement**

This project is supported by the Innovative Health Initiative Joint Undertaking (JU) under grant agreement No 101112145. The JU receives support from the European Union’s Horizon Europe research and innovation programme and COCIR, EFPIA, EuropaBio MedTech Europe, Vaccines Europe and Combinostics Oy.



*transforming AD to protect what makes people who they are*

## RECOGNISED: the eye as a window to the brain

The RECOGNISED project is using innovative eye tests to identify people with diabetes who may be at risk of dementia. Alzheimer Europe is partnering in RECOGNISED, and spoke to project co-lead Noemi Lois to learn about the project's clinical research studies.

Like dementia, the prevalence of type 2 diabetes is steadily increasing in Europe. A chronic disease which affects around 60 million Europeans, diabetes can lead to serious complications such as blindness and kidney failure. It can also affect the brain, damaging nerves and blood vessels and causing problems with memory and thinking. However, type 2 diabetes can largely be prevented by adopting a healthy diet, doing regular exercise, and losing extra weight if obese.

Research also indicates that diabetes can accelerate the development of dementia in people with mild cognitive impairment (MCI). However, not everyone with type 2 diabetes will go on to develop dementia. To understand why, the RECOGNISED project is drawing on another close connection: the biological link between the brain and the retina of the eye.

The retina is the innermost layer of the eye, responsible for converting the light we perceive into three-dimensional images. The retina is part of the central nervous system, developing from the same neural tissue that forms the brain. In RECOGNISED, researchers are exploiting this connection, studying whether non-invasive eye tests and scans could be used to identify individuals with diabetes who are more likely to develop cognitive impairment or dementia.

RECOGNISED, a four-year project funded through the EU's Horizon 2020 research and innovation programme, was launched in January 2020, involving 21 organisations from 9 countries across Europe. Over the last three years, RECOGNISED researchers have been studying the changes that take place in the retina and brain in people with

type 2 diabetes, to find out whether or not these changes are interlinked. RECOGNISED launched its cross-sectional and longitudinal studies in the midst of the COVID-19 pandemic, in November 2020. Despite the challenges linked to COVID-19 restrictions, the 11 RECOGNISED clinical sites, based in Denmark, Italy, Montenegro, the Netherlands, Northern Ireland, Portugal and Spain, have successfully enrolled over 700 participants in the cross-sectional study, and almost 250 participants in the longitudinal study.

To learn more about the RECOGNISED clinical studies, we spoke to Noemi Lois, Clinical Professor of Ophthalmology at Queen's University in Belfast, Northern Ireland. Noemi is the Deputy Coordinator of RECOGNISED and an expert on diabetic eye diseases and their complications, leading the UK arm of the RECOGNISED clinical studies.

### What are the RECOGNISED cross-sectional and longitudinal studies?

Our two clinical studies are closely connected. We hope they will tell us whether eye tests and scans could be used to identify people with diabetes at highest risk of developing cognitive decline and dementia. In the cross-sectional study, we are evaluating over 700 participants aged over 65 years, with type 2 diabetes, at a single point in time. Assessment of the structure and function of the retina and cognitive performance in these participants will help us understand whether changes in the retina are linked to cognitive impairment and, thus, to what is happening in the brain.

Our longitudinal study has recruited almost 250 participants with or without cognitive impairment from the cross-sectional study.



Noemi Lois

In the longitudinal study, we are following participants for a period of 30 months, with assessments of the eye and the brain every 6 months. In the longitudinal study we are also performing detailed brain scans using MRI (magnetic resonance imaging) and PET (positron emission tomography), which will give us additional information about the structure of the brain. Through these studies, we will know whether the retina looks and works like the brain. Potentially, we may be able to see changes in the retina earlier than those in the brain - allowing us to use these retina changes as a predictor of brain disease later on. In summary, together, the results of the retinal evaluations, cognitive tests and brain scans, will show us if the development of cognitive impairment or dementia in people with type 2 diabetes is connected to changes in the retina.

### What retinal tests are being performed in RECOGNISED and what information do they provide?

RECOGNISED is based on the concept that the neurodegeneration which happens in the brain during the development of dementia is paralleled by neurodegeneration in the retina. In the RECOGNISED clinical studies we are therefore performing a series of tests to check the structure and function of retina.

We take photographs of the back of the eye with a standard fundus camera and also with an ultra-wide field camera that allows us to see almost the entire retina. These images allow us to check the appearance of the retina. We can see the "neural" tissue, which is similar to the "neural" tissue we have in the





brain. We can also see the retinal blood vessels, which are similar to those in the brain. To see the retinal blood vessels more clearly, we do additional eye tests called optical coherence tomography angiography (OCT-A) and ultra-wide field fundus fluorescein angiography (UWF-FFA). OCT-A is a non-invasive eye test that allows us to see the blood vessels in the macula, which is the area of the retina responsible for our central sight. UWF-FFA requires the injection of a small amount of a dye called “fluorescein” in a vein in the arm or hand. The injection might be slightly uncomfortable for participants, however the advantage of UWF-FFA is that it tells us how well the retinal blood vessels are functioning. UWF-FFA allows us to see all the vessels in the retina, to see if the blood circulates well through them or not, and to see if some blood vessels have died as a result of diabetes, for example.

We also perform scans of the retina, using a technology called optical coherence tomography (OCT). The retina is made up of several layers, each of which has a different function and is composed of different cell types. Using OCT scans, we can see all the different layers of the retina, so we can determine whether one or other layer of cells are damaged.

Importantly, we also test how the retina functions in response to light of different intensities and how participants process that

information. We do this using a test called “microperimetry”. We check the function of the retina by doing what we call an “electroretinogram” using a novel technique that allows us to do this test in seconds. We also check the central vision of participants.

Together, these eye tests and scans give us a lot of detailed information on the anatomy and function of the neural tissue and blood vessels of the retina, allowing us to understand how these changes might differ between people with type 2 diabetes who have, or do not have, MCI or dementia.

**What neuropsychological and imaging tests are being performed in RECOGNISED, and what information do they provide?**

Our eye tests and scans tell us about changes in the retina in people with type 2 diabetes. In RECOGNISED, we also need to assess changes in the brain, to see whether retinal abnormalities are linked to the development of MCI or dementia. In our clinical studies, we evaluate how the brain is functioning using neuropsychological tests, and look at brain structure using scans.

To assess the level of cognitive impairment in our study participants, we perform a series of neuropsychological tests (e.g. MoCA, SAGE). We also do an in-depth evaluation of cognitive function in each participant, through a neuropsychological test battery that measures domains such as attention, concentration, memory, language, orientation and calculation skills. To complement the tests that are administered by our clinical researchers, participants also complete self-administered tests. Participants are able to explain any symptoms they may be experiencing, work through problem-solving tests, and also provide information on their quality of life, such as whether they have issues with vision, mobility, pain or anxiety.

As mentioned, we also perform brain imaging scans. Using MRI scans, we can look at the structure and size of the brain, and

also check for signs of damage caused by problems with blood vessels in the brain. In selected clinical sites, participants also undergo fluorodeoxyglucose (FDG)-positron emission tomography (PET) scans, which allow us to detect changes in the way that the brain processes glucose. Glucose is an important energy source for brain cells, and people with type 2 diabetes or cognitive impairment often have altered patterns of glucose uptake on their FDG-PET scans.

**How will the clinical research in RECOGNISED benefit people with diabetes or memory problems?**

We are enormously grateful to our study participants for their contributions to RECOGNISED! We hope that our clinical studies will advance research and lead to improvements in the diagnosis and treatment of diabetes and dementia. When RECOGNISED started, we knew that diabetes was a risk factor for dementia, and that the brain and the retina were connected. However, we didn’t yet understand whether retinal tests could be used to correctly identify people with type 2 diabetes with, or at risk of developing, MCI and dementia.

Through the RECOGNISED clinical studies, we will find out if changes in the retina – detected using non-invasive tests and scans - give an indication of what is happening in the brain. As well as helping us to better understand diabetes and dementia, this information will allow us to establish an accurate diagnosis of MCI and dementia much more quickly – opening the door to earlier treatments and access to support. In the future, the RECOGNISED studies could also help doctors to predict dementia risk more precisely, prompting people to make positive lifestyle changes that could help prevent dementia as they age.

**Acknowledgement**



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## LETHE project launches dementia risk-reduction study

The European-funded LETHE project is working on issues related to the early detection and reduction of risk factors linked to dementia. It is conducting a study to explore and understand how technology and digital devices could be used in these types of interventions. Alzheimer Europe interviewed Anna Rosenberg of the Finnish Institute for Health and Welfare and Anna Giulia Guazzarini from the University of Perugia, about this important milestone.

Since its kick-off in 2021, the European-funded LETHE project has been working on issues related to the early detection and reduction of risk factors linked to dementia. LETHE (a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on Artificial Intelligence and distributed Machine Learning) is a four-year project building on the well-known FINGER intervention (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability), a multimodal lifestyle programme which can help to maintain cognitive performance and reduce the risk of decline among older persons at risk of dementia. Among other activities, LETHE is conducting a study to explore and understand how technology and digital devices could be used in these types of interventions. The LETHE study was launched in the spring of 2023 and, after just a few months, all the participants in the four countries were recruited.

### Interview with two of the project's clinical partners, Anna Rosenberg and Anna Giulia Guazzarini

**Can you tell us a bit more about the LETHE study, who is participating and what the participants in this study will be expected to do?**

**Anna:** The study will last two years and it will help us to investigate the feasibility of a digitally-supported, multimodal lifestyle programme in promoting brain health. The



Anna Rosenberg (left) and Anna Giulia Guazzarini (right) with LETHE colleague Tiia Ngandu (centre)

study includes people from Austria, Finland, Italy and Sweden, aged 60-77 years, who have some dementia risk factors and are digitally skilled. Participants will follow this multimodal lifestyle programme either as a structured programme (i.e. with individual and group sessions and support from professionals), or as a self-guided programme. The programme includes several activities that tap into some of the well-known risk factors for dementia and will help participants to reduce their risk in these domains. These domains include physical activity, diet, cognitive and social stimulation, vascular risk management, and sleep and relaxation. To give you a clearer idea, in the domain of physical exercise, they are invited to participate in weekly group sessions with the support of a sports specialist and to also do some additional exercise on their own.

**Can you tell us a bit more about the type of technology and devices that participants will be using in the study?**

**Anna Giulia:** We wanted to benefit from some of the existing technology which has become quite popular and a lot of people are already familiar with, such as smart watches. We have also developed a mobile app which has been specifically designed for this study and is installed on the participants' smart phones. The LETHE app provides support to follow the programme with reminders, helps participants to keep track of their progress and contains information about healthy lifestyle and different questionnaires to fill out during the study. In addition, the smart watch helps us to passively measure several digital biomarkers such as general activity, stress levels and sleep quality parameters. So, to continue with the example that Anna mentioned, for physical exercise the LETHE app will provide support with reminders, videos and tips and the smart watch can also help to monitor different relevant aspects in a passive way, just by wearing this device.

**Why are these types of interventions and studies important for older people, how can they benefit from interventions such as LETHE and what are the main challenges to consider?**

**Anna:** Over the last decades, we have done a lot of research on brain health and risk reduction, so we now have very strong research evidence which points to the fact that adhering to a healthy lifestyle can support both heart and brain health. The FINGER intervention had clear benefits on cognition and cardiovascular health, but also for other aspects that are very important to people such as daily functioning and quality of life. The next step is therefore to think about how existing or new digital tools and devices can potentially help in further refining and optimising the FINGER approach, as these tools enable more personalised recommendations and a more flexible way of following the programme. Our hypothesis is that these tools could support more active and personalised engagement but also help us in reaching out to people who, for different reasons, may not be able to follow an in-person programme. However, adopting new technology can be



difficult for seniors, and finding the optimal balance between digital and more traditional in-person activities is challenging. In this regard, LETHE will generate crucial new knowledge.

**As we understand it, the four countries have already recruited all the participants for the study, which is a huge milestone. Can you tell us a bit about this process?**

**Anna Giulia:** In total, we have enrolled 156 participants (36 in Sweden and 40 each in Austria, Finland and Italy). We have used different strategies for the recruitment which were tailored to the different countries and clinical sites involved. In Italy, our team identified and contacted different local associations for older people. Then, we visited them and presented the LETHE study at informative in-person meetings.

**Anna:** In the other three countries, we used social media to disseminate the information and recruit the participants. Both approaches worked really well and the main conclusion is that the LETHE study has attracted lots of interest. To give you an example, in Finland the social media ad had to be taken down after just three days, as nearly 1,200 people had already left their contact details!

**So, what are the next steps for the project?**

**Anna Giulia:** All the first visits have now been completed, as well the first lifestyle intervention sessions. Participants are motivated to adopt healthy new habits, and the first reactions to the intervention and app are very encouraging. Next, we will continue with the intervention activities and keep collecting participant feedback, which is essential in a feasibility study like LETHE.

**Exploring new horizons: the LETHE sub-study**

In addition to existing technologies that are already part of many people’s daily lives, such as apps and smart watches, LETHE will also be looking at how some other more sophisticated technologies could be used in interventions, aiming to reduce the risk of developing dementia. Some of the study participants will have access to these technologies during the second year of the study:

- **Temì**, a self-navigating personal robot designed to help with different tasks that can help make daily life more convenient. In the study, many of the features of the LETHE app will be accessible in Temì. We hope that participants enjoy having Temì



Bose Frames audio glasses

Temì robot

at home for some weeks and that it provides a more interactive, accessible and engaging experience with the programme.

- **Bose Frames** audio glasses, which use a bluetooth microphone and headphone and allow hands-free interaction with the LETHE app. By wearing the glasses and using the app, participants can listen to its content (e.g. videos, questionnaires, calendar entries, notifications, feedback messages) and receive auditory reminders of, for example, upcoming appointments. This way of interacting with a programme like LETHE is very novel and can be very useful and interesting for our target group.

**The LETHE Advisory Board**



Miriam Pannone

Alzheimer Europe, in close collaboration with projects partners, set up an Advisory Board composed of seven people with an interest in brain health and dementia. Miriam Pannone, one of the members from Italy shares her thoughts on being involved in the project and on the launch of the new study.

“My name is Miriam Pannone. I am 76 years old and a retired professor of Statistics from the University of Perugia. As a user, I am familiar

with digital devices, and I still try to keep up to date with information and communications technologies (ICT). In my professional life, I used ICT because I’ve always been convinced of the importance of ICT in education.

I didn’t know about the LETHE project before I was invited to be part of the Advisory Board. As soon as I got some insight into the goals to be achieved with the study, I accepted with enthusiasm. I felt that I could have the opportunity to contribute to a project investigating how digital devices, within everyone’s reach, could be used to promote a healthy ageing brain. It is the first time in all my life that I’ve been on an Advisory

Board. I had to work hard to fulfil the requirements and I hope that I was able to give some useful support.

For sure, I have learnt a lot. I am now more aware of the importance of the factors that increase the risk of dementia. I am convinced that much could be done in keeping our brains in a healthy condition, strictly connected to the adoption of a healthy lifestyle. The sooner the better!”

**Acknowledgement**

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# PRODEMOS – a collaborative initiative developing a mobile health application to prevent dementia

As the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project draws to a close, Alzheimer Europe looks back at the innovative project and speaks to its co-leads, Edo Richard and Eric Moll van Charante, about their reflections on the project.

## An innovative project

PRODEMOS, a European project funded by the European Union's Horizon 2020 research and innovation programme and the National Key R&D Programme of China, kicked off in January 2018 and came to a close in June 2023. The project, led by Amsterdam University Medical Centre in conjunction with seven partner organisations, aimed to investigate whether a dementia prevention strategy using mobile health (mHealth) accessible to those at increased risk of dementia who are usually not reached by preventive medicine was implementable and could reduce dementia risk factors. From this perspective, the project targeted socio-economically deprived populations in the UK and a population at risk of dementia in China. In this project, Alzheimer Europe was involved in work packages on the coordination and management, crossing cultural barriers and dissemination and communication.

## Crossing cultural barriers and adaptation

In the first phase of PRODEMOS, partners took multiple steps to gather key information for the optimal adjustment and implementation of the mHealth platform. First, they investigated current evidence and existing best practices with respect to prevention of dementia and the use of mHealth in preventive health care with a systematic literature review on the effectiveness of mHealth

interventions on reducing dementia risk of which a manuscript was published. Moreover, they specifically focused on crossing cultural barriers and facilitators for dementia prevention within vulnerable populations in High Income Countries (HIC) and in Low- and Middle Income Countries (LMIC) by using qualitative research methods including focus groups meetings and interviews in the Netherlands, UK and China.

## The mHealth platform

In the second phase, the consortium adapted their previously developed eHealth HATICE platform (based on current evidence for risk factor management) to an mHealth platform for dementia prevention. The mHealth platform was adjusted to be specifically tailored to the target population and to be culturally

appropriate, but also to fit the existing health care structures in both settings. This phase finished with a pilot study among a random sample of end-users from the target population in the UK and China.

## The PRODEMOS trial

In the third and final phase, a large randomised controlled implementation trial was conducted in the UK and China to evaluate the feasibility and effectiveness of the PRODEMOS intervention for dementia prevention. The first participant was recruited in the UK in January 2021. Participants were 55-75 years, were of low socio-economic status (UK) or from the general population (China), had at least two dementia risk factors, and used a smartphone. The recruitment in the main PRODEMOS study was formally ended in April 2023 and the study succeeded in recruiting 600 participants in the UK and 888 participants in China, in spite of major challenges due to the COVID-19 pandemic in this period.

The main effectiveness outcome was change in dementia risk, measured with the CAIDE dementia risk score. Improvement of individual risk factors and cost-effectiveness were also evaluated. Analysis is ongoing and the results are currently being incorporated in a manuscript to be published in an international peer reviewed journal. In parallel, health economic aspects, including a cost-effectiveness analysis, were addressed to inform policymakers on the future course of dementia prevention strategies. Finally, implementation is evaluated using a series of outcome measures.



PRODEMOS General Assembly meeting, Luxembourg, September 2022



## A few words from the project leaders Edo Richard and Eric Moll van Charante

Alzheimer Europe, a partner in the PRODEMOS project, asked Eric Moll van Charante and Edo Richard, the two project co-coordinators, to share their thoughts regarding various aspects of the project.

### Could you explain the background to the PRODEMOS study?

Many risk factors for dementia are highly prevalent across the globe and can easily be treated on a large scale against low costs. These include for instance high blood pressure, physical inactivity, unhealthy diet and obesity. However, it is unknown whether treatment of these risk factors actually reduces the risk of dementia. The expected increase in number of persons with dementia is mainly in low-and middle-income countries. Moreover, preventive medicine is less developed in these countries and risk factors are less well controlled. In high-income countries, those with low socio-economic status have a higher risk and also have less access to preventive health care. Remote coaching using a smartphone app may be an effective way to reach large numbers of persons at increased risk of dementia and help them reduce their risk by motivating them to engage in a healthy lifestyle.

### How well do you think the key aims of the PRODEMOS project were met?

We are proud that the teams in the UK and China have managed to recruit almost 1,500 participants in spite of the major challenges COVID-19 posed, and managed to follow these participants for 12-18 months. Even though the recruitment target was not reached, the aims of the clinical trial were certainly met. Reaching these specific populations was not easy, but through our trial, we have learned a lot about barriers and facilitators to reach and engage these populations over a sustained period of time.

### Acknowledgement

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 779238 and the National Key R&D Programme of China (2017YFE0118800).



Edo Richard

### Can you share some of the insights that may have emerged during the project?

An important insight is that there are more similarities between a population in greater Beijing, China and a low socio-economic status population in the UK, than there are differences. Barriers and facilitators to engaging in an mHealth supported dementia risk reduction strategy were rather comparable. Whether the intervention indeed reduced dementia risk factors is not known yet, since we are still in the process of analysing the data.

### What were the main obstacles encountered in this collaborative work? Has the COVID-19 pandemic had an impact on your ability to move forward as planned?

We encountered several obstacles during the project, but most could be overcome by dedicated teamwork. Recruiting participants from low socio-economic status in the UK whilst adhering to the GDPR guidelines was challenging. The University of Cambridge team has done an amazing job to make this a success - in spite of the many persons who thought we were on a mission impossible. Developing a single



Eric Moll van Charante

smartphone app that can be used in Europe and China was challenging, but possible. We did encounter serious challenges concerning intellectual property, data safety and privacy regulations. But thanks to the fantastic team of Capital Medical University, we found solutions for all challenges. Finally, COVID-19 had major impact on all aspects of the project, but we managed to perform virtually all tasks as planned, with some adaptations.

### Finally, could you share one or two personal highlights from the past years?

The participation and coaching of older people with a low socio-economic background on lifestyle behaviour change using mHealth in the UK is virtually novel in the world and has provided us with many valuable new insights on how to guide this vulnerable, high-risk group of persons. The collaboration with our colleagues in China has been extremely rewarding. The learning experience has certainly been bidirectional. We introduced them into qualitative research methods, which they eagerly adopted. They inspired us on creativity and efficiency to design and run a clinical trial. We are already discussing future collaborative projects.



# Scotland publishes fourth national dementia strategy

On 31 May 2023, the Scottish Government published its fourth national dementia strategy, setting out its vision for the next ten years of dementia policy in Scotland. Alzheimer Europe spoke to Minister for Social Care, Mental Wellbeing and Sport, Maree Todd, about the development of the strategy and its key priorities. We also spoke to Alzheimer Scotland's Director of Policy and Practice, Jim Pearson, to hear his views on the new strategy.



Maree Todd

## This is Scotland's fourth national dementia strategy – what is new in this strategy and how does it build on previous strategies?

With the voices of those living with dementia central to the development of the strategy and its delivery, we have truly made our new dementia strategy Everyone's Story, building on progress made while reprioritising our ambitions to our dementia communities. In setting longer-term ambitions over 10 years, we have also scaled up the ambition of our work to match the change our communities need to see.

Our new dementia strategy sets a 10-year vision for dementia policy of “a Scotland where people living with dementia and their care partners have their strengths recognised, their rights upheld and are supported to live an independent life, free from stigma and with person centred treatment, support and care when and where they need it.”

We know we are building on incredibly positive Scottish policy work in areas such as post-diagnostic support, where we have a world-leading commitment to accessing this for the first 12 months following diagnosis. We are also among the first countries in the world

to embrace lived experience participation in policy development. This has been achieved in partnership with our charity, community and delivery partners, including Alzheimer Scotland and About Dementia. Each of these groups has contributed to the strategy and has a governance role through our National Delivery Group.

Through the public National Conversation we held to help shape the development of the new strategy, we heard that current policies do not always translate to people's experiences. We can and must do more, and in committing to two-year delivery plans during the course of the strategy, we can set out the progress we need to make to deliver real change for people, and measure whether we achieve this.

Our new strategy also recognises the changed landscape we are working in, with the impacts of COVID-19 on our communities sitting alongside a significant increase in community-led developments such as meeting centres for people living with dementia and their families. All of these have helped shape this strategy, which responds to the pressures of the here and now as well as the future ambitions we need to deliver on.

## How was the strategy developed and how were people with lived experience involved in the process?

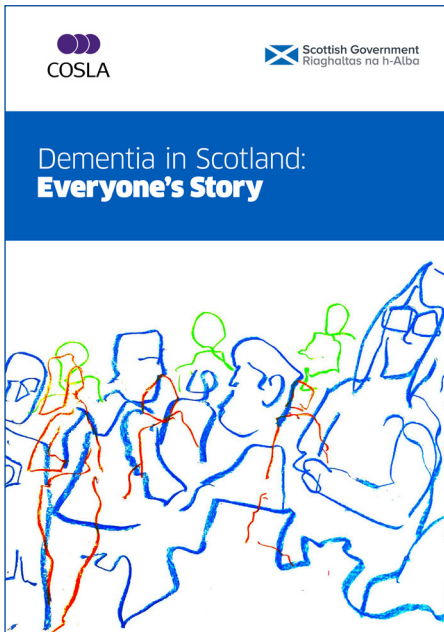
Scotland's new strategy places the voices of lived experience at its heart in order to enable us to tell a 'new story' on dementia policy for Scotland.

To achieve this, we embarked on our most wide-ranging and extensive engagement with people living with dementia, care partners and professionals in communities across Scotland. Over eight months, including through a public National Conversation, we facilitated a dialogue on issues facing people right now, and the ambitions we needed to set over the next ten years. This also included working groups established with academics, researchers and practitioners, and we supplemented these efforts through a review of international evidence on dementia policy.

Building on previous work to engage with established lived experience groups such as the Scottish Dementia Working Group and the National Dementia Carers Action Network, the strategy has been produced through collaboration with our National Lived Experience Panel. Established as one of two governance mechanisms (alongside a National Strategy Advisory Group) for the development and delivery of the strategy, the panel comprises 22 people, 11 are people living with a dementia diagnosis and 11 are care partners (paid/unpaid carers).

“A Scotland where people living with dementia and their care partners have their strengths recognised, their rights upheld and are supported to live an independent life, free from stigma and with person centred treatment, support and care when and where they need it.”





Through working directly with the panel, listening to what works well at a local level and also their concerns and challenges helped to shape the priorities our strategy outlines and truly reflects the needs and ambitions of our dementia communities.

**What will be the priority areas for the first two-year delivery plan?**

Our strategy identifies a number of areas where we will focus our attention to improve the lives of people living with dementia, their families and care partners, with a focus on the role of our communities. This includes:

- Recognising dementia as a condition of the brain that affects the whole person, while upscaling efforts to address its mental health and wellbeing impacts
- Ensuring services and supports are dementia-inclusive and create environments which enable people with dementia to live their best possible life
- Delivering equity of access to information, treatment, care and support for people living with dementia
- Upholding a person’s human rights throughout their dementia journey
- Ensuring people are supported by a skilled, knowledgeable and trauma-informed workforce.

We are now working directly with the voices of people with lived experience and our

charity, community and delivery partners to develop structures for the development, implementation and monitoring of initial priorities. These structures will have representation from across our communities, and be focused around key areas where we need to see progress.

An immediate priority already being actioned on is work to develop a national dementia anti-stigma campaign, targeted at the wider public. This recognises a clear message we heard back of the linkage of stigma towards poorer outcomes and quality of life for people living with dementia.

**Is there funding dedicated for delivering the aims of the strategy?**

Around GBP 2.2 billion per year is allocated by the Scottish Government to provide care and support for people living with dementia. We have also made direct investments into expanding access to post-diagnostic support and community-based models of support (including through an established Meeting Centres Network).

This strategy has been jointly developed with the Convention of Scottish Local Authorities (CoSLA) and our local authority partners, who have primary responsibility for the commissioning and provision of the majority of the care and support our dementia communities access, our charity, community and delivery partners. We are also working together with local authorities and policy areas across Scottish Government to deliver the change people need to see. This includes working with housing, planning, social security and fair work, recognising this must be a collective endeavour. This will help us ensure that commitments we make in delivering on this strategy will be prioritised in funding terms.

The strategy’s ambitions, informed by our engagement process and reflecting the needs

and aspirations of people living with dementia and care partners, also provides a strong and credible basis for how we will deploy our resources in a challenging financial context. This includes a focus on increasing investment in our communities and the support structures and spaces they can provide.

**What will be the key factors for the success of the strategy?**

We know dementia currently affects an estimated 90,000 people in Scotland, 3,000 of whom are under 65. Globally, estimates suggest 1 in 3 people born today will go on to develop dementia. This strategy therefore needs to be Everyone’s Story, as how we see, understand and act in relation to dementia impacts everyone, regardless of gender, ethnicity, additional disability or age.

Building on our understanding and evidence-base of the effectiveness of different policy interventions (including through our review of international evidence), we will work with partners to identify the key factors which underpin and/or impact the delivery of our ambitions in key areas.

We will be agile in setting measures of success that are reflective of people’s experiences and the quality of support provided, in addition to hard data conclusions on numbers of people accessing support, and when this takes place.

We will also learn from our previous strategies, and the importance of staying focussed on delivery. The commitment to working with partners on rolling two-year delivery plans ensures we’ll be held to account on delivery.

Further information on the strategy is available at:

<https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/>

**“ We can and must do more, and in committing to two-year delivery plans during the course of the strategy, we can set out the progress we need to make to deliver real change for people, and measure whether we achieve this.”**

Jim Pearson, Deputy Chief Executive, Alzheimer Scotland, shares the organisation's view of the new strategy



Jim Pearson

Alzheimer Scotland welcomes the Scottish Government's fourth national dementia strategy *Dementia in Scotland: Everyone's Story*, published in June 2023. We commend the level of engagement with people with personal experience of living with dementia and central role they have played in the design of the strategy and will play in the governance and delivery of the strategy. In our view, the new strategy sets out a positive vision for dementia policy and practice in Scotland and identifies key areas that need to change or be improved.

However, the strategy differs from previous national dementia strategies in that it is a ten-year strategy, and it does not make specific commitments or plans for how those areas for improvement will be addressed. The Scottish Government is currently

working with partners to establish the first of a series of two-year delivery plans, by the end of 2023, for addressing the key areas of priority. Alzheimer Scotland is committed to and is currently working along with other partners as part of the National Dementia Strategy Advisory Group and subgroups to contribute to the development of the delivery plans.

This is Scotland's fourth national dementia strategy since 2010. In that time significant progress has been made and we have established collaborative partnerships in Scotland that have driven positive change in areas of diagnosis, post diagnostic support, workforce skills and knowledge, and many other areas. The previous three strategies reflected the priorities that people with personal experience of dementia told us were important to them and were produced collaboratively with key stakeholders from across Scotland. While Scotland can be proud of the progressive national dementia policies that have been developed over the past thirteen years it is also undeniable that key areas of policy have not been fully delivered.

In a report to the Scottish Government, in response to the strategy consultation, we set out the previous commitments that had not yet been fully delivered. Additionally, we made recommendations for actions from earlier national dementia strategies which we believed should be central to this new strategy and which should have renewed and clear promises for delivery.

At present there are unacceptable waiting times to receive a diagnosis and for accessing local community care services, which are

“Alzheimer Scotland is committed to and is currently working along with other partners as part of the National Dementia Strategy Advisory Group and subgroups to contribute to the development of the delivery plans.”

placing untold pressures on families across Scotland. Improving the experience of people with dementia in general hospitals and exploring alternative options to residential care form some of the most critical areas requiring support and investment. We also lack good quality data relating to prevalence and diagnosed incidence in Scotland to help plan, support and evaluate the delivery of the national dementia strategy effectively.

It is Alzheimer Scotland's view a great deal remains to be done to ensure that people with dementia and their families are listened to. For example, the tens of thousands of people with lived experience who support Alzheimer Scotland's Fair Dementia Care campaign to end inequality of access to the health and specialist nursing care, the unequal and unfair charging policies faced by people with advanced dementia. These voices need listened to - and acted upon. Alongside this, the voices of the many individuals with lived experience who helped shaped the three consecutive Scottish National Dementia Strategies since 2010 cannot be forgotten. Implementing these strategic commitments might have been derailed because of the pandemic and the current financial pressures but we need to see a meaningful return to implementing these key commitments if we are to honour the contributions of those with lived experience who have already given so much to support and develop national and local dementia policy. While many of these areas are mentioned as part of the new vision, we look forward to seeing how they will be tackled through the delivery plans.

“It is Alzheimer Scotland's view a great deal remains to be done to ensure that people with dementia and their families are listened to. For example, the tens of thousands of people with lived experience who support Alzheimer Scotland's Fair Dementia Care campaign to end inequality of access to the health and specialist nursing care.”



# Ireland’s incapacity legislation reform embraces supported decision-making

Ireland’s Assisted Decision-Making (Capacity) Act 2015 entered into force in April 2023, reforming legal capacity for adults who required support to make decisions. In this article, Áine Flynn, Director of the Decision Support Service (DSS), explains the background and approach of the new law, as well as the role of the DSS, whilst Helen Rochford-Brennan, Vice-Chair of the Irish Dementia Working Group, shares her views on the new legislation.



Áine Flynn

## Can you give us a background to the development and implementation of the Assisted Decision-Making (Capacity) Act 2015?

The Assisted Decision-Making (Capacity) Act 2015 was signed into Irish law after a protracted legislative process, significantly reforming how we interact with and support adults who require assistance exercising their right to make decisions.

Prior to the 2015 Act, an adult could plan ahead by way of an enduring power of attorney, appointing a trusted person to take decisions about their property and personal care in the event of the adult’s later ‘mental incapacity’. Otherwise, the only available legal mechanism was the court-based wardship system, a form of full adult guardianship under the Lunacy Regulation (Ireland) Act of 1871. When admitting a person to wardship, the court would declare the person to be, ‘of unsound mind and incapable of managing his person or property’. This was long criticised as a blunt instrument, over-broad and disproportionate in its impact. Of approximately 2,200 adults in wardship in 2022, more than half were older adults with dementia.

Through several iterations, the legislation has progressed from a Mental Capacity Bill in 2008 to a more detailed and ambitious Act in 2015, which includes:

- The repeal of adult wardship, with former wards moving to new supports if appropriate
- A statutory functional assessment of capacity
- Rights-based guiding principles
- A three-tier framework of supports for decision-making
- Enhanced tools for advance planning with a new form of enduring power of attorney and advance healthcare directive
- The establishment of the Decision Support Service (DSS).

The 2015 Act was not ‘commenced’ as operational legislation until 26 April 2023. In the intervening period, work was undertaken to establish the DSS and to prepare for the impacts of the Act in areas including health and social care, legal, banking and financial services and in the courts.

## How does it embed the rights of people with dementia, including those found in international treaties such as the United Nations Convention on the Rights of Persons with Disabilities?

Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in March 2018. Article 12.2 of the CRPD states that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

During the development of the 2015 Act, NGOs and disabled persons’ organisations made submissions arguing for better alignment of the Act with the CRPD.

In the 2015 Act, ‘capacity’ is assessed based on a person’s ability to understand at the time that a decision is to be made, the nature and consequences of that decision in the context of available choices. The language aspires to be disability-neutral with no medical component, meaning a person’s diagnosis of dementia is unconnected to the person’s ability and entitlement to make decisions.

The guiding principles in the Act state that an adult, irrespective of their presentation, is presumed to have capacity until the contrary is shown and must be supported as far as possible to make decisions independently. The guiding principles require minimal restriction of rights and freedoms, and respect for privacy, dignity and autonomy. Significantly, the 2015 Act expressly adopts the principle of ‘giving effect to a person’s will and preferences’, rather than a best interests approach, which the Committee on the Rights of Persons with Disabilities has expressly rejected.

The three-tiered framework under the 2015 Act is designed to allow a person to access graduated supports in relation to decisions about property and affairs and personal welfare.



At the lowest tier, a person who believes that their own capacity is or may soon be in question may appoint a decision-making assistant, who helps by obtaining and explaining relevant information and helping the person to communicate their own decision. At the middle tier, a person may appoint a co-decision-maker to make specified decisions jointly with them, as set out in a formal co-decision-making agreement registered with the DSS.

At the upper tier and as a last resort, the court may appoint a decision-making representative to make limited decisions on behalf of a person. The representative must continue to have regard to the person’s will and preferences and may not exercise restraint or deprive the person of their liberty.

In relation to advance planning, enduring powers of attorney have been modified so that these are now registered with and supervised by the DSS. Advance healthcare directives have been given statutory effect, allowing an adult with capacity to create an advanced healthcare directive, to provide an authoritative statement of their will and preferences in relation to treatment decisions. A person may also appoint a designated healthcare representative as their agent, to ensure that their advance healthcare directive is understood and respected.

Article 12.4 of the CRPD requires that measures for the exercise of legal capacity are subject to appropriate safeguards. The new

arrangements under the 2015 Act are subject to procedural checks and balances and are supervised by the DSS for compliance, with potential for escalation to the courts (e.g. where a decision supporter has failed to respect the person’s will and preferences).

Commencement of the 2015 Act also allows Ireland to ratify the Hague Convention on the International Protection of Adults with the Director of the DSS named as the Central Authority. This will facilitate the cross-border recognition of legal instruments in certain circumstances.

**Can you tell us about the role of the DSS?**

In an earlier version of the legislation, it was proposed to call the service the ‘Office of Public Guardian’ but it was argued that ‘guardian’ implied a paternalistic ethos rather than one of empowerment.

In all its functions, the DSS is bound by the guiding principles of the 2015 Act. Unlike Public Guardians in some other jurisdictions, the DSS has no function to manage persons’ money or property and is not a decision-maker of last resort.

The statutory functions of the Director and staff of the DSS might be summarised as duties to promote awareness, provide information, supervise compliance and investigate complaints. Co-decision-makers, attorneys and decision-making representatives submit accounts and periodic reports to the DSS. The Director is also required to

establish external panels of professionals to assist with certain functions.

The Director of the DSS is authorised to publish a suite of codes of practice to provide guidance. It is hoped that the 13 codes that have now been published will make the 2015 Act more accessible to decision supporters, professional persons and service providers and will help them to navigate scenarios that may arise in practice.

**When setting up the DSS, how were people who are likely to be affected by the new law involved in the process?**

To establish the DSS, it was necessary to design and resource a public-facing organisation and develop multiple business processes to deliver our statutory functions.

Following a review of international experience, the DSS has adopted a ‘digital first approach’, meaning that engagement with the service is primarily across an online platform. To accommodate service users with accessibility challenges, we convened focus groups of experts by experience to trial our system and provide comment. The DSS also established a separate stakeholder forum including persons with a range of disabilities and their carers to review our processes and information materials. The draft codes of practice were the subject of a public consultation prior to publication and the response from diverse stakeholders was very valuable.

Most recently, nine DSS ‘champions’, all experts by experience, have led our ‘My Decisions. My Rights’ media campaign. In the campaign, they speak about the importance of seizing opportunities, being treated as equals, and making the decisions that matter to them.

**What do you consider as the key factors for the successful implementation of the Act?**

The response from the public since commencement of the Act has been overwhelmingly positive. To sustain this, it is critical that people have access to reliable

information. The Act is new and complex and it replaces a system that has existed for over 150 years. This brings challenges. The DSS manages queries directly from the public, provides a wide range of information resources in different formats and is available to engage directly with all our stakeholders. It has also been important to build good relationships with professional and representative bodies and at a political level to ensure that this long-awaited initiative is sufficiently supported. The performance of the Act must be kept under review to ensure that it is fit for purpose.

One of the key messages of the DSS is that the legislation is an Act for everyone. Any of us could encounter future challenges with decision-making. One of our champions is Helen Rochford-Brennan, who is well known to Alzheimer Europe. In our public information campaign, Helen speaks about coming to terms with her own diagnosis of dementia and the importance of planning ahead to ensure that her wishes are always known and respected, while she gets on with 'living joyfully'. We hope that this message of positivity will inspire others to engage with this important rights-based legislation.

Further information on the 2015 Act and the DSS is available at:

<https://www.decisionsupportservice.ie>

Videos from the public information campaign are available at:

<https://www.youtube.com/playlist?list=PLBvDzO6iTjklpRBaSArqBzsTDqLCGh9Y>

*N.B This article is intended as an overview of certain parts of the Assisted Decision-Making (Capacity) Act 2015 and related matters and should not be relied on as legal advice or opinion.*

## Helen Rochford-Brennan tells us about “My Journey as a Champion for Legal Capacity Reform: From Concerns to Impact”

My journey into advocating for legal capacity reform through Ireland’s Decision Support Service has been a transformational experience that has empowered not only myself but countless others living with disabilities, particularly those with Alzheimer’s. It all began for me with a concern of human rights and a law rooted in history, today, I am elated to see the positive changes in law that reflect the rights and dignity of all individuals, regardless of their cognitive state.

My involvement in the Assisted Decision-Making (Capacity) Act research, facilitated by the University of Galway Centre for Law and Policy, marked the genesis of my advocacy. As part of my research we looked into the historical context of the Regulation of the Lunacy Act. The archaic nature of such legislation was disturbing; I recognised that people like me, living with Alzheimer’s, deserved modern, empathetic and empowering legal structures.

Contributing to the book “Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories” alongside my fellow researchers became a milestone. We collectively shed light on the real-world impact of outdated laws on individuals’ lives and shared our unique experiences, challenges and aspirations. Our stories painted a vivid picture of the dire necessity for reform. Participation in this research not only gave me a platform to express my concerns but also helped galvanize a movement for change. At every opportunity we lobbied government officials

to finally enact the Assisted Decision Making (Capacity) Act, this was a necessary precursor to Ireland’s ratifying the UNCRPD.

I got the opportunity to co-teach a course bi-yearly with Professor Eilionóir Flynn, which turned out to be a significant step toward spreading awareness and building a cadre of advocates. Equipping students with the knowledge, empathy and understanding required to navigate the complexities of legal capacity reform was deeply gratifying. Witnessing their engagement and passion amplified my own commitment to the cause, and I saw the ripple effect of knowledge translating into action.

Becoming a Champion of the DSS was a natural progression. I was delighted to be asked by the Mental Health Commission to be involved and share the voice of a person with dementia. With first-hand experience of the challenges faced by individuals living with dementia, I felt an inherent responsibility to amplify their voices and champion their rights. This role allowed me to bridge the gap between academic research, personal narratives, and practical change. Advocacy ceased to be a mere endeavour; it transformed into a mission with tangible outcomes.

Today, as I reflect on the path I’ve walked, I am filled with a profound sense of accomplishment. The changes in law brought about by our collective efforts signify a paradigm shift in how society views individuals with



cognitive impairments. Ireland’s DSS is no longer a mere concept; it’s a reality that validates the autonomy, dignity, and humanity of people like me. The recognition of our agency, our personhood, and our right to make decisions about our lives is a testament to the power of advocacy and the resilience of the human spirit.

My journey from concerns about antiquated laws to becoming an instrumental part of legal capacity reform exemplifies the potential of individual advocacy to spark systemic change. Every hour dedicated to this cause, every story shared and every lesson taught has culminated in a brighter future for all those affected by cognitive impairments. The DSS stands as a beacon of progress and I am proud to have played a role in shaping its evolution.



# French Senator authors paper on managing neurodegenerative diseases

In June 2023, the French Parliamentary Office for the Assessment of Scientific and Technological Decisions published a paper on “therapeutic advances in the management of neurodegenerative diseases”. Alzheimer Europe spoke with Florence Lassarade, Senator and rapporteur of the scientific paper to find out more about its findings and its context in relation to dementia policy in France.



Florence Lassarade

**Senator, congratulations on your very detailed and informative paper. What was your motivation for devoting your time to this dossier on the management of Alzheimer’s disease and other neurodegenerative diseases?**

I started my medical internship in the neurology field in the 1980s in Bordeaux, France. We have had general practitioners in my family for five generations. I started these studies with the desire to alleviate, provide support and find a cure, but I was quickly confronted by the lack of treatment in many neurological diseases. This probably explains why I ended up choosing paediatrics. Forty years later, I note that there have been many advances, particularly in the diagnosis of neuro-progressive diseases. There is also a lot of hope in therapeutics. When my colleague Senator Annie Delmont-Koropoulis, who is also a member of the Parliamentary Office for the Assessment of Scientific and Technological Decisions, proposed this topic, I immediately decided to get involved. My motivation was primarily driven by my scientific interest. This is truly a fascinating area of research.

**How would you assess the current situation in France with regards to the early diagnosis and management of Alzheimer’s disease?**

Let me take the example of Saint-Macaire, a city of 2,000 inhabitants located in the south-west of France, where I am elected as a municipal councillor. The Ehpad located in our area welcomes 90 residents and includes a department dedicated to

Alzheimer’s disease (Ehpads are French residential facilities providing care for dependent elderly people). The referring doctor is also in charge of a memory clinic. While I am delighted with the quality of the care provided when a diagnosis of Alzheimer’s disease is made, the lack of neurologists is a real problem. Unfortunately, there is only one to every 50,000 people in France. What worries me is that in the absence of curative treatment, the general practitioner is often reluctant to make and disclose a diagnosis of Alzheimer’s disease. My husband, who was a psychiatrist, also worked hard to ensure that this disease was not confused with depression. The topic of early diagnosis therefore remains a major issue.

In relation to the management of patients and their caregivers, I would describe the situation as quite catastrophic. Although we are increasingly concerned about carers, their status is still not officially recognised. Keeping the patient at home as long as possible is obviously preferable but this choice has its limitations. Although I support the in-home respite programme we call “baluchonnage” in France, I regret that this action is not funded. We have also planned with several members of the Social Affairs Committee of the Senate to visit the Alzheimer Village set up by the city of Dax in the Landes department. But, here again, it is necessary to go beyond the framework of experiments and, above all, ensure the same quality of diagnosis, care and support throughout the country.

**France is one of the few countries in Europe to no longer reimburse current symptomatic treatments for Alzheimer’s disease. What have been the consequences of this decision and the lack of reimbursement?**

I would like to begin by deploring the lack of evaluation of the decision to stop the reimbursement of these treatments. I recently asked a question to the Government on this topic. More generally, this decision is a very negative message to send to neurologists and patients because, according to scientists, these drugs can delay the progression of the disease by two years. The cost of EUR 30 per month should be reimbursed and covered by society.

I also note that in France, when a drug is not reimbursed anymore, it is also not prescribed, as patients can no longer afford it. This decision has therefore undermined the credibility of molecules that had proven their worth. This is a truly regrettable error.

**There is huge expectation around amyloid immunotherapies as new treatments for Alzheimer’s disease. How do you perceive the risk/benefit balance of these treatments?**

I draw a parallel with cancer drugs. The hope and expectation is the same. We could use the system of temporary authorisation, but I felt a great reluctance from the Ministry of Health and Prevention on this point. I fear that the approach is purely a budgetary and financial one. That being said, the fact that

the United States already use these treatments is an asset because we will quickly have more real world information on the risk/benefit balance.

French pharmacologists are currently against these immunotherapies due to the side effects observed on brain imaging scans, but I remain optimistic and in favour of a treatment that can remove amyloid plaques. Although the correlation between plaque removal and clinical symptoms is difficult to establish, these new medicines are nonetheless a source of considerable hope.

**Is France ready for the arrival of these new treatments?**

Were we ready to deal with COVID? No. It is a matter of political priorities and commitments. I would add that this issue does not only concern people with the disease, it is also essential for their caregivers. These

treatments would cost EUR 2,000 per month, excluding costs such as the provision and availability of nurses. What about the interest of society itself to invest in the future? Alzheimer’s disease concerns all of us. I am also in favour of systematic consultations at the age of 65 including a memory assessment.

**Let us ask one last question. France was for a long time a model for the rest of Europe with a very ambitious plan for Alzheimer’s disease, from 2008-2012 and significant dedicated funding for research, diagnosis and management of the disease. Do you think a new plan should be introduced?**

That is absolutely a no-brainer. Here again, I would draw a parallel with the Cancer Plan which is producing many advances, as was the case for the Alzheimer Plan in its time. We need continuity of action, especially in our overseas territories which are now completely deprived.

I am also very concerned about the state of French research and the lack of attractiveness of university careers. Today, young researchers are turning down positions as chairs in neurology. That said, everyone can understand their desire to go abroad after being paid the minimum wage during their formative years. It was clear to see, during the health crisis, that specialists are getting older and older. However, the Government does not seem to be concerned by the absence of new emblematic leaders. It chose to focus its efforts on hospital emergency rooms, having almost entirely abandoned all other services, for years. This choice indicates a severe lack of forward action and planning. This is not acceptable, but I am prepared to take on this difficult challenge.

The scientific paper is available at: [https://www.senat.fr/fileadmin/Office\\_et\\_delegations/OPECST/Notes\\_scientifiques/OPECST\\_note38.pdf](https://www.senat.fr/fileadmin/Office_et_delegations/OPECST/Notes_scientifiques/OPECST_note38.pdf)

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# European Commission proposes new legislation to harmonise legal protections for adults in need of support

In May 2023, the European Commission introduced two legislative proposals, with the first aiming to improve the way in which legal protections, such as power of attorney, operated between EU Member States and the second seeking to bring EU Member States into the HCCH 2000 Protection of Adults Convention. Alzheimer Europe spoke to European Commission Head of Unit (Civil Justice), Andreas Stein, about the proposals and the motivation behind them.



Andreas Stein

## Can you provide an overview of the Commission's proposed Regulation and Council Decision?

The number of adults who may need legal protection or legal support to handle their personal or financial interests is increasing in the EU. This is in part due to the ageing of the population and age-related disease (including Alzheimer's disease), and in part due to the increasing number of persons with disabilities of all ages. Currently, those adults face various legal difficulties in cross-border situations. These difficulties may, for instance, arise when an adult's representative needs to act abroad to close a bank account or where a protection measure taken by a court in one country needs to be invoked abroad.

In the European Commission, we are aware that these problems can significantly complicate the lives of those adults and their representatives and may result in situations where the adult's rights are compromised. We wanted to improve the situation for those adults living in the European Union who have ties to more than one country.

Therefore, in May 2023, the European Commission adopted two legislative proposals concerning the cross-border protection of adults.

The first proposal, for a EU Regulation, will govern cross-border cases among EU Member States. It will lay down common rules on judicial cooperation in cross-border cases within the EU, in relation to which country's courts will have jurisdiction to take measures of protection, which country's law will be applicable to a case and how measures of protection of adults are recognised in other EU countries. Besides measures of protection taken by national courts in order to protect or support adults, it is more and more common that adults themselves appoint in advance a representative who will support or represent them once they are no longer in a position to protect their interests themselves. The Regulation will also ensure that such "powers of representation" can produce their legal effects in other Member States. Finally, the Regulation will also provide rules on the cooperation among Member States' authorities in matters concerning the protection of adults, as well as rules establishing mandatory digital communication, a European Certificate of Representation, and interconnected registers.

The second proposal, for a Council Decision, will oblige EU Member States to join an international convention in the field of the protection of adults – the HCCH 2000 Protection of Adults Convention. The Convention

will then apply among Member States and the non-EU countries that have joined the Convention. At the moment, these are Switzerland, Monaco and the United Kingdom (with respect to Scotland) but we hope that the ratification by all EU Member States will also make the Convention more interesting for third countries.

We expect that this common legal framework will tackle the existing difficulties faced by adults in cross-border situations and address the current gaps and inconsistencies in the legal protection of adults.

## What was the motivation for the Commission's decision to develop these measures, including the European Certificate of Representation?

When preparing this initiative, we were alerted by many stakeholders about the problems encountered by adults who were placed under protection measures, or who had granted powers of representation, in cross-border situations. They had no certainty as to whether their wishes would be respected in other EU countries, or whether they could access their assets abroad and were often caught up in lengthy judicial proceedings. Courts and public authorities were facing language barriers and difficulties to



exchange information due to the different legal systems.

Therefore, the Commission pursued three objectives when considering an initiative in the area of the protection of adults. The first was to protect the fundamental rights and interests of the adults, including the right to autonomy, access to justice, equality and the right to be heard, the right to property and the right to free movement. The second was to strengthen legal certainty and predictability in cross-border dealings. Finally, the third was to improve the effectiveness and speed of cross-border proceedings concerning the protection of adults.

To that effect, common rules applicable to cross-border cases concerning the protection of adults are necessary in particular to establish which court has jurisdiction, which law is applicable, what are the conditions to recognise a foreign measure and how authorities can cooperate. Both the EU Regulation and the international Convention include such standard private international law rules.

In addition, the proposal for the EU Regulation goes further than the international instrument in order to further facilitate the cross-border dealings in the EU where the number of people with cross-border ties is significant and where the close judicial cooperation among Member States is a norm. Therefore, the Regulation on the protection of adults builds on what was done in other EU instruments in the area of judicial cooperation in civil matters. The Regulation will thus further simplify the rules on recognition of protection measures and streamline the circulation of powers of representation and authentic instruments. It will deepen the cooperation between Member States' authorities in cross-border procedures concerning the protection of adults and provide the basis for digitalising some of those procedures. Through the system of interconnection of national registers, the Regulation will ensure that the information about protection measures or about the powers of representation granted by an adult is available to authorities throughout the EU when they need this information to ensure cross-border continuity of the protection.

The EU Regulation also establishes a European Certificate of Representation. Currently, problems often arise when representatives need to prove their powers to private entities such as banks or healthcare institutions, especially when those entities are located in other countries. The Certificate should address these problems and avoid unnecessary costs or burdens. It will enable representatives of adults to easily and efficiently show in other Member States their powers to represent an adult. This measure thus responds to a practical need reported to us by legal practitioners and civil society alike. The Certificate will also exist in all the official EU languages, which will significantly reduce translation costs. It will be optional for representatives whether they wish to request the Certificate, but EU countries will be required to issue it if requested by a representative.

**“ The proposed Regulation will increase legal certainty, reduce red tape and avoid judicial proceedings for people with dementia, their carers or any person providing support.”**

**What practical effect will these changes have for people with dementia, their families and carers?**

The proposed Regulation will increase legal certainty, reduce red tape and avoid judicial proceedings for people with dementia, their carers or any person providing support. Take the example of a person with dementia who has savings or a second home in another country or travels frequently to that country. A person may be appointed to support this adult with dementia, either through a protection measure, or through powers of representation drawn up by the adult before the illness prevented them from protecting their own interests. This person designated as a representative will have the possibility to ask for a certificate of representation, which will have to be accepted by banks, notaries or medical staff in all other EU countries. This will make it much easier to manage financial and personal affairs abroad.



Even for those of us who do not have any sickness or any link with another EU country, the proposed Regulation will ensure that, should our situation change, our wishes recorded in powers of representation or advance directives will be respected everywhere in the EU.

In case persons with dementia have links with another country and are caught up in a difficult cross-border case, a mechanism of cross-border cooperation between the authorities (central authorities or competent authorities) will offer practical solutions. Examples of the need for such cooperation include situations where a person in need of support is missing, where family members or friends need to be located abroad or where legal aid is needed to institute judicial proceedings in another country.

At the global level, the HCCH 2000 Convention also makes the lives of people with dementia easier. With those non-EU countries which have joined the Convention (Monaco, United Kingdom, with respect to Scotland, and Switzerland), automatic recognition and cooperation mechanisms between authorities will avoid or solve many problems arising in international situations.

**How will the Commission monitor the implementation of the Regulation?**

First of all, the European Commission will gather statistics on the implementation of the Regulation. In fact, the proposed Regulation contains the obligation for authorities to use digital means to communicate with each other. Thanks to the digital tools used by those authorities, the EU Member States and the European Commission will have an easy access to statistics, for instance on the number of communications and the length of proceedings.

EU countries will also have to set up a register of protection measures, and, where applicable, of powers of representation. This initiative will also provide greater visibility on the number of protection measures and powers of representation, as well as the number of information requests from abroad.

Finally, the European Commission will also closely monitor the development of case law under the Regulation and the Convention, as well as any problems signalled by central authorities or courts. At the regular meetings of European Judicial Network in civil and commercial matters which will be devoted to the Regulation, questions regarding the implementation of the

Regulation will be collected and discussed by all stakeholders.

**What are the timelines for the legislation? Is the legislative process expected to be completed before the elections next year?**

The legislation is currently at the stage of a proposal. Therefore, several steps still need to be taken before the two instruments will apply.

The Council Decision obliging all Member States to join (or remain) parties to the HCCH 2000 Protection of Adults Convention needs to be adopted by the Council after receiving the consent of the European Parliament. Once the Council decision is

adopted, Member States will have two years to finalise the process of joining the HCCH 2000 Protection of Adults Convention.

The proposal for an EU Regulation needs to be adopted by the European Parliament and the Council. We are hopeful that the legislative process will be smooth and will be concluded as soon as possible but it is questionable whether adoption can take place before the European Parliament elections next year. The Regulation will then start to apply 18 months after its adoption. However, Member States will have additional time to put in place some of the new technical solutions for digital communication and interconnection of national registers.



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# Looking at two years of implementing the European Strategy for the Rights of Persons with Disabilities

In March 2021, the European Commission published the European Strategy for the Rights of Persons with Disabilities 2021-2030, setting out priority policy areas for the decade ahead, many with relevance for people with dementia, their families and carers. Alzheimer Europe spoke to European Commission Director (Social Rights and Inclusions), Katarina Ivanković-Knežević, to find out about progress on its implementation.



Katarina Ivanković-Knežević

## Two years on from the publication of the Strategy, what have been the success stories so far?

A lot has happened since the adoption of the Strategy for the Rights of Persons with Disabilities 2021-2030 back in March 2021. We have established the Disability Platform, to bring together United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) focal points from all Member States and organisations of persons with disabilities to support the implementation of the Strategy. The Platform acts as the channel for both mutual learning and looking ahead to what more needs to be done.

In September last year, the Disability Employment Package was launched to provide guidance to Member States, employers, and public authorities, on practical measures and guidance to make it easier for persons with disabilities to participate in the labour market. The package consists of seven outputs and we will progressively develop them until 2024.

At the end of 2022, the AccessibleEU was launched as a service contracted by the Commission to an external consortium of accessibility expert organisations for up to four years. Its purpose is to support implementation of EU accessibility legislation, by bringing together relevant national accessibility experts,

create a one-stop-shop for knowledge on accessibility, train accessibility professionals, and sharing of good practices in accessibility policies. On 4 July 2023 we gathered experts to celebrate the launch of AccessibleEU. The Commissioner of Equality, Helena Dalli, and the President of ONCE Social Group, Miguel Carballeda, also took part in the event. The aim was to acquaint participants with the work carried out by different stakeholders. We wanted to hear about their needs and difficulties in implementing accessibility and reflect on how to better develop and focus the activities of AccessibleEU.

Now we are working towards the adoption of another flagship initiative of the Strategy. The Commission adopted a legislative proposal in September for a European Disability Card to make it easier for persons with disabilities to enjoy free movement across borders in the EU through mutual recognition of the European Disability Card and European Parking Card for persons with disabilities. The idea is that when cardholders travel to another Member State, they benefit from the same preferential conditions as any person with disabilities from the Member State they visit when they access services.

Other achievements of the Strategy so far include the Commission's own Renewed Human Resources Strategy to lead by example,

to ensure the inclusion of persons with disabilities, and in collaboration with other recruiting EU institutions.

We have also developed a monitoring framework for the Strategy that is publicly available on our website, ensuring that public information is available on implementation progress.

“The Strategy aims to improve all persons with disabilities’ quality of life through ensuring access to their fundamental rights.”

## For people living with dementia, what forthcoming work will be of greatest relevance?

The Strategy aims to improve all persons with disabilities’ quality of life through ensuring access to their fundamental rights. For that, the Strategy takes account of the diversity of disabilities and the increased prevalence of disabilities with age, as almost half of persons aged above 65 report some form of disability. Moreover, through its intersectional perspective we focus on addressing the specific barriers faced by persons with disabilities who are also at the intersection



of identities (e.g. gender, racial, ethnic, sexual, religious), or in a difficult socioeconomic or other vulnerable situation.

Persons with disabilities have the right to high-quality healthcare, including health-related rehabilitation and prevention. Further action is needed as persons with disabilities report unmet needs for medical examination four times more often than persons without disabilities. The COVID-19 crisis revealed weak spots in health systems, in particular regarding persons with disabilities living in institutions with limited access to emergency and intensive care.

The Commission will address issues related to health and disability through the Steering Group on Promotion and Prevention (SGPP) for the sharing of validated health-related good practices to support Member States in their health reforms.

Later this year we will present guidance on independent living and inclusion in the community, to provide Member States with additional support, anchored in practice, towards the transition from institutional to community-based solutions for persons with disabilities. Next year, the Commission will also present a framework of excellence for social services addressed to persons with disabilities. These two initiatives go hand in hand, as true inclusion in the community of

persons with disabilities can only happen if local, quality services are available, affordable, inclusive, and accessible.

The Commission guidance will take a practical approach, exploring good examples from Member States' experiences in this area, and notably, in the use of EU funds. To do so, we count on the contributions of the members of Disability Platform sub-group on independent living which was created in April this year.

**Will the forthcoming election have any implications for the implementation of the Strategy?**

At the moment of the publication of the Strategy in 2021, there were in place various national rules that deprived large number of EU citizens with disabilities of the right to participate in elections including on the European Parliament elections, because of their intellectual disabilities or mental health issues. In last two years that has been addressed as some Member States undertook reforms in this field. Still, there are, in our opinion, too many persons with disabilities that cannot exercise their right to vote due to lack of accessible polling stations and information on elections.

In that context, through this Strategy, the Commission is working with Member States in the European Cooperation Network on Elections to support enhanced electoral participation and accessibility of European elections, including for citizens with disabilities. In the framework of this cooperation, we will develop a guide of good electoral practice addressing participation of citizens with disabilities in the electoral process.

This work will foster full political participation in the democratic process for persons with disabilities, leading to a better representation in the EU institutions of the needs of persons with disabilities.

**Both at a European and national level, what role can civil society play in supporting the implementation of the Strategy?**

Civil society already plays a key role in the implementation of the Strategy. Persons with disabilities and their supporting network



know what their needs are and what are the corresponding solutions that they prefer. Local, national and EU authorities are the ones who should collaborate with them to implement the target actions needed.

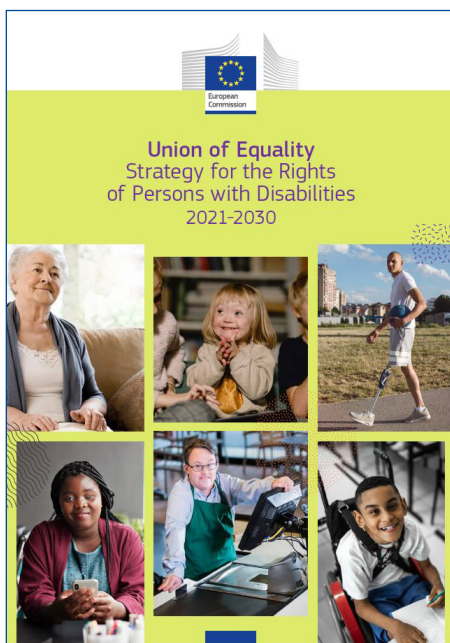
Through the Disability Platform, we work with persons with disabilities and their representative organisations and Member States to make sure that their needs are leading the actions of this Strategy.

Moreover, the great participation in the public consultation of the European Disability Card legislative initiative is also a good example. 3361 replies were received, 2632 of them from persons with disabilities. This shows that the perspective of persons with disabilities plays an important role in the development of this initiative.

However, a lot remains to be done. A key turning point is to realise that persons with disabilities' rights are human rights – the same as everyone else's. And this means that the issues need to be addressed by society as a whole, and not only by persons with disabilities and their supporting network.

This is why we decided to launch the 'Together for rights' communication campaign, to raise awareness of the rights of persons with disabilities at EU level and their realities. So, to help join forces to achieve a true Union of Equality, an easy but powerful next step could be to share the available materials of this campaign. Together we can raise our voices for persons with disabilities to enjoy their fundamental rights, just like everyone else.

Further information on the Strategy and the Together for Rights campaign is available at: <https://ec.europa.eu/social/main.jsp?catId=1556&langId=en>



# People with dementia represented at European Parliament of Persons with Disabilities

On 23 May 2023, the 5<sup>th</sup> European Parliament of Persons with Disabilities (EPPD) on the subject of “Building an inclusive future for persons with disabilities in the EU” took place on in the hemicycle of the European Parliament in Brussels, Belgium. Alzheimer Europe was represented at the event by the Chairperson and Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD).



Members of the EWGPWD attend the EPPD

This event, held every five years, was co-organised by the European Disability Forum (EDF) working closely with European Parliament’s President, Roberta Metsola, MEP, cemented the European Parliament’s commitment to realising the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its role in guaranteeing that Article 10 of the Treaty on the Functioning of the European Union is upheld: “In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.”

The event brought together around 700 disability advocates from across the European

Union to discuss the role of the European Union in the context of Disability Rights. Alzheimer Europe was represented by the Chair of the European Working Group of People with Dementia (EWGPWD), Chris Roberts and Vice-Chair, Kevin Quaid. Their supporters Jayne and Helena, Dianne Gove (Director for Projects) and Daphné Lamirel (Project Officer) also participated in the meeting.

During the session, a number of high-profile speakers were present, including European Commission Vice-President for Values and Transparency, Vera Jourová, European Commissioner for Equality, Helen Dalli and President of the European Parliament, Roberta Metsola, MEP.

The EPPD was divided in three main sessions with different topics: breaking barriers: free movement and full participation; fighting for our rights – combating inequality, social exclusion and poverty, and, disability – inclusive resilience. During these sessions, speakers discussed the growing problem of poverty, social exclusion, cost of living, independent living, inclusion in education and labour market.

More information on the 5<sup>th</sup> Disability Parliament is available:

<https://www.edf-feph.org/5th-european-parliament-of-persons-with-disabilities/>



Helena Dalli



Yannis Vardakastanis and Roberta Metsola



## The EDF 2024 European Elections Manifesto

On this occasion, EDF also presented the “Manifesto on the 2024 European Elections” which introduces the roadmap of the European Disability Forum’s campaign. The Manifesto contains a number of demands based around five key areas:

- Guarantee the participation of persons with disabilities in the political and public life of the EU
- Realising a Union of Equality for persons with disabilities with the CRPD as its compass
- Becoming a more social Europe
- Embracing accessibility – allowing free movement in Europe
- Protecting persons with disabilities in Europe and beyond.

Specifically, the Manifesto calls for:

- Ensuring the right to vote and stand as candidates in European elections
- Establishing strong services focused on disability rights in EU institutions: a new



Directorate-General for Equality and Inclusion in the European Commission under the leadership of the Commissioner for Equality; a Disability Committee in the European Parliament; an Equality Configuration in the Council

- Enacting stronger legislation to protect the rights of disabled passengers
- Establishing a Disability Employment and Skills Guarantee
- Guaranteeing the availability and affordability of assistive technologies
- Ensuring the EU Budget supports independent living and disability inclusion in the Green and Digital transition.

Speaking on the subject of Manifesto, the EDF President Yannis Vardakastanis stated: “Persons with disabilities want to be full citizens of the European Union and the participation in this landmark event showed that. The will of the movement is clear: EU institutions must ensure we can participate in the democratic process and in the policies shaping our Union, and they need to build an inclusive Europe together with us.”

More information about the Manifesto is available at: <https://www.edf-feph.org/publications/eppd-manifesto-2023/>

## Chris Roberts addressing the European Parliament of Persons with Disabilities



Chris Roberts

Chris Roberts took the floor during the session focused on “Fighting for our Rights – combating inequality, social exclusion and poverty”. He highlighted the importance of increased funding for services and support for people with dementia and national dementia plans,

emphasising that “we will not be forgotten or left behind” and “nothing about us without us”. You can read his full speech below and it is available to watch at the following link: <https://youtu.be/74XCw6fEAX8>

“Hello, and thank you for allowing me to have a voice for the millions who live with a diagnosis of one of the conditions that lead to dementia. My name is Chris Roberts and I am the chair of the European Working Group of People with Dementia facilitated by Alzheimer Europe.

Living with dementia will and does disable us especially as it progresses. But our rights as individuals, as humans, our disability rights, our employment rights along with any support we might receive are still not there and still not recognised. We’ve lived with inequality which makes us socially excluded. Most of them are on their own, alone and in poverty.

Many countries do not have an action plan for dementia which results in little or no support for those living or affected by dementia which at the moment is one of the biggest killers in the world. Understanding is better and diagnosis is better. But still unreliable or non-existent for the majority.

More investment and funding for services, education and support not just across Europe but globally is desperately needed equally and ethically. This is for your grandparents, your parents, yourselves and your children, dementia is not racist or political. It does not care about your background, who you are or which country you are from

Dementia is increasing globally and rapidly. This cannot be tolerated. This must be improved. We will not be forgotten or left behind, but we need your help as we cannot do this alone nor should we. Nothing about us without all of us. Thank you.”



# A Global Collaboration for the Implementation of a Training and Support Programme for Informal Caregivers of People with Dementia

As part of the World Health Organization’s Global Action Plan on the public health response to dementia 2017-2025, an iSupport Network developed between researchers seeking to share and spread good practice. In this article, two members of the network, Mauricio Molinari Ulate and Soraia Teles de Sousa, describe the network and its appearance at the 2023 International Psychogeriatric Association International Congress.

The World Health Organization’s (WHO) [Global action plan on the public health response to dementia 2017-2025](#), envisions a world in which dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

The majority of care for the approximately 55 million people currently living with dementia is provided by unpaid family members or close friends (i.e. informal caregivers). This is especially true for low- and middle-income countries (LMICs) where over 60% of people with dementia live but access to formal dementia services remains scarce, as outlined in the 2021 WHO [Global status report on the public health response to dementia](#). According to the report, informal caregivers spent on average five hours per day providing support to a person living with dementia. Estimates are substantially higher in LMICs where existing formal dementia services are scarce or concentrated only in urban areas exacerbating access barriers. Furthermore, services tend to be underutilised due to stigma or lack of knowledge about their existence. Similarly, the availability of, and access to, dedicated caregiver support services also remain very limited in LMICs.

As a result, informal caregivers often face financial, social, and psychological stressors

which have an impact on their physical and mental health. To prevent this from happening, caregivers need access to evidence-based information, training, and services (see also [WHO’s Blueprint for dementia research](#)), as well as social and financial support. Psychosocial interventions for caregivers have demonstrated promising outcomes. These include the reduction of burden, stress, depressive symptoms, and anxiety, as well as an increase in subjective well-being, ability and knowledge, physical health and social support and potential delays in institutionalisation of the person with dementia. Reflective of this evidence, the Global dementia action plan set the target of 75% of countries

providing support and training programmes for carers and families of people with dementia by 2025 (global target 5).

With the support of the Government of the Netherlands and the US Alzheimer’s Association, WHO developed [iSupport](#), an accessible, online, evidence-based programme aimed at providing education and training to dementia caregivers in order to improve their knowledge, skills and wellbeing. WHO provides general guidelines to support countries in adapting the intervention to local contexts and needs. Since the launch of the generic English version in 2019, iSupport has been or is being adapted, field-tested, and implemented in over 40 countries and 37 languages worldwide, with valuable insights being gathered concerning its feasibility, accessibility, efficacy, and sustainability across diverse cultural contexts.

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Soraia Teles de Sousa (iSupport Portugal)



Mauricio Molinari Ulate (iSupport Spain)



Members of the iSupport Network presented at the 2023 International Psychogeriatric Association International Congress in Lisbon, Portugal

**A global collaboration: The iSupport Network**

Under the umbrella of ‘The iSupport Network,’ research teams from around the world have formed an organically grown support mechanism that convenes monthly to discuss good practices related to adapting, developing, and implementing iSupport across various populations and cultures. The network’s primary objectives are to promote mutual learning, foster harmonisation of research efforts, and facilitate knowledge sharing.

The iSupport Network had its first international appearance during the 2023 International Psychogeriatric Association International Congress in Lisbon, Portugal this summer. In two symposia, network

members shared their up-to-date research findings and lessons learned on the adaptation and implementation processes and users’ perspectives from diverse cultural backgrounds.

The ongoing discussions among network members provide valuable insights regarding opportunities and persisting challenges associated with iSupport adaptations and implementations. Lessons learned have implications for enhanced future adaptations and potential development costs/sustainability considerations going forward. For instance, ongoing usability and acceptability studies in different countries played a pivotal role in identifying design issues and usage patterns of the programme, leading to valuable recommendations for

“Under the umbrella of ‘The iSupport Network,’ research teams from around the world have formed an organically grown support mechanism that convenes monthly to discuss good practices related to adapting, developing, and implementing iSupport across various populations and cultures.”

“The network is open to new members, organisations and research teams that would like to benefit from iSupport and the supportive collaboration that has been created.”

enhancing iSupport’s accessibility and user engagement. The exchange among network members also led to the replication of successful strategies for trial design and participant recruitment in studies aimed at testing the usability, feasibility and effectiveness of iSupport. Most recently, the collaboration among network members led to successful international grant applications such as the recently awarded grant by the National Health and Medical Research Council of the Australian Government for “A ‘culturally tailored iSupport model’ for carers of people with dementia” led by Prof. Lily Xiao of Flinders University with the support of other network members.

The network’s future endeavors involve continuing to share the network’s learnings and translate them into concrete implementation guidance. Network members also seek to pursue shared funding opportunities to enhance not only the global uptake of iSupport, but also to further improve the intervention and generate outcomes applicable to e-health interventions aimed at improving the quality of life, quality of care and well-being of individuals living with dementia and their caregivers.

The network is open to new members, organisations and research teams that would like to benefit from iSupport and the supportive collaboration that has been created. To learn more about iSupport or to join the network, visit [www.iSupportfordementia.org](http://www.iSupportfordementia.org) or contact Katrin Seeher at: [seeherk@who.int](mailto:seeherk@who.int)

You can also contact the authors of the article at: [maumolula@usal.es](mailto:maumolula@usal.es) and [stsousa@icbas.up.pt](mailto:stsousa@icbas.up.pt)



# European Group of Governmental Experts on Dementia meets in person

In its first meeting of 2023, the Group met in a hybrid meeting to discuss a range of dementia policy developments, including opportunities for a greater focus on dementia in EU health and research programmes, implementation of new initiatives at a national level and ongoing work in the World Health Organization (WHO).



The group met during Alzheimer Europe's public affairs meetings in Brussels, Belgium

On 6 and 7 June, the European Group of Governmental Experts on Dementia held a hybrid online and in person meeting in Brussels, Belgium. The meeting is the first of two scheduled for 2023 and marked the first time the group had met in person since 2019. At the meeting, 18 European countries were represented, with attendees also in addition to representatives from the World Health Organization (WHO), from the European

Commission's European Health and Digital Executive Agency (HaDEA) and DG Research & Innovation (DG RTD) and from Alzheimer Europe. Over the course of the two-day meeting, the group heard about national dementia strategies and policies, as well as European and international policy developments.

At the national level, representatives from health ministries updated the group on

recent developments in their countries, including the development of new national dementia strategies in Scotland and Slovenia. In addition, members shared progress on the implementation of dementia strategies in Austria, Belgium (Flanders), Czech Republic, Germany, Iceland and Ireland, updates were also provided from colleagues in Cyprus and Poland.

At the European level, representatives from the European Commission presented on a number of different areas. From DG RTD, it was highlighted that a flagship initiative on brain health was expected in 2025, aiming to bring brain initiatives under one umbrella, with the intention of accelerating the delivery of preventive, diagnostic, therapeutic and care solutions to foster brain health in citizens and patients. The European Health and Digital Executive Agency (HaDEA) provided an overview of different health-related programmes it oversees, including the EU4Health programme, explaining the different funding mechanisms available. In particular, a number of currently open calls, including a Joint Action on Dementia and other neurological conditions which has a budget of EUR 4 million.

During the meeting, Alzheimer Europe provided an overview of the previous EU Joint Actions on Dementia, giving participants an overview of the ALCOVE and Act on Dementia projects, to inform discussions about potential interest in the current call. It also provided an overview of its recent work and activities related to dementia policy.

Regarding global developments on dementia, the WHO updated delegates on some of its ongoing dementia initiatives, including changes to reporting for the Global Dementia Observatory, whilst the Netherlands highlighted recent activities of the World Dementia Council and the G7 in relation to dementia, whilst also drawing attention to the Dutch Government's plans for a High-Level Meeting on Dementia during October 2023.

The Group is scheduled to meet again online, on 14 December 2023.



# The importance of giving a voice to people with lived experience

People with lived experience – both those with a diagnosis of dementia and their carers/supporters – are working hard across Europe, on advocacy, campaigning, Public Involvement and awareness-raising activities. We spoke to five people from the European Working Group of People with Dementia and the European Dementia Carers Working Group to find out more about the great work they are all doing, at local, national and international level.

We spoke to three members of the European Working Group of People with Dementia (EWGPWD) and two members of the European Dementia Carers Working Group (EDCWG) and asked them to tell us about any advocacy, campaigning, Public Involvement or awareness-raising work around dementia and dementia care, especially (though not exclusively) at national level. We asked them to tell us a bit about it and about whether this work is being done together with a national working group and/or national Alzheimer association. We also asked them why they became involved, what this work brings them and what they feel they have been able to contribute as a person with dementia or as a carer. We encouraged them to tell us how their work in these areas helps inform their work with the EWGPWD or EDCWG and finally, we asked whether they had any requests to

address to policymakers in their countries, to help ensure policies and funding nationally and across Europe are moving in the right direction, to uphold the rights of people with dementia and their supporters and to allow them to access the best possible quality of care and have a good quality of life.

## Lieselotte Klotz, member of the EWGPWD, Germany

I would like to share my personal experience of being diagnosed with dementia and my volunteer work for people with dementia, particularly regarding my participation in advocacy groups, campaigns, Public Involvement, and awareness raising at regional, national, and international levels. My first-hand experience with illness and therapy gives me valuable knowledge of the

realities of life dementia. I also provide care for my mother who is 87 and has Alzheimer's disease.

My lived experience supplements the specialist knowledge of experts in the work I am now doing.

In addition, I have knowledge and experience from my 20 years or so of professional activity in the healthcare sector as well as around 30 years of experience in the field of medical technology, and then information technology and digitisation. Despite my diagnosis, I can still draw on some of the skills I have developed over the years. Not always, and not for everything, but I am able to contribute meaningful input and knowledge.

This sometimes surprises or even makes "people without dementia" suspicious. "How can someone with dementia still be so competent?" they often ask, in committees and at events. Technology (e.g. mobile phone, computer and various assistance systems) partially compensate for my lack of cognitive abilities and enable me to cope with the effects of dementia on my everyday life. I exercise physically and mentally every day, so that the abilities I still have don't disappear too quickly and when it comes to things that I can no longer manage alone, I ask for help. In short, I try as much as possible to keep busy and I stay connected with my loved ones and the people around me. Aside from that, I concentrate on the things in life that I enjoy and that are feasible. And I fight for every inch of life.

The various international, national, and regional working groups in which I participate are made up of experts, professionals and other committed individuals who care about the concerns of people with dementia and are committed to promoting understanding, knowledge, and support for people with dementia and their families and loved ones. Together as a team, we develop creative ideas and new strategies to raise awareness in society, break down prejudice and ensure better care and support options, for example within the framework of the National Dementia Strategy I am a member of the "Living with Dementia" Advisory Board of the Deutsche Alzheimer Gesellschaft (DALZG)



Lieselotte (Lilo) Klotz with the Living with Dementia Advisory Board at German Alzheimer association conference 2022

Berlin. The Advisory Board consists of people living with dementia who bring this perspective, and advise the Board of DALzG Berlin.

I am also a member of the German Center for Neurodegenerative Diseases (DZNE) Patient Advisory Board, where I raise awareness about dementia and communicate with the public as an ambassador for the DZNE.

Still at a national level, the project “PART of the University of Rostock: Patient Advisory Council for Participatory Research” is about the active involvement of people with lived experience of a disease in the research process. I was asked to contribute my expertise as a person affected by dementia. The “PART Advisory Board” aims to network patients, relatives, researchers, patient representatives and organisations and other relevant interest groups.

At the political level, I am actively involved in topics related to the National Dementia Strategy. Personal exchange with those responsible in the federal ministries, participation in the conference National Dementia Strategy 2022/2023 and various lectures on the strategy, from the perspective of a person with dementia at national and also regional level are the most important activities of the past two years. And finally, at the European level, in October 2022, I was nominated by the DALzG to become a member of the EWGPWD.

The participation of those affected and their families in committees makes it possible to dispel myths and misconceptions about dementia and to provide a more realistic picture of the condition. This promotes understanding and creates a more inclusive society. We can also make valuable recommendations for practical solutions and help assess interventions, so that decisions and measures better fit our needs.

My work allows my voice to be heard, through active participation in decisions that affect my life and my care. It increases my sense of empowerment and self-determination, as I can actively participate in shaping policies and programmes that have a direct impact on me.

I thrive on the fact that this work enables me to help others, to give them hope, encouragement and practical advice and to serve as a role model. I also enjoy the support and positive feedback I receive, the new perspectives I gain and the fact I get to develop myself personally. All of this gives me a sense of purpose and belonging.

Through our advocacy and public involvement work, we have the opportunity to influence political decision-makers and decision-making bodies. We advocate for appropriate policies and funding that address the needs of people with dementia and their carers. By representing their concerns at national and European level, we can ensure that policy and funding move in the right direction.

I encourage policymakers to support investment in intelligent assistance systems, sensors and telemedicine and encourage their integration into the care infrastructure. I would also emphasise the importance of community-based care and support structures. Such approaches allow people with dementia to remain in their familiar surroundings and continue to be active in their communities. Developing and funding community centres, day care facilities and outpatient services can help provide comprehensive support for people with dementia and their carers.

Funding to support training and education programmes in dementia care, and making these widely available to family members, carers and medical staff is equally important and I would also emphasise the need to invest in dementia research to develop

innovative treatment approaches and explore preventive measures.

Finally, I would encourage policy makers to promote new and creative solutions that improve access to quality care and a good quality of life for people with dementia. By advancing these causes, we can ensure that policies and funding adequately address the needs of people with dementia and their supporters, and provide the resources needed to provide dignified and quality care.

**Réal Larnou, member of the EWGPWD, Belgium**

As part of the ‘Flemish working group for people with dementia’ I am involved in awareness raising work on topics chosen by the members of the working group and coordinated by the Flemish Alzheimer’s Association (Alzheimer Liga Vlaanderen).

Actions include smaller or bigger campaigns, like our recent initiative on respectful communication as the foundation for an inclusive society. I was a part of the eight video statements in which the members of the working group offer a clear call to action for language use that does justice to the daily reality of people with dementia. In addition, we wrote a media manifesto together to make the written and audio-visual press aware of the impact of language and images on the quality of life of people with dementia.

Life doesn’t stop after a diagnosis, that’s why I strongly believe that we can still add value to society as experts by experience. Being part of the Flemish and European working groups of people with dementia enriches me as a



Réal Larnou (second from left) at a Flemish working group meeting, Mechelen

person, through regular contact and collaboration with my colleagues and friends in the working groups. Focusing on the lived experience of people with dementia makes you look at the condition differently.

Although our scope is different, for sure both working groups inspire each other. It's key to reinforce each other's initiatives, but also at a personal level my work in Flanders offers me motivation and insights that are helpful for my engagement in the European working group.

More structural involvement of persons with dementia and their caregivers in policy work is vital to move forward. Across Europe we see steps in the right direction to enhance this involvement.

In Flanders our working group of people with dementia, the recently started new working group for caregivers of people with dementia and the Flemish Alzheimer's Association who puts time and energy in both working groups deserve to be equal partners in policy work like other stakeholders. Our voices and insights should be the quality check in all future policy actions and dementia strategies.

### **Shelagh Robinson, member of the EWGPWD, United Kingdom (England)**

Sport United Against Dementia is a pioneering Alzheimer's Society UK campaign raising funds and awareness to tackle dementia - as a team, to improve lives now and in the future, for current and former players, staff, supporters and fans across the nation who are affected by dementia.

I am an 83 year-old woman who has Alzheimer's disease and loves football. I am a lifelong Manchester United fan and so I was delighted to be asked to go to Hotel Football in Manchester to meet with one of my all-time heroes, Denis Law, a former Manchester United player. Denis had himself just had a diagnosis of vascular dementia. Once I had got over being star-struck, we had a valuable conversation, being interviewed by former United star and now dementia campaigner Gary Neville. Denis found it hard to believe that I had been diagnosed for ten years. With very little knowledge of dementia, he was expecting a very rapid decline and was

reassured by my lived experience. The film they made of our meeting went viral on the internet, spreading the message to half a million football fans and raising vital funds at the same time.

Later on in the year, I made my first visit to Wembley Stadium for the England versus Switzerland match. All revenue from this match went to the Alzheimer's Society and the players wore shirts without names, in acknowledgment of the difficulty people with a diagnosis of dementia can have with names. Prior to kick-off, I was interviewed on the Wembley pitch, by England 1966 World Cup hero Geoff Hurst, about the challenges of dementia and about how sport, and football in particular can be so important for maintaining a sense of normality after a dementia diagnosis.

Apart from the personal pleasure I got from these events I felt that I was demonstrating that, in spite of the diagnosis, I am still the same person with the same passions, the same ability to communicate - as well as the same ability to hero worship.

Shelagh's interview can be watched, here: <https://youtu.be/44VLsAg2ATO> (Shelagh starts at min 6:10)



*Denis Law and Shelagh Robinson*

### **Trevor Salomon, Vice-Chairperson of the EDCWG, United Kingdom (England)**

Little did I know, back in 2018, the impact that this newspaper article -

<https://www.dailymail.co.uk/news/article-5484381/Husband-Sainsburys-dementia-sufferer-tells-heart-lifting-story.html>

- would have on my life as a carer which up until this point had been the same as pretty much all unpaid dementia carers who quietly go about the never ending challenges of looking after someone living with this progressive disease. In my case it was looking after my wife, Yvonne

It had never occurred to me that a story about her employer keeping her working for 4½ years after her diagnosis of young onset dementia would turn out to be almost unique. It suddenly seemed that many newspapers, magazines, tv and radio stations globally wanted to cover our family's experience and so too did dementia charities, in particular Alzheimer's Society here in UK.

As someone who had been formally trained in media relations and public speaking I felt compelled, when asked, to use my voice to talk not only about Yvonne's journey from diagnosis to retirement but also about what it was like transitioning from my full time international marketing role to full time carer.

Initially I spoke to new employees of Alzheimer's Society at their induction days, presented at conferences and continued to undertake press interviews. My situation soon changed because by May 2019 I was exhausted and could no longer look after Yvonne 24/7 and so, as a family, we took the decision that the best possible care she could receive would be in a care home.

The onset of the COVID pandemic in March 2020 and the resultant lockdown of care homes, with doors permanently closed to all visitors until April 2021, became a game changer for me. There was huge media interest in how dementia residents were suffering during this time and the impact it was having on their immediate family members, like myself, and I appeared regularly on television (with film crews using my garden for interviews) and spoke via Zoom to politicians





Trevor Salomon acting as host at this year's Alzheimer's Society Annual Conference

about the need to relax the cruel visitation restrictions imposed on care homes.

This year I became Chair of the Lived Experience Advisory Panel for a three year international technology project the objective of which is to help people with dementia retain their independence <https://dementia.longitudeprize.org/> and I was the recipient of a Dementia Hero Award for Campaigns and Influencing from Alzheimer's Society. I would never have believed such an opportunity and such recognition would come my way.

Currently I volunteer my time for five dementia organisations including running a small support group for elderly carers. I find it very hard to decline requests to be involved because I feel passionately about raising awareness of the realities of living with dementia, the need for social care funding and especially supporting other carers all of which gives me privileged insights into my role as Vice-Chair of the EDCWG and how I can contribute.

Dementia clearly derailed my intended plan for retirement. Yvonne and I wanted to travel and immerse ourselves in other cultures but it was obviously never meant to be.

**Liv Thorsen, member of the EDCWG, Norway**

Through my husband's participation in the National working group of people with dementia, as a part of National Association for Public Health in Norway, I meet as a carer

four times a year. Various research projects are presented and both those with a diagnose and we as carers gives input. We have met the Minister of Health and gave input to national plans, for example the "Dementia plan" and "Stay safe at home". We also give input on information materials distributed by the National Association for Public Health.

Locally, together with the municipality's Dementia Coordinator, I give courses for employees in the service industry on the theme of a "Dementia-friendly society". In 2023, we hold courses for 75 taxi drivers, employees at the library, at the city shopping centre and to the politicians.

I do a lot of communication work, give courses in the county for couples which one has dementia diagnosis, and are between 50-65 years old. This year we have an election in Norway, and I attend a group directed by The National association of public health (NFFHI) in our county who is working towards the different political parties.

In April I led a "sofa dialogue" with a well-known Norwegian author who has Alzheimer and just published a book from his daily life. A bit earlier my husband and I participated in a conversation for the audience after a theatre play about dementia.

As a board member of NFFH Innlandet, I was asked if my husband could become a member of the national working group for people with dementia, (NWGPWD) and he attended in 2022. I was asked because

I had been visible through my involvement locally, at county level, as well as my political involvement.

This work gives me more and more knowledge and a greater overview of what is happening nationally, regionally and locally.

Holding courses, various events, following research gives me more security to be a member of the EDCWG.

Through the NWGPWD, where my husband is a participant, we regularly meet decision-makers to whom we can give input on what is important.

Norway has a National Dementia Plan published by the government, which is revised regularly, and here we recognise input given by patients and carers. All this activity makes me more secure when I meet both patients, carers, professionals and politicians.

There are many good tasks written in the National plan, but there is often a gap when it comes to implementation and practice in the municipalities. As a politician, I have both a responsibility and an opportunity to influence the politics in this area.

I have an appeal for our politicians to have a greater focus on the quality provided to people with dementia and their supporters, so that they will experience the best possible quality of care and a good quality of life. Much is required by laws, but not on the quality of life.



Liv Thorsen (second from left) taking part in Norway's national dementia week

# NHS England publishes joint guide with Alzheimer Europe on intercultural dementia care

Earlier this year, NHS England worked with Alzheimer Europe to update its 2020 Intercultural Dementia Care Guide, aiming to raise awareness of the challenges people from ethnic minority communities face when accessing dementia care and help narrow the health inequalities gap. We spoke to Professor Alistair Burns, NHS England's National Clinical Director for Dementia and Older People's Mental Health, to find out more about the project.



Alistair Burns

## What key messages from the original 2020 guide really resonated with NHS England and how did this joint venture come about between NHS England and Alzheimer Europe?

In July 2023, our chief executive Amanda Pritchard said: "We've got potentially a million people in this country who've got dementia now. It's the biggest killer in the UK." We know that the number of people living in England with dementia from an ethnic minority background is expected to double by 2026. We also know that people from ethnic minority communities often face delays in dementia diagnosis, barriers to services and a lack of culturally competent dementia care.

Reducing healthcare inequalities is a key priority for NHS England, and so we were keen to help address this. We wanted to create some

resources to support health and care staff, as well as some resources to raise awareness of dementia and how to access care with communities at risk of health inequalities.

The first thing we did was some desk-based research to find out what existing guidance was already available. We were really impressed with the Alzheimer Europe 2020 Intercultural Dementia Care Guide which was well-written, had input from relevant industry experts and included practical tips that health and social care staff could put into action.

As it was written for a European audience, we approached Alzheimer Europe with a request to update the document so that it would be relevant and applicable across England. We also wanted to include some additional signposting to local support and add some content from our e-learning module – which was also in development at the time.

We were really pleased that Alzheimer Europe allowed us to use their existing brilliant resource as a foundation to our own offer.

## Why is this such an important publication?

A clear need for this type of information and guidance has been highlighted by many reports including a 2022 Alzheimer's Society review which showed inequalities in diagnosis, care and support for the South Asian community.

As part of NHS England's commitment to reducing healthcare inequalities, we were compelled to investigate what we could do as a national organisation to support health and care staff working across England to improve the access, experience and outcomes of dementia patients from ethnic minority communities.

NHS England's Dementia and Healthcare Inequalities Improvement teams worked closely together to form a working group which included representation from Alzheimer Europe, charities and dementia health and care professionals.

We also worked very closely with Meri Yaadain, a specialist organisation supporting South Asian patients in the North of England who also supported Alzheimer Europe's original 2020 intercultural guide.

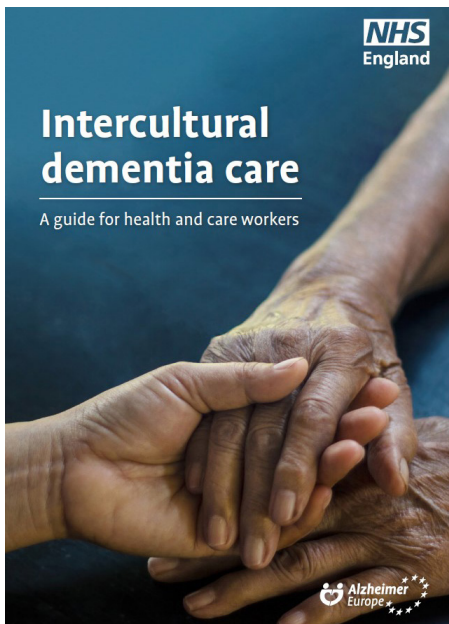
The publication is important because it brings together all the learning from Alzheimer Europe, as well as input from our working group, authors of our new e-learning module and people with lived experience. We hope it will act as an informative resource for staff, as well as give people and teams practical advice on how they can tailor the way they deliver or design dementia services in the future.

## How does NHS England plan to use it?

We have published the guide [on our website](#) and shared it with our network of dementia







clinical leads. As part of the campaign for Dementia Action Week, we also shared the guide with relevant stakeholders so that they can cascade the guide to their networks

– this includes care home organisations, relevant charities and organisations that work with ethnic minority communities.

We continue to promote the guide wherever possible – including regularly across our social media channels.

Feedback we have received on the guide so far has been very positive and we were pleased to see the [WHO Dementia Observatory Knowledge Exchange](#) recently add the publication to its platform.

**The guide was launched during Dementia Action Week. Were there any other materials or publications launched by NHS England during the week that may interest our readers?**

The guide was part of a suite of materials designed to support both healthcare professionals and communities regarding intercultural dementia care.

In addition to the guide, we also produced:

- A [new free e-learning module](#) for health and care staff in partnership with the Royal College of Psychiatry,
- [Two new culturally competent activity booklets](#) for use in care settings; one tailored for South Asian communities and one tailored to Black Caribbean/African communities and
- A [new leaflet](#) designed for ethnic minority communities – for Voluntary, Community and Social Enterprise (VCSE) and faith organisations to use to raise awareness of dementia signs and symptoms and how to access support.

We hope that these resources support staff and communities in delivering and accessing better dementia care. We also hope they continue the conversation around the role we can all play in reducing healthcare inequalities.



# PAVING THE WAY FOR BETTER BRAIN HEALTH

Our commitment in Alzheimer’s disease (AD) has the single goal of delivering holistic, preventative, and management solutions that will support patients, their families and caregivers throughout their dementia journey, making a meaningful difference to people’s lives.

August 2023  
EMEA-PIP-23-00082



# Managing dementia in dual-heritage families

In this article, Dr Mohammed Akhlak Rauf MBE, Founder & Director, Meri Yaadain CiC, United Kingdom (UK) and Dr Mary Tilki, Patron of the Cuimhne Irish Memory Loss Alliance, UK, discuss some of the challenges encountered when trying to manage dementia in dual-heritage families and couples. For the purposes of this article, the term ‘dual-heritage’ also includes the term ‘mixed-race’.



Mohammed Akhlak Rauf



Mary Tilki

Dementia affects all families in different ways. Changes in behaviour in dementia, can often be explained by habits, customs and traditions from an earlier period in life. These may be unknown to partners or family carers. Differing worldviews can lead to different perspectives on causes and interventions. There is evidence that the numbers of people with dementia from minoritised ethnic communities is increasing and will continue to do so. Minoritised communities are less knowledgeable about dementia, seek help later, often in crisis and are less likely to be offered external help. Intercultural care too, can only be effective where service providers have moved from cultural awareness through to cultural competency. Where one partner develops dementia in a dual-heritage relationship, any limitations in awareness of the partner’s culture can potentially lead to ignorance relating to the culturally appropriate social and personal care needs of the partner living with dementia.

Recent census data demonstrates that the fastest growing ethnicity group in the UK are those in the ‘mixed-race’ category. Although

the profile of this group is younger, their parents and possibly grandparents, from different ethnic backgrounds belong in the older age groups. Nevertheless, dual-heritage couples are unique in that they have had to traverse a journey that has encountered a number of barriers from the acceptance of their relationship by the communities of both partners and their exposure to racism and prejudice.

As dual-heritage couples in the UK, many faced stigma in their communities, their children faced racist abuse in schools and on the streets, and the couple being ostracised for marrying outside their respective communities. Whilst dual-heritage couples have usually coped well with holding together their relationship, when one individual in that relationship is affected by dementia, there is little in the way of social support to help their mixed cultural values and traditions.

It is the later years in that relationship that could be the most testing for either of the couple, especially for the partner providing care. The individual affected by dementia may revert to their first language, adopt behaviours accustomed to their heritage rather than those adopted throughout their married life with a partner. For example, speaking a different language, raised on eating different foods, listening to different music, perhaps dressing differently and possibly being of a different faith.

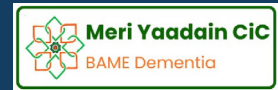
This issue may not be as prominent as expected in places such as the UK, but the history of people marrying outside of their culture – such as Polish, Ukrainian and Irish

women marrying English men, or men from the Caribbean, from South Asian, Mediterranean or from the Middle East, was not hidden by unaccepting societies during the 60’s and 70’s. Some were outcast from their family or community; but were neither fully accepted in their spouse’s. It is those very same people who may now need to support their partner from a different cultural heritage with aspects of their personhood which may be unfamiliar to the partner undertaking care of their dementia. Some families may see symptoms of dementia as a result of mental illness, spirit possession, a test of faith or punishment from a higher being and as such, something to be tolerated or about which nothing can be done. There may also be reluctance by the younger generation to challenge family hierarchy.

It is difficult enough when the caregiving partner feels they are losing their partner to dementia, but where there is a change in culture, language or even social values or norms based on cultural heritage, the loss must feel more profound. Migratory experiences and lived experience relating to racism and prejudice can lead to one of the two partners being faced with dealing with aspects that go beyond their relationship and the many years of living together as a couple. A huge challenge for the care giving partner is that their partner’s formative language, culture, faith, values and traditions may be unknown to them or their family.

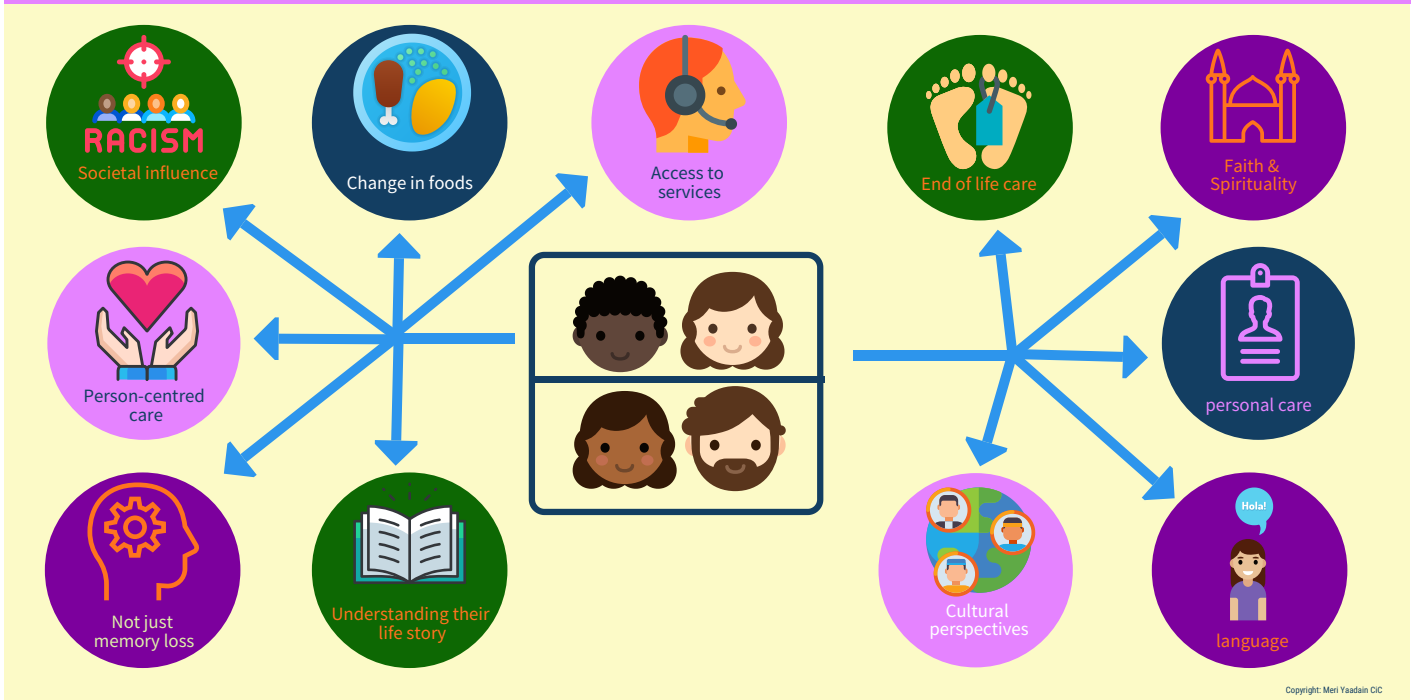
Several aspects come to mind when considering what may become a challenge:

1. Language – usually an obvious challenge if the person with dementia reverts to their first language, leaving the partner with a difficulty in being able to communicate with them.
2. Faith – if the person living with dementia reverts to a faith that they lived with in their earlier years, the partner giving care, may face a challenge in being able to support their partner to fulfil religious or spiritual obligations.
3. Culture – thinking about dress, music, social norms, the partner providing the care may find it difficult to provide cultural support if they are unfamiliar with



# Dual-heritage families and caring for dementia

## Factors to take into consideration



Copyright: Meri Yaadain CiC

lived experiences of their partner before they married.

4. Services – being able to access appropriate support requires a number of factors. Information which is relevant to the person living with dementia, including language and images that are relatable may be lacking. Mainstream services rarely understand the nuances of cultural appropriateness which are needed by the dual-heritage couple, both as caregivers and care recipients. Like many seldom heard and underserved groups, communities and people in dual-heritage families are not ‘hard to reach’. However, services need to reach out to them rather than simply adopt an ‘our doors are open’ perspective.

5. Stigma and societal challenge – there are still some challenges in accepting dual-heritage couples. There is often a lack of, or unwillingness to, understand and support the partner with dementia where the couple are from different ethnic groups. Not totally understanding or being familiar with the cultural heritage may mean the caregiving partner being judged by the wider family network or neighbours’, for example not being able to cook food that is authentic to cultural styles.

Worldviews on what dementia is and how it affects people can be very different between cultures. In dual-heritage relationships, family carers may not be aware of the different worldviews and therefore unable to portray the perspectives of their family member.

Stigma and suspicion arising from past experiences of social and health services and a fear of institutions coupled with seeing dementia as a taboo can lead to hesitancy in reaching out to services. Where services have a lack of knowledge and cultural competency, their ignorance could lead to families seeing their support as inappropriate and unhelpful.

Knowledge of dementia is often lacking in minoritised communities, but the knowledge about coping with dementia in dual-heritage families is even less available. If the voices of these couples are seldom heard, they become irrelevant in the wider research, debates and narratives associated with care. However, we would argue that that there are additional difficulties for dual-heritage couples and families being able to access appropriate support.

## Dementia and the LGBTQ+ community

Everyone’s experience of dementia is unique, but there are many additional challenges that LGBTQ+ people affected by dementia may face. We spoke to Paddy Crosbie, founding member of the Dementia Carers Campaign Network, Ireland and Dianne Gove, Director for projects at Alzheimer Europe. Paddy shares his personal insights in this area, while Dianne provides her professional perspective, rooted in her role as chair of the expert working group responsible for our 2022 report on sex, gender and sexuality.



Paddy Crosbie (right) with his husband Derek

### Paddy Crosbie, founding member of the Dementia Carers Campaign Network, Ireland

Paddy Crosbie lives in Dublin and cared for his late husband Derek who sadly passed away in November 2021. Paddy has been involved with the Dementia Carers Campaign Network in Ireland, since its beginnings in 2013. He has been involved in policy consultations, political advocacy, raising awareness of the issues affecting carers of those living with dementia, through media, and using the arts as an innovative way of communicating to a wider audience outside the dementia community. Prior to retiring early to care for Derek, Paddy worked in local government.

#### Paddy shares his experience

I live in Dublin and cared for my late husband Derek who sadly passed away in November 2021. I have been a member of the Dementia

Carers Campaign Network in Ireland under the auspices of The Alzheimer’s Society of Ireland (ASI), since it began in 2013. This involvement has led me to be involved in policy consultations, political advocacy, raising awareness of the issues affecting carers of those living with dementia, through media, and using the arts as an innovative way of communicating to a wider audience outside the dementia community. Prior to retiring early to care for Derek, I worked in local government.

I hope that I can share some insights into both my role as a carer for my husband, as well as our relationship and some of the difficulties we encountered as a gay couple, in our life together. We were concerned that this could be an issue in accessing the care that was needed, but thankfully we were delighted, surprised and perhaps lucky (though of course this should not be a matter of luck) to receive excellent and unbiased support. I know from friends that it is not always the case particularly prior to recent changes in legislation in Ireland.

At the time of Derek’s diagnosis, at the Memory Clinic at St James’s Hospital in Dublin, we met with social worker Matthew Gibb who helped us immensely to deal with the

diagnosis. He helped us both to feel more confident that we could “get through this” and his wise advice to keep Derek doing what he could for as long as possible was a great mantra for us both to live by and help us navigate the journey we were beginning.

He told us about the Irish Dementia Working Group (IDWG) which was being set up and which I felt would provide welcome cognitive stimulation for Derek, along with allowing him and others with dementia to have their voice heard. Derek became a founding member of the IDWG and his involvement, I feel, did slow down his need for full-time care and was a highly positive experience. The need for extra care at home however, did arise and so I began to source it and because he was under the age of 65, Derek wasn’t initially entitled to home care. It should be remembered that at this time, when I began looking for support, it was very difficult, as we were not legally recognised as a couple (Ireland legalised same-sex marriage in 2015). Derek’s mother was considered as his next of kin and not me - something I found very difficult as we were together for 24 years when he was finally diagnosed with early onset Alzheimer’s disease.

I knew that Derek would want a male carer and would not be as comfortable with a female carer. It took quite some time to get the required care in place, but when it eventually happened, the carer, Stephen, was wonderful as he fully understood and accepted our relationship as a gay couple, considered both of our needs and opinions and was sensitive to Derek’s desire to continue to do as much he could for as long as possible. It was very fortunate that there was a change in Ireland just as Stephen was about to start with us, meaning Derek then qualified for home care, which reduced the large financial impact.

As Derek’s condition progressed, it became evident that more carers would be needed so with Stephen’s help, I managed to get two other carers in the team and we worked out

“thankfully we were delighted, surprised and perhaps lucky (though of course this should not be a matter of luck) to receive excellent and unbiased support.” Paddy Crosbie



“As I reflect, while writing this article, I find I am very proud of my country, Ireland, for having made important social and legal changes around LGBT rights and same-sex marriage.”  
*Paddy Crosbie*

how it would progress and thankfully it was successful.

I must explain that I was fully aware of a legacy that we were dealing with. When Derek and I met in 1988, homosexuality was illegal (it became legal in Ireland in 1993) and so we, particularly Derek, were understandably concerned about discrimination and how we would be accepted as a gay couple. Derek had always been very cautious about bringing strangers into our home as he had witnessed, first hand, bricks being thrown through windows of friends in same-sex couples. Strangers therefore made him nervous at times.

That residual fear stayed with me and when accessing care for Derek I was careful to ensure that there was not a parade of different strangers coming into the house. The need for consistency is so important in the

care of someone living with dementia. My insistence on this approach made it difficult, at times, to get any care at all, as the three carers we had agreed on were not always available.

I began to realise that another level of care was now needed and so I sought out day-care services, which were provided by the ASI. It was really important to me to always be upfront about our relationship when seeking any services for Derek. I looked to the ASI, to engage with their day care services, as we were “embraced” by the staff there and our relationship was highly respected.

In April 2020, Derek collapsed at home. This was the start of the COVID pandemic, so I was not allowed to go with him in the ambulance and during the eight weeks Derek remained in hospital, we were not allowed to see each other. It was heart-breaking to be apart, and all the harder for me as I came to the realisation that I would no longer be able to look after Derek at home, a concern that was confirmed to me by his consultant at the hospital. This meant having to try and find a nursing home during COVID - a daunting task, especially given that so many nursing homes are still run with a religious ethos, and I was so afraid that, as a gay couple, we would not be accepted for care and this

would be a real problem. It was so wonderful to find a newly-built, privately-run nursing home and which was superb from that point of view. We were both welcomed as a couple and our relationship was treated with the respect I wanted.

“I do hope that I can show others not to be afraid to stand up and say who they are.”  
*Paddy Crosbie*

All in all, the most difficult thing for me was not accessing or connecting with care services but rather it was seeing Derek being taken away from me, bit by bit. There is no pathway for that and each day is different, so you have to hope what you are doing is right. As I reflect, while writing this article, I find I am very proud of my country, Ireland, for having made important social and legal changes around LGBT rights and same-sex marriage. I do hope that I can show others not to be afraid to stand up and say who they are. It is hard, I fully understand, but being honest is the best way and in doing so, I was able to achieve a much better quality of life and level of care for my darling Derek, which makes me feel so proud.

## Dianne Gove, Director for Projects, Alzheimer Europe

Dr Dianne Gove joined Alzheimer Europe in December 1996. She contributes towards several EU-funded projects in relation to ethics and Public Involvement, supports the members of the European Working Group of People with Dementia (EWGPWD) and leads Alzheimer Europe’s ethics work on disability and inclusion. She chaired the expert working group responsible for our 2022 report on sex, gender and sexuality.

**Dianne shares details of Alzheimer Europe’s expert working group report on sex, gender and sexuality and discusses that are of particular relevance to people with dementia and carers from LGBTQ+ communities**

In 2021, Alzheimer Europe set up an ethics working group to focus on sex, gender and

sexuality. Our main aim was to raise awareness amongst health and social care workers about these issues and how they impact on the everyday lives of people with dementia. A further key goal was to promote the right of every person with dementia to be treated with respect and to have access to timely diagnosis, treatment and good quality care and support.

It is often assumed that people with dementia are heterosexual (“straight”), married or have been married, and that they identify as either male or female. This reflects what is known as heteronormativity, namely the assumption that everyone is straight, that romantic and sexual relationships are always between one man and one woman, that this is the only “normal” or “natural” way to express



Dianne Gove

sexuality and attraction and that people all identify (in terms of gender) with the biological sex they were assigned at birth (known as “cisgender”). This is all seen as the norm and anyone not conforming to this is considered as deviating from that norm. These assumptions fuel homophobia and transphobia. While matters of sex, gender and sexuality are relevant to everyone with dementia, there are additional challenges with regard to the wellbeing, safety and rights of people with dementia from LGBTQ+ communities, many of whom have experienced prejudice, discrimination and violence in the past.

People tend to live within networks of relationships, with partners, friends, acquaintances and outsiders in which self-identities are constructed collectively, in collaboration with those people. People present their “real selves” (i.e. their perception of themselves that they want other people to recognise and accept as being who/what they are) and the expectation is that this self will be accepted by others. As dementia progresses, this collaborative process may gradually become more one-sided. People with dementia may start to need more support from other people and greater recognition and understanding of who, and what, they are presenting themselves to be in terms of their gender identities. The management of gender and sexual identity by people with dementia from LGBTQ+ communities involves specific challenges with regard to “coming out”, avoiding “being outed” and “passing”, as well as challenges in relation to their rights and identities being recognised, accepted and equally valued.

When it comes to research and planning services and support, sex, gender and sexual identities are often overlooked or not considered relevant to people’s experience, needs, wishes or rights. At times, they are nevertheless noted, particularly when they clash with

**Recommendations from our 2022 report:**

The report written by our expert working group on sex, gender and sexuality provides a number of recommendations on how policy makers, health and social care professionals and students of health and social care, among others, can ensure that people with dementia do not meet with prejudice and discrimination based on their sex, gender identity and sexuality, but rather that these factors are considered so as to provide appropriate care and support that is both adapted to their personal needs and mindful of their rights. Here are some of these recommendations:

- Reflect on your own assumptions about gender, sexuality and relationships.
- Don’t assume that everyone with dementia is cisgender and heterosexual.
- Don’t impose or let your own moral standards and beliefs restrict other people’s behaviour and opportunities with regard to sexuality and relationships.
- Include friends, partners and chosen family in the care and support of people with dementia.
- Create and communicate a feeling and atmosphere of safety and acceptance of everyone.
- Support everyone’s ability to establish and maintain meaningful relationships and to express their sexuality.

heteronormative assumptions. For example, Jacques may become “Jacques who used to be Jaqueline” and has dementia, and not the hairdresser, avid football fan and loving father of three children. Annabel may become “the lesbian woman with dementia” and not the retired nightclub singer and botanist.

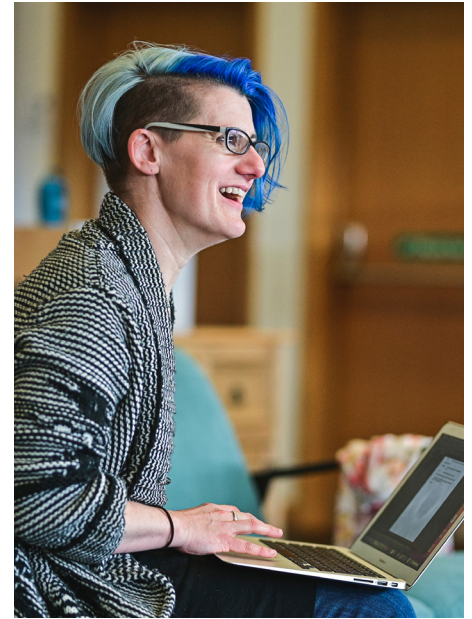
People with dementia from LGBTQ+ communities, as well as their carers, are often exposed to blatant or subtle discrimination, hostile attitudes and behaviour, inappropriate humour and “banter”, violence and microaggressions (subtle verbal or nonverbal behaviour, committed consciously or not,

that is directed at a member of a marginalised group, and has a harmful, derogatory effect) within the health and social care system that should be providing them with support and care. Sometimes, this is in the form of informal restrictions of legal capacity. This might, for example, involve attitudes, practices and rules which hinder the free expression of sexuality and relationships of LGBTQ+ people in residential care homes. Similarly, prejudice and homo/transphobia may lead to sexuality and relationships between LGBTQ+ people being portrayed as a “challenge” or a “medical problem” to be controlled.

“People with dementia from LGBTQ+ communities, as well as their carers, are often exposed to blatant or subtle discrimination, hostile attitudes and behaviour, inappropriate humour and “banter”, violence and microaggressions within the health and social care system that should be providing them with support and care.” *Dianne Gove*

# “Es & Flo” – a play celebrating love and exploring some of the difficulties faced by same-sex couples when one has dementia

The award-winning play “Es & Flo” celebrates the love of an older lesbian relationship, while giving the audience an insight into some of the difficulties faced by same-sex couples seeking care, when one of them is diagnosed with dementia. Wales Millennium Centre produced the play which ran both there and at the Kiln Theatre in London. We asked playwright Jennifer Lunn to tell us more about her inspiration for the play.



Jennifer Lunn

**Your play “Es & Flo” celebrates the love of an older lesbian relationship. It also gives some insight into difficulties faced by same-sex couples when one partner needs to access dementia care. What drew you to this topic and what is the primary message you want to convey with this work?**

I started writing Es & Flo about ten years ago, not long after the death of my grandmother who had lived with vascular dementia for about ten years. 2013 was also the year that equal marriage came into law in England and Wales, which raised the question for many long-term LGBTQ+ couples about whether they wanted to formalise their relationships in that way. I was very struck, at that moment, by the fact that we had people whose lives had included homosexuality being illegal, Section 28 (a legislative designation for a series of laws across Britain that prohibited the “promotion of homosexuality” by local authorities, introduced by Margaret Thatcher’s Conservative government, it was in effect from 1988 to 2000 in Scotland and from 1988 to 2003 in England and Wales), the AIDS epidemic, Greenham Common (Greenham Common Women’s Peace Camp was a series of protest camps established to protest against nuclear weapons being placed at RAF Greenham Common in Berkshire, England, between 1981 and 2000) and now this huge new shift.

Those two ideas around dementia and the changing status of and attitudes towards LGBTQ+ people came together for me as I wondered what the impact of dementia might be on a long-term LGBTQ+ couple, especially if they hadn’t been publicly “out”. Thus, Es and Flo were born. A couple who had met in the 1980s and been together ever since but who had kept that relationship hidden.

At first, to try and gain custody of Es’s son, then to protect Es’s job as a teacher/head teacher, and later, because Es didn’t want to let her son down. They were, to all outside eyes, simply friends - Flo the lodger whom Es had taken in.

By the time the show was finally finished and produced this year, another ten years had



Doreene Blackstock (left) as Flo and Liz Crowther (right) as Es





Adrianna Pavlovska (left) as Beata and Doreene Blackstock (right) as Flo

passed and over 42,000 LGBTQ+ couples have been married. Kasia, the little girl in the play, is eight and has only ever lived at a time when equal marriage existed in Wales, where the play is set. There is a wonderful conversation between her and Es where she casually asks why she and Flo aren't married and then says, without even looking up from her colouring, "Some girls marry girls. Get over it." For me this really dramatised the situation for older LGBTQ+ people who may have hidden their sexuality and their relationships for many years and now find themselves being told to "get over it", and I wanted to talk about this, particularly in terms of how we support these people, if and when they need to access dementia care.

**Secrets are a strong theme in the play. Tell us about this theme, particularly in connection with the LGBTQ+ community, where many people felt obliged to keep secrets, even in the recent past, to ensure their own safety or to protect their loved ones. How does the secret-keeping unravel, when Esmé (Es) develops dementia?**

We first meet Es and Flo on Es's 71<sup>st</sup> birthday. It is clear that her memory is going, but we see both her and Flo masking and sidestepping the issue. Flo is trying to persuade Es to sign lasting power of attorney (LPA) forms, which would give power of attorney to Flo

when the time came. However, Es is resistant as she still refuses to tell her son about their relationship. When Beata, a carer arranged by Es's son, arrives to help Es and is followed by Catherine, Es's daughter-in-law, wanting to move Es into assisted living in London, the forty-year-old secret of their relationship threatens everything. Not understanding that they are a couple, Catherine tells Flo "You've obviously been a good friend to her, but it's time to let us take over now." In that moment, we see just how powerless an unrecognised partner can be.

It is Kasia, Beata's daughter, who is the key to the unravelling of the secret. Es is instantly at ease with the little girl and, with her guard down, she answers Kasia's innocent questions truthfully. She tells Kasia all about a 'pretend' wedding that she and Flo had and with a passing kiss on Flo's lips, unwittingly outs them to Beata who says that they must tell Peter and Catherine if they want to stay together. However, Es continues to resist, despite Flo's protestations. I was interested by the idea that someone living with dementia and feeling out of control of so many things, might fight to hold onto this one bit of control they have – even if the consequences were something they absolutely didn't want. The couple's secret is finally revealed to Catherine, when Es falls at home and Catherine arrives to find Flo cradling Es in her arms.

Later in the play, another of Es's secrets, the reason she left her husband, is revealed to Catherine by Es when she is in hospital and disorientated. She mistakes Catherine for someone from her past and tells her how Jim pushed her down the stairs and that she cannot go back. She poignantly asks her to look after her son (Catherine's husband), leaving Catherine with a new understanding of this complicated family dynamic.

Watching Es slip between different levels of lucidity throughout the play, in a way which I hope is truthful to the early years after a diagnosis, and watching Flo struggle with how and when to step in, without disempowering the woman she loves, felt very important to me. Too often the portrayal of dementia on stage or screen goes from someone losing their keys to not knowing anyone in a very short space of time, when in fact we know this journey is long, complex and not linear. Someone's lucidity and memory will come and go all the time, depending on all kinds of factors including stress, tiredness and unfamiliarity with their environment. This makes for wonderful drama in the play, but is of course often heart-breaking and so difficult for everyone living through it.

**The way that you depict some of the facets of dementia, as experienced by the diagnosed person, their partner and others close to them is very realistic. How did you achieve this? Were the characters inspired from real life or did you involve people with lived experience in the process in some way?**

My family navigated ten years of my grandmother's dementia, constantly re-negotiating our relationships with her and trying always to find the love and humour that still existed throughout. Lots of Es is based on my grandmother and I hope that other people will recognise some of the masking techniques that she would use. I also worked on a number of creative reminiscence projects with people living with dementia and their family carers and so have observed countless couples experiencing similar journeys to that of Es and Flo.

Another huge influence on the play was the writings of Wendy Mitchell who was

diagnosed with young-onset dementia at the age of fifty-eight. She is an incredible advocate for people living with dementia and her first book “Somebody I Used to Know” gave me some important insights into the experience of the person living with dementia. It really strengthened my wish to place the play in the middle of that time where Es is still very aware that she is forgetting and is struggling with that experience. Wendy’s descriptions of her last few attempts at cooking fed specifically into a scene in the play where Es tries to make toast and nearly starts a fire.

Our wonderful director, Susie McKenna, also brought her own experiences of navigating dementia with family members to the production and that was hugely important in helping our fantastic performers Liz Crowther (Es) and Doreene Blackstock (Flo) to create the incredibly truthful performances they gave.

I hope that we not only presented a truthful version of dementia but also explored how good care and support can make this experience a bit easier. I was absolutely thrilled to read a blog written by Lyn Romeo, Chief Social Worker for Adults at the Department of Health in the UK, where she wrote about the play and how Beata, the carer, “demonstrated fundamental principles of social work and good social care practice.”

The blog is available at:  
<https://socialworkwithadults.blog.gov.uk/2023/06/14/celebrating-pride-month/>

**Congratulations on receiving the Popcorn Writing Award (2020) and the Nancy Dean Lesbian Playwriting Award (2022), and on the play’s success with critics and theatre-goers alike. What has the feedback been about what they have found so compelling about the story and the characters?**

Winning prizes and getting lovely reviews in the press is great, obviously! And I hope that the attention those brought to the play also raised some awareness around the topics we were exploring. I had never imagined that the Government’s Chief Social Worker would be writing about us in her blog, but it is amazing to be reaching out beyond our theatre audiences in that way. The most important thing, I think for all of us as a company, though,

was the audience response. We had so many people come up to us after the show to share stories of their own experiences. We heard a lot from people whose parents or older relatives had lived with dementia. We heard from a woman whose family had taken in an older gay man when his partner had died and he had been left with nothing, as their relationship was not recognised. We heard from dementia care nursing staff who talked about how they wanted to be able to better support LGBTQ+ people in their care and who had encountered families trying to push through LPAs without proper consultation with their family members. And we spoke to a lot of couples who were spurred on by the play to complete LPA forms and other paperwork to firm up their own relationships.

I hope that the play, whilst focussing on an LGBTQ+ relationship and highlighting the specific challenges around that experience, rings true for anyone who has had dementia touch their lives. To see not just the overarching emotions but also the tiny details of this journey played out is, I hope, reassuring and validating. Theatre exists as a way of letting us know we are not alone and also allowing us to consider, from a distance, how we might act in certain situations. At its heart Es & Flo is a play about love and that I think is the thing that resonates most strongly with audiences. It is at the heart of every relationship affected by dementia and is what ultimately survives beyond everything else.

**The Greenham Common Women’s Peace Camp features heavily in your play. Is there a particular reason?**

Greenham Common was the place where these two characters met and it felt right to have it present for a number of reasons. It is a play about memory and I wanted to find a way of, amongst the frustrations and challenges of living with dementia, showing how these two women had lived and loved throughout their 40 years together. The stories they tell serve to underpin the strength of that love which holds them together as they enter this new chapter of their lives.

The other aspect of Greenham that felt very important to feature was that of community and chosen family. For many LGBTQ+ people,

chosen family is what they rely on and Greenham Common was a place where women in the 1980s really began to discover that. Greenham was a place where women went to protest nuclear weapons, but once there, discovered new ways of living and loving which led to them forming new and wonderful communities. The play echoes that, as the five women of the play start at odds with each other in many ways, with Flo determined to reject any intruders as she tries to manage Es’s dementia on her own. But by the end of the play these women are a family and, whilst we know that Es’s journey will not be plain sailing, we know there is this strong support network in place to help.

**Do you have plans to write other works on topics related to dementia and the LGBTQ+ community?**

I started writing because I wanted to see stories and hear voices that we don’t traditionally see. Most of my work features LGBTQ+ characters and I think themes of memory will always feature as it is such rich territory in stories. I hope that it becomes much more common to see more older characters, more LGBTQ+ characters and more truthful depictions of those living with dementia – particularly those in the earlier stages of their dementia journey when they are still very much living their lives, contributing to society and having full and loving relationships.



Liz Crowther (seated) as Es and Doreene Blackstock as Flo (standing)



## People with young-onset dementia tell the Netherlands not to write them off in TV series “Restaurant Misverstand”

Henriette Brons, Corporate Communications Teamleader at Alzheimer Nederland, gives us some background about the series – how it came about and why it is important for the people with dementia who were involved and how it helped towards ensuring a more inclusive society, with a better understanding of dementia.



Henriette Brons

“Because I’m important!” says Pieter, as he firmly prods the chest of the Minister of Health, who is watching Pieter and his colleagues take part in a special catering assignment. This is just one of many moments in the Dutch TV series *Restaurant Misverstand* that stops everyone in their tracks. Of course you’re important if you have dementia. Everyone is important. So why do we need to make a TV series about it? Because a lot of people have the wrong impression of dementia. It is more than just ‘forgetting things’, and it doesn’t only affect older people. But more importantly: life doesn’t stop

immediately after the diagnosis. You can still participate in society and have a fulfilling life. Henriëtte Brons, team leader of corporate communications at Alzheimer Nederland, tells us about three seasons of *Restaurant Misverstand*.

In 2019, we were approached by Talpa Media Network to ask whether we would consider working with them on a Dutch version of ‘The Restaurant that makes mistakes’. This series follows people with young-onset dementia, as they set up and run a pop-up restaurant under the watchful eye of a famous chef. They

work in the kitchen and wait tables. Our English sister organisation told me about their experiences working on the original: a fabulous, worthwhile project, which showed how much people are capable of when they work together. And more importantly: just how deeply these people with young-onset dementia are affected by the environment around them. Things in this restaurant may be a bit slower than you’re used to, or you might get the wrong order, but does it really matter? Really? If something going wrong becomes the norm, stress levels drop and fewer ‘mistakes’ are made. Happy staff, happy customers, and a world where it’s okay to make a mistake.

### An adventure for the participants and the show’s creators

One in every five Dutch people will develop dementia during their lives. 70% of people with dementia live at home. Dementia also affects younger people (<65 years), people who are still leading very active lives. Many of them have to stop work once they’ve been diagnosed and soon become isolated. *Restaurant Misverstand* seeks to highlight both these groups. What is the impact of dementia on your life when you’re still in your prime. Who are you if your work and hobbies gradually become impossible? What are you still able to do? Or perhaps we should say: what will the people around you still let you do? Are they asking too much or too little?



Pieter in action at the Restaurant Misverstand



Making a series like this is no mean feat. The people involved must be made aware of the impact. Their vulnerability is exposed on national television. Many of them don't realise that not only their friends and family will get a glimpse of their life with dementia, but also old classmates from school, their children's friends, the local baker, all kinds of people. The good, light-hearted moments, but also the intense sad moments.

It was a big adventure for Alzheimer Nederland too. There was a risk that the audience, but also our own people at grass roots level, would get the wrong message. Not everyone with dementia can work, or wants to work. Young people are usually reasonably fit, but hospitality is a stressful industry, even for people who don't have dementia. How do you stop people from laughing if someone makes a mistake? How do you keep everyone happy and healthy during the intensive filming days?

I was delegated to oversee the series as a representative of Alzheimer Nederland, including the casting with potential participants and their families. We wanted the programme to feature different types of dementia, men and women from every corner of the Netherlands and from different backgrounds. I was also present during filming and it was an intensive process. My main objective was to make sure that the right message would reach the audience and that nobody regretted taking part.

**How? With a dementia-friendly TV crew, case managers and genuine support**

Not every TV crew is necessarily patient and able to take a step back. They are primed to get the best shots. So we were lucky that the TV company Concept Street understood exactly what we wanted. They got a suitable team together, headed by an experienced, empathetic chief editor. From director to camera operator, and from presenter Johnny de Mol to head chef Ron Blaauw: the entire crew took the *Samen Dementievriendelijk* (Dementia Friends) training course to learn more about dementia. Hotel rooms were checked to see if they were dementia friendly, and a lovely team of taxi drivers took care of the transport to and from the restaurant.

**José: 'I'm allowed to make mistakes here'**

"In the final episode of the second season, José talks about her experiences during the TV adventure. She explains it perfectly: "Restaurant Misverstand is like a fairy-tale. You leave your house in the morning and step into a different world. A world where everyone has dementia, and you're just one of them. I don't have to be careful about not making a mistake. I'm allowed to make mistakes here. (She sobs gently). I want to live in a world like this forever. I don't want to walk on eggshells. Not just for me, but for my children too. They don't have to be proud of me, but the fact that they can see that I'm a different mother here makes me so very happy."



We're all moved, even the camera operator wipes away a tear. How on earth have we as a society managed to make these people feel that they have to walk on eggshells?!

*In loving memory of beautiful José, who cheered us all up with her ever-present sense of humour, and who sadly passed away just before the series was broadcast.*

Professor Marjolein de Vugt played an important role in the programme. She is the head researcher in various studies into the performance and care needs of people with young onset dementia and their loved ones. Her expertise was invaluable for the programme. She tested the participants before and after filming, to see whether the activities in the restaurant had benefitted their wellbeing. The conclusion: without exception all participants felt happier, even though the work had been intense and sometimes frustrating. They especially enjoyed the fun of working together with their colleagues. One of the participants even managed to write his name on a piece of paper, something he hadn't been able to do before. This was thanks to a stimulating environment and a renewed feeling of confidence. Fair to say that this was only a temporary result, but it was a very special moment.

I myself was always present during the project, but as I'm a communications manager and not a nurse or psychologist we invited a dementia case manager behind the scenes,

not just for possible emergencies, but also to look after the families and talk to them about the home situation. This was much appreciated.

**Three successful seasons and a mission accomplished**

The first series was broadcast on Dutch TV in August 2020. Two more series with new teams followed. Applications to take part flooded in. A lot of people with dementia want to be active, do something positive, experience something new, and so our mission has been accomplished. Everyone is happy and proud that they took part. They had a great time, laughed and cried together. People made friends for life. Not just the participants with dementia, but their partners and children too.

Three series were broadcast, each attracting an average audience of 700,000 viewers per episode, which are good figures for the Netherlands. The reactions on our social media were overwhelming. Healthcare professionals were particularly encouraging. "Finally a



Restaurant Misverstand Team 2021, with Marjolein de Vugt (right)

different view of dementia”, “See? Life doesn’t end with dementia”, “A series with laughter and tears, a real reflection of life with dementia”.

The participants became popular celebrities within our organisation, and certainly gained a place in my life. Three of the men from season one are now living in a special unit for young people with dementia. Ron Blaauw and I went to visit them recently. It was an emotional reunion.

### Spin-off

In response to the TV series, we were approached by various restaurants and companies keen to offer a job to someone with dementia (often on a voluntary basis). A lovely gesture, but not as simple as it may seem. The thing the participants enjoyed most was working alongside other people with dementia, ‘partners in crime’. And good care and supervision is essential.

So in 2021, we launched the *Onvergetelijke Kookclub*, a cooking club for people with dementia and their care-givers, inspired by *Restaurant Misverstand*. Every month, a chef

### Sonja: ‘That feeling of belonging is so important’

“*Restaurant Misverstand* made me feel as if I belonged”, says Sonja. She was 52 when she was diagnosed with Alzheimer’s disease. “That feeling of belonging is so important”. Sonja waits tables in *Restaurant Misverstand*. “As soon as I walked into the restaurant with two plates, I’d forgotten which table they were for. So I went back into the kitchen. Table five. But where’s table five? And which plate is for which diner? The best part was working with people with the same condition; we were all in the same boat. We could make mistakes and laugh at the same things. And shed a few tears, of course. But we’re used to that. It wasn’t always easy, but we made the most of it. I took part because I wanted to help raise the profile of early-onset dementia. When people hear dementia, they tend to think of old people, but I’m a young woman with a family. It’s good that we’re making programmes like this. I hope it will change people’s attitudes. I have dementia, but that doesn’t make me crazy or stupid.”





and a team of volunteers help people to cook a meal, which they eat together afterwards. This project is now being run in 30 locations.

Unfortunately, it has been announced that *Restaurant Misverstand* will not return to our TV screens. We are still in touch with the participants and their partners and we organise reunions. Every week my WhatsApp explodes with messages and photos. They visit each other if possible, keep each other posted on their personal situations or just wish each other a happy weekend. It's heart-warming really. Some of them are now in our 'Advisory Platforms' at Alzheimer Nederland. They come together, consult with us and offer advice about various issues and themes close to their hearts.


**New insights**

The series was more of a learning curve than we'd expected. For instance, people

with dementia fare better when they are not over-stimulated but also, perhaps more importantly, when they are not under-stimulated. It is important for them to challenge themselves so that they can discover what they're capable of. The feeling of pride if something works at the tenth attempt is incomparable. It's okay to make mistakes, and you see people's confidence grow if the environment stays calm. It's a simple tip for the people around someone with dementia: if you stay positive and encourage people, they can often do more than they, or you (as a family member or caregiver), think. People with dementia don't lose their capacity to learn. You can teach someone through repetition and by doing things together. It might take a bit longer, but perseverance pays off!

It's a fine balance, however, as some things can be too difficult and extremely frustrating. So you have to manoeuvre your way between 'too difficult' and 'worth trying'. I personally learned something that I'll never forget. Searching for

the 'correct' words to say that you can laugh with someone with dementia, but never at them, I was corrected myself by one of the participants. "I'd rather you laughed at me if I do something funny. Then I can join in. There's nothing worse than those well-meaning looks when you know you've said or done something a bit out of leftfield. Having a laugh puts things into perspective, and then we can all carry on as normal." Check. And yes, we laughed an awful lot.



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## New book “FAQs on Dementia” aims to give readers definitive expert responses to their many and varied questions on dementia

Dr Tom Russ is a consultant psychiatrist in NHS Lothian, Network Champion of the NRS Neuroprogressive and Dementia Network, and Director of the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh. Michael Huddleston is Alzheimer Scotland’s Dementia Advisor for Mid and East Lothian. He provides advice and information for people living with dementia and their families, and works closely with local Health and Social Care Partnerships. They tell us more about their new book “FAQs on Dementia”.



Tom Russ



Michael Huddleston

### What led you to write “FAQs on Dementia” and why did you feel that it was important to write this book?

Both of us work with people with dementia, Michael with the charity Alzheimer Scotland and Tom as a doctor in the UK National Health Service and in research. We had noticed that we were often asked similar questions by the people we come into

contact with. At the same time we were aware that people living with dementia and their families may find it difficult to find answers to their questions. While there are a number of sources of reliable information about dementia (as well as many unreliable ones!), it can be a confusing landscape to navigate and it seemed like there was a need for a single place where people could find answers to the most commonly asked

questions. We approached Sheldon Press who were interested in a book in their “FAQs on...” series and so we set to writing.

### What research was undertaken for this publication and who was involved in it?

We wanted the book to be useful and answer the questions people are actually asking. We know many people with dementia and their families are active on social media so we took to Twitter to ask people for questions they thought were important - either questions they wanted answered or questions they would have wanted answers to at an earlier stage. We also asked people we knew and colleagues to suggest questions. We are very grateful to everyone who suggested a question.

“ We wanted the book to be useful and answer the questions people are actually asking. We know many people with dementia and their families are active on social media so we took to Twitter to ask people for questions they thought were important.”

We grouped the questions together into chapters like “How can I reduce my risk of dementia?”, “Should I take part in research?”, or “How can I live well with dementia?” Once we had this basic structure, we divided the questions between us and began answering them. Much of our time in our jobs is spent answering questions like these with the people with dementia we work with. This meant that the process of writing felt a bit like pouring out everything that was in our heads onto paper.

Both of us are closely involved with Alzheimer Scotland, the main dementia charity in Scotland. They provide support services across the whole of Scotland and Michael is part of this as the Dementia Advisor for two counties close to Edinburgh. Alzheimer Scotland have generously funded the Alzheimer Scotland Dementia Research Centre and the Alzheimer Scotland Brain Tissue Bank – both of which Tom runs – for more than a decade.

“ We were delighted that Alzheimer’s Society selected it for their book club and are looking forward to hearing what their readers made of it.”

Because of this, we were delighted that the Scottish Dementia Working Group and the National Dementia Carers’ Action Group (NDCAN) contributed a foreword to the book. These are national, member-led campaigning and awareness raising groups for people living with a diagnosis of dementia and carers of people with dementia, respectively. We were also delighted that Alzheimer’s Society selected it for their book club and are looking forward to hearing what their readers made of it.

**Who is the book for? Is it exclusively aimed at people with dementia or is it also addressed to carers and family members?**

Without trying to be all things to all people, we did try to address both the person with dementia and their carer or family members at different times. Much of the book is directed at the person living with dementia or who is worried about their own memory. However, in some questions, there is a separate section aimed at carers and two chapters are specifically for them: “How can I best support a person with dementia?” and “Self-care as a Carer”. We want everyone who has a question about dementia to find an answer in this book.

**What can readers expect to get from your book and what do you hope it will achieve?**

Our main hope is that this is a useful book where people can find answers to important questions about dementia. The answers to the questions are short and easy to read so everyone should be able to find what they need. It is not meant to be a book to read from beginning to end, but one to dip into, perhaps looking at different questions at different times. We have attempted to cover every stage from risk reduction in mid-life through to the last stages of very advanced dementia and death.

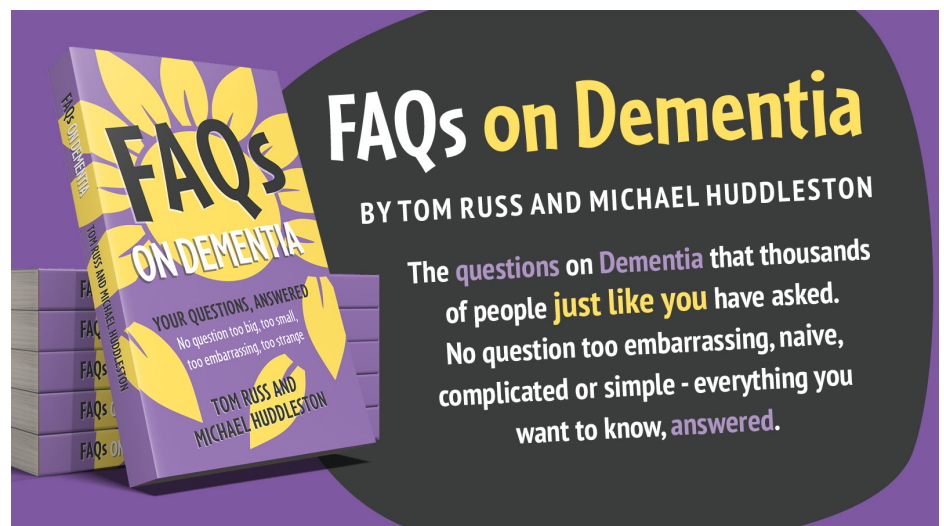


Tom Russ (left) and Michael Huddleston (right) at an event in a local Edinburgh bookshop

“ The answers to the questions are short and easy to read so everyone should be able to find what they need.”

We’re keen for everyone to be able to have access to this book. While it is available for sale (of course), we’re also encouraging libraries to stock it. We donated six of our free author copies to the libraries in Edinburgh and held a small book launch at a local library. We were very pleased to

be invited back to run a session on World Alzheimer’s Day in September. Tom even donated a copy to the wonderful library in Lerwick, Shetland, during a recent trip there! Whatever your situation, we hope you find the answers to your questions – either in our book or elsewhere.





## How Finland is seeking to respond to the challenges posed by dementia and to promote brain health

Following the appointment of new government in Finland in June 2023, Alzheimer Europe spoke to Ministerial Adviser, Satu Karppanen, and Senior Specialist, Seija Viljamaa, from the Ministry of Social Affairs and Health to shed some light on the recent strategic policies and what the priorities of the new government mean for people living with dementia.



Satu Karppanen



Seija Viljamaa

**WHO's Global Action Plan on the Public Health Response to Dementia 2017-2025 emphasises the strategic approaches of Member States to the treatment and prevention of dementia. Finland has had its National Memory Plan 2012-2020 and National Programme on Ageing 2030. What is the key impact of these programmes? How does Finland take dementia and the growing number of those who live with it into account at the strategic level?**

Finland's policy is to take a broad and phenomenon-based view of key societal issues

in its strategic programmes and to do away with diagnosis-based programmes. For this reason, measures to prevent and treat dementia were included in the National Programme on Ageing. The thematic content of this programme also provides good

“the measures being implemented in the National Programme on Ageing include, for instance, the development of lifestyle guidance in the wellbeing services counties that were launched as from the beginning of 2023 and especially the prevention of memory.”

support to the treatment and prevention of memory-related diseases. The National Programme on Ageing defined a shared direction and cross-administrative means for preparing for the ageing of the population. The programme encourages efforts to minimise the impact of ageing on functional capacity and to build a financially, ecologically and socially sustainable service system.

In this respect, the measures being implemented in the National Programme on Ageing include, for instance, the development of lifestyle guidance in the wellbeing services counties that were launched as from the beginning of 2023 and especially the prevention of memory symptoms and the postponement of the onset of dementia with the FINGER operating model developed by the National Institute for Health and Welfare. The application of this operating model has been linked to a broader memory service path model that seeks to enhance the prevention of dementia symptoms, develop the early detection of dementia, improve access to services and describe good practices in effective service provision solutions after diagnosis. The model has been developed in cooperation with a wide network consisting of experts, professionals in the field, organisations and experts by experience. The project work is ongoing and will be concluded at the end of 2023.

One of the key tools for national guidance of memory-related issues is the quality recommendation for older people, which have been drawn up since 2001. The quality recommendation has always recognised that dementia is a key factor behind the service needs of older people, and it has also been aware of the increase in the number of those with diseases as the population ages. It has always included guidance on dementia, including on the prevention of



“Another statement in the programme that safeguards good treatment for persons with dementia is that legislation clarifies the right to end-of-life care, ensuring good end-of-life care to everyone, regardless of where they live or are treated, as well as expertise and availability of palliative and end-of-life care and taking relatives into consideration during such care.”

the underlying disease and to those living with the condition. The current quality recommendation was drafted in parallel with the National Programme on Ageing, with aligned thematic content. Thus, the implementation of the recommendation and the programme has been mutually supportive. The quality recommendation is currently being updated. The new recommendation will come into force as from the beginning of 2024. The quality recommendation pays attention to issues such as the right of persons with dementia to self-determination, which can be supported with a care and service plan that promotes the inclusion of the will and opinions of the client in the implementation of care and everyday life. The quality recommendation also considers the age-friendliness of the housing and living environments of persons with dementia, including communal living.

**After the Parliamentary elections in April 2023, Finland got a new Government in June. How does the new Government Programme take dementia and services for those with the disease and their loved ones into consideration? What practical measures will be taken?**

The Government Programme has recognised the need to support the functional capacity of older people and to this end has allocated appropriations and organisational grants to parties in the third sector and parish actors for the care of the elderly living at home and family caregivers. In addition, appropriations for the promotion of health to organisations, foundations and other actors will be increased and allocated for the support of the functional capacity of older people, coping at home and family caregivers. Supporting functional capacity also prevents the development of memory symptoms and the onset of dementia.

The Government Programme includes many statements on measures for older people,

which partly concern people with dementia as well. For instance, the programme states that service guidance will be developed so that special attention will be paid to older people who require a lot of services. This group includes some people with dementia. Another statement in the programme that safeguards good treatment for persons with dementia is that legislation clarifies the right to end-of-life care, ensuring good end-of-life care to everyone, regardless of

“In Finland, research on dementia is funded and carried out widely. The aims include identifying new risk factors related to Alzheimer’s disease and the disease mechanisms, as well as thereby developing better sampling to predict dementia and treatment methods.”

where they live or are treated, as well as expertise and availability of palliative and end-of-life care and taking relatives into consideration during such care. Likewise, a statement regarding the improvement of the safety, effectiveness and appropriateness of pharmacotherapy for older people and persons with multiple illnesses by means of pharmacotherapy guidance and overall assessments of medication also benefits those with dementia symptoms and dementia.

The Government just started its work in the summer, and thus a detailed plan for the practical measures is still being drafted and will be specified in more detail in the early autumn.

**From the perspective of the Ministry of Social Affairs and Health, what are the key near-future challenges posed by dementia? What should be invested in?**

In the view of the Ministry of Social Affairs and Health, evidence-based preventive measures and early detection of dementia

are of key importance. Related development work and the implementation of operating models that have been proven to be effective should be continued extensively in the wellbeing services counties. In Finland, research on dementia is funded and carried out widely. The aims include identifying new risk factors related to Alzheimer’s disease and the disease mechanisms, as well as thereby developing better sampling to predict dementia and treatment meth-

ods. Research efforts also seek to diagnose dementia among those of working age as early and correctly as possible.

It is also essential to develop the service system so that it meets growing service needs and especially the rising number of service users with dementia. Accordingly, legislation has been developed in recent years to support living at home. For instance, legislation includes the obligation to organise home care regardless of the time of day when appropriate to meet the needs of service users. On the other hand, legislation has also been developed with respect to housing services, so that they provide sufficiently diverse options for the different needs of clients. For instance, service users who feel unsafe living alone at home due to memory symptoms, causing fear and anxiety, may be placed in communal residences that provide not only suitable accessible housing but also activities that support their social functional capacity, and other social and healthcare services that meet their individual needs.

## Working together to build a memory-friendly society in Finland

To coincide with the 33<sup>rd</sup> Alzheimer Europe Conference taking place in Helsinki, Finland, Alzheimer Europe spoke to the Executive Director of the Alzheimer Society of Finland – Muistiliitto, Katariina Suomu, about the important work taking place in the country to build a memory-friendly society.



Katariina Suomu



The roots of the Alzheimer Society of Finland – Muistiliitto are in local activities. In the late 1980s, it was noted that there was a need to provide support for the relatives of people with dementia. At the time, dementia had just begun to be recognised as a separate neurological disease. Local dementia associations were quickly established around Finland. In 1988, the Alzheimer Society of Finland was established under the name Alzheimer Keskusliitto. Today, Muistiliitto, is a non-governmental patient organisation whose vision is to foster a memory-friendly society in which those with dementia and their loved ones can live a good life. The practical work has changed in some respects, but much has remained unchanged. Since the early days, the society has worked in close cooperation with researchers, public services, other organisations and companies.

“A memory-friendly society is a broad concept that needs to be elaborated. Of course, the idea is that when someone is concerned about their own memory and cognition, or that of a loved one, they have prompt access to tests and the correct, reliable diagnosis. You don’t have to deal with the uncertain new situation on your own. The right information, medication, rehabilitation and the necessary individual services are part of an effective service path and memory-friendly society,” explains Katariina Suomu, Executive Director of Muistiliitto.

“Memory-friendliness means much more than just functional memory clinics, though such clinics are a necessity. Longevity is rising fast

in Finland. In the future, the majority of Finns will have to deal with a progressive memory-related disease in their daily lives – either their own or that of a loved one. We need to give even more thought to whether our built environment is dementia-friendly – what are our homes, public spaces, traffic routes and sports facilities like? How can people continue to enjoy their beloved hobbies and live good lives, even after the onset of dementia? And how will employers react to those with early-onset dementia – is the work flexible enough to enable them to stay on?” says Katariina Suomu.

Muistiliitto’s mission is to provide support for the everyday lives of people with dementia and their loved ones, develop expertise and new means to help them, and influence societal decision-making. Member associations in particular offer services close to people’s daily lives: counselling, peer support as well as recreation. Local associations also carry out many development projects and engage in close cooperation with public social and healthcare service providers.

“Muistiliitto works for people with dementia and their loved ones – this is a joint effort with its member associations. Participation and the active role played by those with dementia are now much stronger than in the early days of the organisation. People with dementia work with us as volunteers, experts by experience and influencers. Their own voices are heard,” says Katariina Suomu.

As a concept, memory-friendliness may sound soft, but it’s important to remember that it involves fundamental human rights. The work of Muistiliitto is based on international

conventions on human and basic rights, such as the UN Convention on the Rights of Persons with Disabilities.

“Unfortunately, the rights of people with dementia are still not fully realised in Finnish society, such as with respect to services for the disabled. There is still a need for advocacy work,” notes Katariina Suomu. Our human rights include the right not to be discriminated against. Dementia is still stigmatised – fortunately, this stigma is slowly fading. “For this, we can thank those with dementia and their loved ones who talk openly about the disease in their own social circles and the media,” says Suomu. Although the number of people with dementia will increase in the years ahead and services will be under pressure, society should not talk about a “disease burden” – this would be stigmatising. No one wants to feel that they are a burden to others.

The word “dementia” is seldom used in Finnish – instead, we use the word “muistisairaus”, that means, “memory disorder”. “Dementia” is considered disrespectful in the Finnish language, as such, the term is not used in everyday language and is mainly reserved for medical contexts. In addition, as a term, “memory disorder” covers all such diseases.

“In addition to memory-friendliness, it is increasingly important to talk about inclusion – people with dementia are equal actors with the right to self-determination. It is essential to promote the right to self-determination and inclusion at the level of both legislation and attitudes. Progress has been made in Finland, but there is still plenty to be done in the future,” says Katariina Suomu.

# Openness about dementia helps to dispel fear about the condition

In this article, Mauri Laine, a person with dementia living in Mikkeli, Finland, shares his experience of living with the condition and how, for him, letting others know about a diagnosis is not the end of the world, even if it may seem that way at first.

## Openness dispels fears

Mauri Laine was diagnosed with Alzheimer's disease at working age. He found it important to be open about the diagnosis right from the start. Consequently, he talked about his disease to colleagues and familiar market vendors alike.

Mauri has noticed that many people with dementia feel ashamed and abstain from telling anyone about their condition. He encourages others like him to not turn inward. "It takes a lot of energy to hide the disease, whereas open speech about it allows you to live freely," he advises.

## Transition to retirement

Mauri was familiar with dementia, as many of his father's family members developed a condition in old age. He sought examinations well in advance, but it was only the second examination that revealed a perceptual issue. At the time, he acted as substitute vicar.

He says that one of the first problems caused by the disease was having trouble with strategies. In addition, he began to forget things at work. Once he stood at the altar wondering why everyone else were standing too. "I looked at my papers and realised that I still had to recite the Benediction."

After being diagnosed with Alzheimer's, Mauri retired. Experience of his father's disease made it easier to accept the diagnosis. "I never tried to fight it. This is what I was given, and I live by it."

## Part of a memory association

Soon after the diagnosis, Mauri joined a local memory association. The association had a movie group, with which he filmed three movies, enjoying the intense and creative activities involved in the process.

After his diagnosis, he also discovered literature and writing. Today, he reads at least 100 pages per day and spends plenty of time working on his own pieces. "Writing cause-ries and poems has helped me process the disease," Mauri explains.

In addition, Laine is an avid ice hockey fan and never misses the local club's games. In the summer, he also goes to watch football.

Mauri visits the local memory association's peer support group once every two weeks. He also participates in the activities of The Alzheimer Society of Finland's national working group of people with dementia and caregivers. It is a group that promotes issues important to people with dementia and their families. "The activities have involved magnificent networking and peer support. I have truly enjoyed them."

**“ I try to make an impact through my own example. I gladly talk about my condition and give examples of how it shows.”**

Memory-related diseases are increasingly discussed in Finland, and the diagnosis of former President Martti Ahtisaari, for example, has increased people's awareness. However, Laine says that there is still a lot to learn. "I try to make an impact through my own example. I gladly talk about my condition and give examples of how it shows."

*Mauri Laine was interviewed by Anne Leinonen, Communications Coordinator, The Alzheimer Society of Finland.*



Mauri Laine



# University of Eastern Finland showcases multidisciplinary research approach for neuroscience

The University of Eastern Finland (UEF) is home to a unique Neuroscience Research Community, integrating biological neurosciences with data sciences, neuro-innovations and neuro-ethics, including projects examining the creation of smoother operations for drug trials and launching a legal clinic for people with dementia. This article examines some of these projects, as well as hearing from Professors Eino Solje and Anna Mäki-Petäjä-Leinonen about exciting research underway in the country.

expertise is built around biomarker studies and clinical drug trials, diagnostics, prevention and treatment of dementia. With its cooperation network, the unit also has the capacity to examine the genetic background, risk factors and pathogenesis of polygenic diseases.

Boasting 20 years of experience and excellent networks in Finland and abroad, the Unit provides services across the world, ranging from clinical drug trials to molecular biology. It has facilities for sampling, clinical assessments and drug administration, and it houses a biomarker laboratory. In addition, it is home to neuropsychologists, physicians and research nurses, as well as financial and contractual experts. In addition, a large number of academic researchers work in the unit.

## UEF NEUROSCIENCE

RESEARCH COMMUNITY



Anna Mäki-Petäjä-Leinonen



Eino Solje

Building on a long-standing history of top-level research, the UEF's multidisciplinary Neuroscience Research Community (NEURO RC) aims at earlier diagnosis, prevention and better treatments for neurodegenerative diseases and epilepsy. In recent years, the community has expanded its horizons to social and data sciences, law and innovation management.

### UEF Brain Research Unit offers a platform for drug trials for dementia

The Brain Research Unit (BRU) at the University of Eastern Finland is a key infrastructure of the NEURO RC. The BRU conducts high-level clinical research and drug trials, collaborating both with research groups and the pharmaceutical industry. Its core

### A balance of industrial and academic projects

Although designed for drug trials, the BRU's infrastructure also caters to the needs of academic research. The unit's expertise in drug trials is ideal for academic follow-up, intervention and cross-sectional studies, as is evidenced by, for example, the famous FINGER study, originally led by Professor Miia Kivipelto.

"Drug trials make the maintenance of such an infrastructure economically feasible, and conducting both academic research and drug trials is also a way to keep things interesting," says Adjunct Professor Eino Solje, Specialist in Neurology, who's been leading the BRU since 2023.

The Unit's current academic projects include, for instance, the Genetic Frontotemporal dementia Initiative (GENFI), an international study involving both patients, their siblings and children.

The unit is also involved in translational research. For example, samples provided by BRU are employed to investigate disease mechanisms and biomarker candidates with iPSC stem cell technology, while simultaneously examining the same phenomena in living patients and analysing their samples in the biomarker lab.



## UEF BRAIN RESEARCH UNIT

### Smoother-running and more complex drug trials

With support from the European Regional Development Fund, a new development project, launched in March 2023, will promote business-driven innovation in clinical research.

Entitled *The UEF Brain Research Unit 2.0*, the project will create an operating model for clinical research in brain health. Among other things, solutions will be sought to streamline operations and to utilise the opportunities provided by health data, the Biobank of Eastern Finland and digitalisation in support of clinical trials.

The project is carried out in collaboration between experts from the university, health sector companies and the North Savo Wellbeing Services County, including Kuopio University Hospital. It is funded by the Regional Council of Pohjois-Savo from the European Regional Development Fund.

According to Solje, the future of the Brain Research Unit will highlight extensive international networks and consortia, interdisciplinary and open-minded research, close collaboration between patients and patient advocacy groups, as well as increasingly complex drug trials. They can involve, for example,

the administration of a drug into the cerebrospinal fluid space, or advanced isotope studies of the brain.

“We can’t compete with costs globally, but we can certainly be trailblazers when it comes to quality,” Solje points out.

### Clinical studies with extracranial current and nocturnal EEG

In addition to BRU, Solje leads a research group focusing on dementia in the working-age population. “We seek to develop new diagnostic tools, including blood and cerebrospinal fluid biomarkers, as well as extracranial magnetic stimulation.”

They have shown, for example, that neurofilament light chain (NfL) measured from a blood sample strongly correlates with the progression of frontotemporal dementia. In another study, blood glial fibrillary acidic protein (GFAP) was shown to distinguish patients with frontotemporal dementia from those with primary psychiatric disorders or healthy individuals.

The group is part of the FinFTD research network, focusing on frontotemporal dementia, but studies other early-onset neurodegenerative diseases as well, especially hereditary ones. Issues relating to the ethics of gene studies in the context of dementia also constitute a particular interest.

In an ongoing project, Solje’s group studies the effect of extracranial alternating current on the clinical picture of dementia. “It has already been shown to impact cognitive processing in Alzheimer’s disease, and we are now examining it in longer treatment period as well as in frontotemporal dementia and Lewy body disease. In addition, we explore the possibilities of nocturnal electroencephalogram in understanding these diseases and in improving their diagnostics.”

### Researchers launch a Legal Clinic for people with dementia

BRU is also a platform for interdisciplinary research, with its latest collaboration involving scholars of law. “Dementia poses a wide range of challenges for everyday functioning, with potential consequences to the legal status of the person affected. Impaired memory and cognitive functions, neuropsychiatric symptoms, such as impulsive behaviour, and problems with understanding or producing speech and written language may result in a myriad of legal problems,” says Professor Anna Mäki-Petäjä-Leinonen, who leads the Neuro-Ethics and Law research team at UEF’s Centre of Law and Welfare.

“Dementia may, for example, hinder a person’s access to justice, as well as social welfare and health care services, and it can affect the management of their financial affairs. There may be family law issues, such as the appointment of a legal guardian. People with dementia are also particularly susceptible to abuse, and sometimes they are the ones abusing people around them.”

In the multidisciplinary study, her team examines the association of different stages of dementia with the patient’s legal status and the realisation of their rights.

A Legal Clinic will be established at BRU as part of the study. The study will be piloted in autumn 2023 by recruiting ten people with a progressive neurodegenerative disease for examinations and interviews with their adult relatives. Data from the pilot phase will be used in the development of the Legal Clinic.

“The study findings can be used to influence legislation, decision-making and social debate, as well as to support the inclusion of people with dementia.”

### Ageing population faces increasing legal problems

Mäki-Petäjä-Leinonen’s Neuro-Ethics and Law research team focuses on the legal status and legal protection of people with brain diseases and other disabilities. The aim is to ensure that patients and their families, despite the illness, have the opportunity to

# UEF | Center of Law and Welfare



live a good life with dignity and to be recognised as full members of society.

“As the number of older people and people with dementia grows, there is also an increase in legal problems experienced by them,” says Mäki-Petäjä-Leinonen, who is Finland’s first Professor of Law and Ageing.

“Combining empirical knowledge with doctrinal legal research allows us to obtain a comprehensive picture of the legal rights and access to justice of this vulnerable group. People with brain diseases, carers and their organisations will also be involved in co-designing and co-creating research, and in promoting their legal rights. Many persons with brain diseases and other disabilities are

fully capable of representing themselves and their peers.”

A recent research project provided practical guidelines on what constitutes a good death at home, and how family carers can be supported in their role and in their bereavement process.

### Art workshops and lessons from the COVID-19 pandemic

In the *Justice for Older People – Experiences of an Ageing Finland* project, more than 300 older people and their family members have shared their experiences of problems in access to justice, how those barriers were removed and where they sought help.

In the *Shadows in Paradise? The Rights of People Living with Dementia in a Welfare State* project, led by Professor Kaijus Ervasti, similar issues have been approached with art workshops, in addition to interviews, surveys and free-format texts from people with dementia and their family members. Drawing on the research material collected in the project, author Minna Lindgren has also published a novel in 2023 on the theme of the project.

In another current collaboration, Mäki-Petäjä-Leinonen’s team focuses on how older people and people with dementia were able to access justice during the pandemic. An international comparison of different regulatory solutions during the pandemic will also be made. The aim is to develop sustainable solutions for safeguarding well-being in future health crises, building on the experience of managing the COVID-19 pandemic.

“All our projects involve collaboration with civic organisations and patient advocacy groups, such as the Alzheimer Society of Finland and the Age Institute. The projects are highly interdisciplinary, bringing together expertise from law, social policy, social services, social psychology, management, gerontology, sociology, medicine, journalism, art and literature.”

Future aims include a wider implementation of co-research involving study subjects. The team will also broaden its research from the rights of older people and people with dementia to address marginalised groups of older people, different sectors of life and certain narrowly defined problems.

### Further information on UEF’s neuroscience research

Neuroscience Research Community: <https://www.uef.fi/en/research-community/neuroscience-neuro>

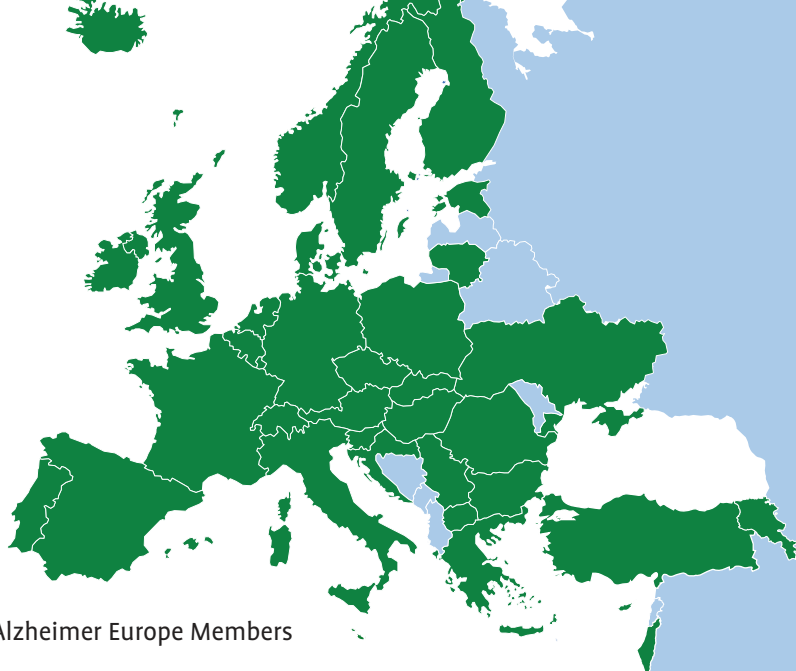
Brain Research Unit: <https://uefconnect.uef.fi/en/group/brain-research-unit-bru-clinical-trial-unit/>

Neuro-Ethics and Law research team: <https://uefconnect.uef.fi/en/group/neuro-ethics-and-law-research-team/>











































Centre of Law and Welfare: <https://uefconnect.uef.fi/en/group/center-of-law-and-welfare/>



# Our members are helping people with dementia and their carers in 37 countries



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 <b>ARMENIA – YEREVAN</b> Alzheimer's Care Armenia	 <b>HUNGARY – BUDAPEST</b> Social Cluster Association	 <b>POLAND – WARSAW</b> Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera
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 <b>CYPRUS – NICOSIA</b> Cyprus Alzheimer's Association and Related Dementias, Forget-Me-Not	 <b>JERSEY – ST HELIER</b> Dementia Jersey	 <b>SPAIN – MADRID</b> Fundación Alzheimer España
 <b>CZECH REPUBLIC – PRAGUE</b> Czech Alzheimer's Society	 <b>LITHUANIA – VILNIUS</b> Demenzija Lietuvoje	 <b>SPAIN – PAMPLONA</b> Confederación Española de Alzheimer (CEAFA)
 <b>DENMARK – COPENHAGEN</b> Alzheimerforeningen	 <b>LUXEMBOURG – LUXEMBOURG</b> Association Luxembourg Alzheimer	 <b>SWEDEN – STOCKHOLM</b> Demensförbundet
 <b>ESTONIA – TALLINN</b> NGO Living with Dementia	 <b>MALTA – MSIDA</b> Malta Dementia Society	 <b>SWITZERLAND – BERN</b> Association Alzheimer Suisse
 <b>FINLAND – HELSINKI</b> Alzheimer Society of Finland (Muistiliitto)	 <b>NETHERLANDS – AMERSFOORT</b> Alzheimer Nederland	 <b>TURKEY – ISTANBUL</b> Türkiye Alzheimer Derneği
 <b>FRANCE – PARIS</b> France Alzheimer	 <b>NORTH MACEDONIA – SKOPJE</b> NGO Institute for Alzheimer's disease and Neuroscience (IAN)	 <b>UKRAINE – KYIV</b> Nezabutni – Charitable Foundation
 <b>GERMANY – BERLIN</b> Deutsche Alzheimer Gesellschaft e.V.	 <b>NORWAY – OSLO</b> Nasjonalforeningen for folkehelsen	 <b>UNITED KINGDOM – EDINBURGH</b> Alzheimer Scotland
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