Alzheimer Europe hosts reception in European Parliament to encourage candidates to sign the Dementia Pledge 2024

Margaret McCallion who is living with dementia is a co-author of a new book about occupational therapy and dementia

Füsun Kocaman of the Turkish Alzheimer Association discusses a project developing search and rescue methodologies for people with dementia in emergencies and missing cases

New Maltese dementia strategy

Minister for Health and Active Ageing Jo Etienne Abela and Parliamentary Secretary for Active Ageing Malcolm Paul Agius Galea discuss the country’s new strategy
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I am pleased to introduce the 45th edition of our Dementia in Europe magazine, which contains a number of interesting developments and activities in the field of dementia.

We open the Alzheimer Europe section looking back at the capacity-building Alzheimer's Association Academies from January and February, which focused on artificial intelligence (AI) and modifiable risk factors.

Turning to projects in which Alzheimer Europe is involved, we hear from Miia Kivipelto and Niranjan Bose, co-leads of the newly launched AD-RIDDLE project, which will look at how to improve the prevention, detection and diagnosis of dementia. In the next article, Anna Žabicka provides an introduction to the REBALANCE project, which is exploring the use of focused ultrasound as a novel approach for the treatment of Alzheimer’s disease. To round off this section, we look at the progress of the AI-MIND project, as it reaches its mid-term point, with promising results in both the generation of new data and the development of digital AI tools for screening brain connectivity and dementia risk estimation.

Moving onto the policy section, we are delighted to feature an article with the Maltese Minister for Health and Active Ageing, Dr Jo Etienne Abela and Parliamentary Secretary for Active Ageing, Dr Malcolm Paul Agius Galea, who outline the country’s new National Dementia Strategy, “Reaching New Heights”. Additionally, we are pleased to hear from Anthony Scerri, Vice-Chair of the Malta Dementia Society, about the organisation’s reaction to the new strategy.

As we are in the midst of election-season at a European level, the following article takes stock of the progress of Alzheimer Europe’s EU elections campaign, including a recap of our highly successful European Parliament reception. I am delighted to see the engagement across the different levels of the campaign and especially among our members – this work is vitally important and provides a strong foundation for us to continue our policy work into the second half of 2024!

Staying at the EU level, we hear from Katarina Ivanković-Knežević from the European Commission about the European Disability and Parking Cards, and what this important development in European disability policy means for people living with dementia. The final article in this section provides a brief overview of some of the fruitful and constructive discussions which took place at the most recent meeting of the European Group of Governmental Experts on Dementia.

In our final section, Dementia in Society, we open with an article featuring people living with dementia, however, on a topic not often talked about: What it is like for a person with dementia to take on the role of carer themselves? We spoke to Petri Lampinen, Lieselotte Klotz and Helen Rochford-Brennan to share their experiences of supporting close family members in need of care.

The next article features a fascinating collaboration between our member, Confederación Española de Alzheimer y otras demencias (CEAPA), and Momentum Spain, using the popular video game Fortnite and famous streamers, to raise awareness of dementia amongst younger people.

We are pleased to highlight an important new book: “Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia”, edited by Fiona Maclean, Alison Warren, Elaine Hunter and Lyn Westcott, highlight the important role of occupational therapists in helping people with dementia to have a better quality of life. The book features contributions from professionals, as well as from people with lived experience, including members of our European Working Group of People with Dementia, Chairperson, Chris Roberts and Vice-Chairperson, Margaret McCallion.

In the penultimate article, Füsun Kocaman of the Turkish Alzheimer Association outlines an innovative Erasmus+ project of the Turkish Ministry of Interior which aims to develop training materials to enhance the skills and knowledge of search and rescue personnel in cases involving people with dementia.

The closing article of this edition takes a look “behind the headlines”, with Betty Tijms and Pieter Jelle Visser of the EPND (European Platform for Neurodegenerative Diseases) project, who share their work which has categorised five biological sub-types of Alzheimer’s disease – a vital development in improving our understanding of the condition.

I hope you find this edition both interesting and useful and as we head into the summer months, I wish you a relaxing and re-energising season!
Alzheimer Europe “Academies” explore Artificial Intelligence and modifiable risk factors in dementia

So far in 2024, Alzheimer Europe has held two sessions of its popular online “Alzheimer’s Association Academy” series: One on Artificial Intelligence and one on modifiable risk factors. These capacity-building workshops bring together representatives of national Alzheimer’s associations with members of the European Working Group of People with Dementia and European Dementia Carers Working Group, to learn about the latest advances in dementia research, policy, care and treatment from experts in those fields.

Artificial Intelligence and dementia

On 23 January 2024, Alzheimer Europe hosted its first Alzheimer’s Association Academy meeting of the year. The Academy meeting, which was moderated by Angela Bradshaw (Director for Research, Alzheimer Europe), was focused on the topic of Artificial Intelligence (AI) and dementia, and welcomed over 70 registrants from 18 countries.

The first two speakers, Holger Fröhlich (Fraunhofer SCAI, Germany) and Ira Haraldsen (Oslo University Hospital, Norway) showed how AI can power new research innovations aimed at improving dementia detection, diagnosis, prevention and treatment. Prof. Fröhlich highlighted some of the challenges facing healthcare systems, many of which lack the capacity to screen, diagnose and adequately treat people with Alzheimer’s disease (AD) and dementia. Explaining that AI algorithms have the power to support more accurate, personalised diagnoses and detection, he outlined the goals of a newly-launched pan-European research project called PREDICTOM. This project, funded by the Innovative Health Initiative (IHI), is creating an AI-enabled platform comprising screening and diagnostic tools that could be deployed in the community and in the primary care setting. Holger also spoke about the ADIS project, which is evaluating correlations between sleep disturbances and markers of neuroinflammation, using machine learning.

Prof. Haraldsen, speaking next, focused her presentation on the AI-MIND project, a Horizon 2020-funded project which is developing tools for dementia risk screening in people with mild cognitive impairment (MCI). The AI-MIND tools, which are built around powerful machine learning algorithms, aim to shorten the diagnostic period from months or years to a matter of weeks. She explained how tools such as the AI-MIND Connector, which analyses data from functional brain networks measured using EEG and MRI, could provide access to a more personalised, rapid diagnosis delivered in the doctor’s office.

The next presentation was entitled “AI for rare disease diagnosis: a perspective for AD”, delivered by Marcelo Martinez Conti of Foundation 29. Foundation 29 was launched by Julian Isla, whose son has a rare disease called Dravet Syndrome. Julian Isla and Marcelo Martinez Conti, who both have a background in computer science and IT, wanted to accelerate and improve the diagnostic process, and empower patients and their families to use, understand and share their clinical data. Foundation 29 therefore set out to develop AI-powered tools for doctors and patients, to support clinical decision-making and patient-driven diagnosis. Mr Martinez Conti presented the dxGPT tool, which uses the ChatGPT system of large language models to suggest possible diagnoses when provided with information about symptoms. On the data side, the nav29 prototype tool is a personal health platform for patients to consolidate and share their medical records, ask questions about their health, and access summaries of patient-doctor interactions.

The next speakers, Soraya Moradi Bachiller and Daphné Lamirel (Public Involvement Officers at Alzheimer Europe), offered the perspectives of people living with dementia and their carers on AI. These perspectives were drawn from Public Involvement (PI) consultations in the context of research projects such as ADIS, eBRAIN-Health, AI-MIND and PatternCog. Both presenters identified some common themes in the responses, such as data privacy and confidentiality, bias and discrimination, and the impact of AI on the patient-doctor relationship. Explainability was also highlighted as an important consideration for people with dementia and their carers, including clear accountability for decisions made using AI-powered tools – coupled with access to tailored post-diagnostic support with actionable outcomes for patients.

The final speaker of the day, Saila Rinne, from the Directorate-General for Communications Networks, Content and Technology (DG CONNECT) at the European Commission, highlighted several recent AI
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Policy developments, including the new AI Act proposal, and the launch of AI and brain health research programmes by the European Commission. The AI Act proposal, for which provisional agreement was reached in December 2023, will categorise and regulate AI based on its risks to cause harm to individuals and society. Specific rules for high-risk AI aim to protect citizens from potential harm, whilst regulatory sandboxes (a regulatory sandbox is a framework set up by a financial sector regulator to allow small-scale, live testing of innovations by private firms in a controlled environment under the regulator’s supervision) are intended to promote innovation in a safe space.

Turning to research and innovation, Ms Rinne described a new European partnership for brain health, bringing together the JPND, NEURON, and the Human Brain Project as well as the Virtual Human Twins initiative, which aims to improve access to personalised prevention, early diagnosis, and tailored clinical pathways for all EU citizens. Concluding, she emphasised that patients and the public are the key stakeholders in these initiatives, explaining the EU approach to involving the public through advisory boards and representatives with lived experience of disease.

Modifiable risk factors for dementia

On 22 February, Alzheimer Europe’s second Alzheimer’s Association Academy meeting of the year was moderated by Jean Georges, (Executive Director, Alzheimer Europe) and focused on the topic of modifiable risk factors for dementia. The meeting welcomed 58 participants from over 20 countries.

Sebastian Köhler, professor of Neuroepidemiology at the University of Maastricht was first to present, discussing the links between hearing loss, cognitive decline and dementia both in diagnosis and as a modifiable risk factor. He discussed the current research on the topic, concluding that hearing loss is gaining increased attention as a risk factor for cognitive decline and dementia with consistency in literature and general consensus amongst experts, but that evidence regarding hearing aid usage benefits remains inconsistent. Hearing loss as a modifiable risk factor continues to be researched and studies so far do not distinguish between the types of hearing loss (hearing loss versus impaired auditory analysis due to brain atrophies). It was also noted that the studies available did not investigate whether hearing loss leads to cognitive impairment or whether it is secondary to cognitive impairment.

Dr Neus Falgàs from the Hospital Clinic de Barcelona then spoke about sleep disturbances in AD and the ADIS project. She explained the importance of sleep for brain health and outlined the sleep alterations that occur in people with AD, noting that these are frequent and that they start from the early stage of AD. They also have a negative impact on the person and their family, becoming one of the main reasons for hospitalisation. Sleep disturbances are also common in Lewy body dementia (LBD) and follow a similar pattern to those in AD. Dr Falgàs also noted that therapeutic and preventative strategies are limited and have
secondary effects. She noted that patient education should focus on developing a regular schedule of sleep, ideally following the circadian rhythm (sleeping at night and being awake during the day), adding that pharmacological sleep aids should be limited in use. Sleep apnoea was mentioned as a vascular risk factor that lowers resilience to stress and negatively impacts neural regeneration.

Nicola Veronese, Gerontologist and professor at University of Palermo, Italy then gave a talk on physical activity for the prevention and management of MCI and dementia. He presented a study which demonstrated that the positive effect of exercise was comparable to that of donepezil and explained how the European Geriatric Medicine Society (EuGMS) plans to develop specific guidelines with the involvement of several European scientific and patient societies. The study found that physical activity should be promoted for primary prevention of AD. For MCI, mind-body interventions (tai chi or yoga) were shown to have a small positive effect in global cognition. Exercise in patients with MCI and AD has global positive effects and will help to decrease the rate of disability, he said. He shared the positive physiological effects of physical activity on memory, noting that it decreases stress, improves neuroplasticity and maintains hippocampal volume (which is negatively affected by social isolation). He recommended 30 minutes (minimum) of physical activity, at least two to three times per week, noting that getting patients involved in group physical activity could also help to combat social isolation.

Jeroen Bruinsma, Assistant Professor at the University of Maastricht discussed his work in the LETH project with regards to lifestyle-related behaviour change for dementia risk reduction. He described the project’s research on preventive interventions of diet, exercise, cognitive training, monitoring vascular risks through sleep, social activity, relaxation, limiting or avoiding alcohol and cigarettes with a digital twin app based on the FINGER protocol. This app can be used on a smartphone and Fitbit watch, and it provides recommendations based on the FINGER protocol. Adherence is being monitored, following up with motivational messages and the data gleaned so far shows that dementia risk is considered abstract, leading to ambivalence towards changing behaviours. It also showed “all-or-nothing” thinking about lifestyle change, with people feeling that change had to be radical, resulting in a lack of tangible goal setting. Negative self-image and behavioural control, particularly where previous attempts had failed, reduced the willingness to make further attempts at lifestyle change. Jeroen Bruinsma acknowledged that lifestyle change for dementia risk reduction is complex, requiring more communication of risks, raising awareness and knowledge and the need to support participants. Personal contact and support is key to engagement, he stressed.

During a panel discussion, the speakers agreed that it is necessary to look at both individual interventions as well as public health initiatives, with the goal of making policy and environmental changes that will benefit people and encourage healthier living. They also acknowledged the fact that making changes at a national level is slow and often complicated to achieve. On an individual level, people should be encouraged to do what they find fun and feel that they can achieve. The speakers reiterated the need to present people with all of the options for lifestyle modification, giving as much choice and autonomy as possible to help people decrease their risk or slow progression.

Acknowledgement

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AD-RIDDLE: a new European initiative to improve the detection, diagnosis and prevention of Alzheimer’s disease

The Innovative Health Initiative-funded AD-RIDDLE project was launched earlier this year, aiming to bridge the gap between research and precision medicine. To find out more, Alzheimer Europe spoke to AD-RIDDLE project leads, Miia Kivipelto and Niranjan Bose.

Alzheimer’s disease is an epidemic that is hiding in plain sight. In Europe, around 9 million people are living with Alzheimer’s disease (AD): this number will exceed 14 million by 2050. With an estimated societal cost of EUR 392 billion in 2019 alone, AD has far-reaching impacts on families, communities, health and social care systems. AD stands at the predominant cause of dementia, contributing to 60-70% of cases, and ranking among the top 10 causes of death worldwide. Of these, however, AD is the only one that cannot currently be cured.

Yet there are many reasons to be optimistic. Twenty years after the last approval of an AD medicine in Europe, a new wave of innovation has yielded the first disease-modifying therapies for AD. Unlike existing symptomatic treatments, these innovative drugs target the underlying biology of AD, removing amyloid plaques that clog up the brains of people with AD. Clinical trials have demonstrated that anti-amyloid therapies can slow cognitive decline in people who are in the early symptomatic AD stages. Already approved for use in the United States, Japan and China, anti-amyloid therapies are currently being reviewed by European regulators. With decisions due this year, there is real hope that patients in Europe may soon be able to access medicines that can slow AD progression, promoting quality of life and wellbeing.

However, there is also reason for optimism here. Recent advancements suggest that blood tests for AD may be closer than ever to becoming a reality. Like amyloid beta, tau proteins build up in the brains of people with AD, mirroring the development of symptoms such as memory loss and confusion. By measuring the circulating levels of harmful tau proteins, the new generation of blood tests can detect the presence of AD pathology, even before cognitive symptoms arise. Importantly, head-to-head comparisons indicate that these blood tests are just as accurate as their cerebrospinal fluid counterparts – but are less costly and invasive.

Effective treatment, however, depends on a timely diagnosis. Pen-and-paper cognitive tests, followed by lumbar punctures and brain scans, currently form the mainstay of AD diagnosis. Unfortunately, AD diagnosis faces significant limitations. Brain scans and lumbar punctures are not widely accessible, and detecting early cognitive decline – when treatments are likely to be most effective – remains a challenge, particularly in the primary care setting. Under- and mis-diagnosis are therefore major problems for individuals and healthcare systems.

Commissions underlined the value of risk reduction from a public health perspective: by adopting healthier habits across the life course, around 40% of dementias could be prevented. This holds profound implications for healthcare systems, societies and individuals. Delaying dementia onset, and slowing cognitive decline, would allow people to live better, for longer. Moreover, when implemented on a broad scale, initiatives like FINGER could have the potential to save millions in health and social care costs.

Thanks to these and other advances, we stand at the cusp of a new era for Alzheimer’s disease. Research has proved that risk reduction, early intervention and dementia prevention is possible.

“With new research on the efficacy of multi-domain lifestyle interventions and the promise of disease-modifying therapies, there is renewed hope for patients, caregivers, and healthcare providers, and a window of opportunity for substantial progress.”

Miia Kivipelto
However, challenges remain in translating research into policies and practices that improve patient outcomes and care in a sustainable, scalable and equitable way across different healthcare settings. For patients to benefit from these innovative diagnostics, treatments and interventions, healthcare systems, hospitals and healthcare professionals will need to fundamentally adapt the way they diagnose, treat and care for people with AD.

This is where the AD-RIDDLE project comes in. AD-RIDDLE is an IHI-funded project aiming to meet the urgent need for effective, large-scale solutions to prevent, diagnose and treat AD. Alzheimer Europe is a partner in the AD-RIDDLE consortium, which includes 24 public and private sector organisations, and is funded for a period of five years (2024-2029).

To find out more, we spoke to the co-leads of AD-RIDDLE: Miia Kivipelto, Professor of Clinical Geriatrics at Karolinska University Hospital, and Niranjan Bose, Managing Director of Health & Life Sciences at Gates Ventures.

What is the background to the AD-RIDDLE project?

Miia Kivipelto: AD progresses gradually from an asymptomatic stage to mild cognitive impairment and, eventually, to dementia. We now know that there is a window of opportunity for early intervention in AD, when symptoms are still fairly mild. For example, clinical trials show that anti-amyloid therapies such as lecanemab and donanemab have a greater benefit when treatment starts at an earlier disease stage. It is also never too early to start reducing our personal risk of dementia. In our FINGER studies, we found that a multidomain lifestyle intervention had the largest effects at the younger end of the participant age spectrum (60-77 years).

However, diagnosis is often delayed: around 60-75% of adults with AD never receive a formal diagnosis or are diagnosed late. This means that a precious window of opportunity for early intervention is often missed. Research shows that there is enormous potential for personalised prevention of AD, as well as opportunities for improved diagnosis and treatment. In AD-RIDDLE, we want to make this potential a reality, by tackling challenges at all steps along the clinical pathway.

What is personalised prevention, and how can it benefit people at risk of AD?

Miia Kivipelto: We know that risk and protective factors for dementia and AD co-exist and interact across the lifespan. An individual’s overall risk is determined by the balance of these risk and protective factors. For example, carriers of the APOE ε4 genetic risk allele are particularly susceptible to the harmful effects of unhealthy lifestyle habits, such as smoking, excessive alcohol consumption. Cardiovascular factors also influence our individual risk for dementia and AD. This complexity suggests that a one-size-fits-all approach may not suffice. Instead, tailored, life-course strategies targeting various risk factors are likely necessary for effective prevention. This is where personalised prevention comes in: to reduce their specific risk for dementia, older adults may benefit from personalised, multidomain strategies tailored to their genetic risk profiles and lifestyle habits.

How will AD-RIDDLE enable early detection, prevention and treatment?

Niranjan Bose: We understand that taking a one-size-fits-all approach to AD detection, prevention and treatment would not be successful. Diagnostic and clinical management pathways vary across and within countries, with diverse approaches to testing, follow-up, and reimbursement. At an individual level, AD patients are also more likely to benefit from personalised interventions and therapies that are tailored to their risk profile, symptoms and disease stage.

This is why AD-RIDDLE is creating a modular toolbox platform, enabling health systems and healthcare providers to mix, match, and tailor its component tools to their specific requirements. The platform will also have multiple entry points and means of engagement for patients, caregivers and clinicians. Our goal is to make the AD-RIDDLE platform as flexible and inclusive as possible. So, we are providing solutions, tools and resources that can be easily adapted to different healthcare settings, community contexts, and individual needs.
What are the components of the AD-RIDDLE toolbox platform, and how will they work in practice?

Miia Kivipelto: The AD-RIDDLE toolbox platform will provide tailored support at all stages of the clinical pathway, for healthcare providers as well as patients and caregivers. It will feature a digital community engagement portal for patient self-assessment and referral, advanced screening tools for accurate diagnosis, and a decision support toolkit for healthcare providers. Platform algorithms will generate personalised recommendations, for treatment such as lifestyle interventions and drug therapies that are tailored to each patient’s needs.

As Bose explained, we want the AD-RIDDLE platform to benefit patients and healthcare providers across diverse settings - from memory clinics to primary care and the broader population outside of healthcare systems. A real-world testing study will span a range of European countries and healthcare settings, providing evidence to support implementation. Data from the study will be hosted securely on the European Platform for Neurodegenerative Diseases (EPND), an IMI2-funded initiative which will make datasets available for additional research and discovery. This follows the approach we founded in the World-Wide FINGERS network, where we are sharing data to advance research and accelerate global efforts on dementia prevention.

Who are the partners in AD-RIDDLE?

Niranjan Bose: By leveraging the strengths of the public and private sectors, cross-sector collaborations like AD-RIDDLE are in a unique position to expand and improve access to health innovations. In AD-RIDDLE, we have 24 multi-disciplinary partners with wide-ranging expertise and experience, including companies, non-profit organisations, regulatory bodies, and academic researchers.

The AD-RIDDLE platform will be based on existing technology, biomarkers, tools, and lifestyle interventions. We are building on the groundwork laid by Miia and her team at Karolinska University and through the FINGERS Brain Health Institute, leveraging their world-leading expertise and infrastructures for dementia prevention. Our consortium includes organisations developing blood-based diagnostics for AD, such as Fujirebio, C2N, Sanofi, BarcelonaBeta Research Center, and the Universities of Gothenburg and Lund. Our partners Amsterdam UMC, Cambridge Cognition, Combinostics and Neotiv bring a wealth of experience in digital cognitive assessments, remote monitoring and decision support tools. We are also partnering with healthcare institutions and data analysis experts, to learn how to deploy AD-RIDDLE tools in real-world settings, including Region Stockholm, Imperial College, Università degli Studi di Perugia, the University of Eastern Finland, the University of Leicester, Maastricht University and VU University Medical Center. Societal engagement, implementation research and equitable access are being addressed with our partners at the Davos Alzheimer’s Collaborative, NICE, Alzheimer Disease International and Alzheimer Europe.

Over the next five years, we expect AD-RIDDLE to generate evidence for clinical implementation of precision diagnostics, and new interventions and therapies. Together, I believe we can advance the “last mile” of bridging innovation from research to the real-world setting.

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Exploring the potential of focused ultrasound in Alzheimer’s treatment: Insights from the REBALANCE project

Anna Žabicka, PhD candidate (University of Vienna) and Senior expert at the Institute of Clinical and Preventive Medicine, University of Latvia discusses the REBALANCE project, in which Alzheimer Europe is involved.

Alzheimer’s disease, characterised by progressive memory loss and cognitive decline, presents significant challenges to medical researchers worldwide. The project entitled “REBALANCE - Mechanisms of focused ultrasound-mediated brain cleaning coupled with enhanced mechanosensation”, explores a novel approach using focused ultrasound that hopefully could help people with Alzheimer’s disease.

Focused ultrasound (FUS) is a non-invasive technology that uses targeted sound waves to influence brain tissue. This method has the ability to temporarily open the blood-brain barrier (BBB), a protective layer of cells that guards the brain against harmful substances while allowing essential nutrients to pass through.

Normally, this barrier is very selective about what it lets through, so as to protect the brain. When FUS is applied, sound waves gently vibrate the cells that make up the BBB. This vibration temporarily loosens the junctions between these cells, much like opening a gate in a fence. These openings allow molecules through, that normally could not get through this barrier, such as certain medications.

This can be particularly useful in brain diseases. Temporarily opening the BBB can also enhance the removal of beta-amyloid plaques, proteins strongly associated with Alzheimer’s disease. After the FUS procedure, the barrier naturally closes back up, restoring its protective function. In addition, FUS may induce beneficial neuromodulation or altered nerve activity, which will be explored in the REBALANCE project.

Researching Piezo1 receptors

In the REBALANCE project, researchers are exploring the synergy between the mechanical stimulation provided by FUS and targeted pharmacotherapy. A particular focus is on Piezo1 receptors, which play a crucial role in brain cells’ ability to detect and respond to mechanical stimuli. The activation of Piezo1 can stimulate the microglia cells – the primary immune cells in the brain and spinal cord that are first to respond and remove microbes, dead cells, and different protein aggregates. This stimulation also enhances their ability to engulf and digest harmful proteins like beta-amyloid that can accumulate in the brain and form plaques in Alzheimer’s disease. Piezo1 activation might also enhance the waste clearance in the brain by the so-called glymphatic system. To sum up, the project hypothesises that FUS, by activating mechanosensitive Piezo1 channels, not only enhances the microglia’s ability to phagocytose beta-amyloid but also facilitates the overall clearance of the brain through improved glymphatic flow and increased BBB permeability. These enhancements are vital for efficient waste clearance from the brain, a process that is often compromised in people living with Alzheimer’s disease.

The goal of REBALANCE

The goal of the project is to understand how FUS and FUS combined with Piezo1 drugs work together and take promising results from preclinical research to early-phase human studies. The project carefully considers ethical aspects to address any concerns from various perspectives, including the translation of the data and results of preclinical research to early-phase human studies. Therefore, the project also conducts focus groups and interviews not only with basic scientists or clinicians but also with people living with dementia and their supporters. With this inclusive approach, the project aims to ensure that the research project is not only scientifically rigorous but also takes into account the perspectives and concerns of people with dementia and their supporters/carers.

The project consortium

The project unites several research institutions across Europe and Canada. This partnership leverages a wide range of expertise and resources, enhancing the project’s capacity to tackle complex scientific questions and ensuring successful outcomes. Key partners involved include: The University of Eastern Finland (UEF), which has pioneered the investigation of Piezo1 as a potential therapeutic target in Alzheimer’s disease; the University of Luxembourg (UNILU), known for its clinical studies on Alzheimer’s disease and expertise on biomarker discovery for Alzheimer’s disease; Leiden University Medical Center (LUMC), which contributes significant experience in electroencephalogram (EEG) recordings of brain activity in vivo models; French National Institute of Health and Medical Research (INSERM), providing advanced imaging techniques to study glymphatic flow and BBB dynamics; University of Toronto, a
leader in the development and application of FUS technology, enhancing the project with its cutting-edge research and clinical trial expertise and University of Latvia (UL), focusing on the ethical aspects within the project, including ethical challenges in preclinical to clinical translation process and Public Involvement (PI).

Alzheimer Europe’s involvement

The University of Latvia is also collaborating with Alzheimer Europe and the Alzheimer Society of Finland. Alzheimer Europe’s role is to provide input on and assist in organising qualitative research focus groups with people with dementia and carers. Both organisations also contribute to discussions about PI in preclinical and clinical research in the context of dementia as well as on ethical issues.

First consortium meeting (Riga, Latvia)

In early April 2024, all partner organisations convened in Riga, Latvia for the first annual meeting of the project. The agenda included a review of the first year’s progress, planning future tasks, and discussing the necessary support from colleagues. Additionally, the partners explored potential collaborations within smaller groups and concentrated on achieving the project’s overall deliverables. The second day of the meeting was dedicated to addressing the ethical challenges associated with the project and Alzheimer’s research more broadly. Alzheimer Europe was represented at the meeting by Public Involvement Officer Daphné Lamirel and Chairperson of the European Dementia Carers Working Group Sonata Mačiulskytė, who participated in the second day’s workshop. The workshop provided invaluable contributions to critical discussions on a range of complex ethical issues. The day featured a workshop that explored key questions such as the reproducibility of results, the translatability of preclinical findings, the involvement of organisations representing people living with dementia due to Alzheimer’s disease and their supporters in research, the impact of conflicts of interest, the importance of publishing negative results, the evaluation and communication of preclinical research outcomes to potential human study participants, strategies for conveying the uncertainties of the research to the participants of human studies and the broader society, among others.

By adopting a holistic and ethically mindful approach, REBALANCE seeks to make substantial progress in understanding potentially highly beneficial non-invasive treatment options for Alzheimer’s disease. Simultaneously the project members responsibly acknowledge that the complexity and thoroughness of such research studies take significant time and require thorough ethical and social considerations.

A few words from project coordinator, Tarja Malm, Professor in Molecular Neurobiology, Head of the Neuroinflammation Research group, University of Eastern Finland

“The molecular mechanisms underlying the beneficial effects of FUS are poorly known, which limits the full translation of FUS into the therapeutic arena. It is likely, that FUS impacts several key mechanisms known to be impaired in AD. Mechanosensitive receptors are likely candidates to mediate these effects. By the joint effort of our multidisciplinary teams, we are hoping to shed light into these events and hopefully further enhance the therapeutic efficacy of FUS.”

Acknowledgement

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The AI-Mind project reports on significant progress

Global efforts between collaborators working on the AI-Mind project are at a point of coming to fruition with new data generated and the development of AI digital tools for dementia prevention.

Funded by Horizon 2020, the AI-Mind project officially started in March 2021 for a duration of five years. The goal of the project is to develop artificial intelligence (AI) digital tools for screening brain connectivity and dementia risk estimation. These tools aim to support healthcare professionals in their diagnosis and enable them to predict which people with Mild Cognitive Impairment (MCI) will eventually develop dementia. AI-Mind has now reached its mid-term, marking the successful completion of half of its milestones and deliverables and marking thus a pivotal moment in its journey.

The AI-Mind study

The AI-Mind study is at the heart of the project and it helps to develop and validate AI-based tools to predict who is likely to develop dementia. The AI-Mind study, launched in January 2022, is the largest European study of this kind aiming to recruit 1,000 participants with MCI across four European countries: Finland, Italy, Norway and Spain. It is important to acknowledge the monumental effort made by the clinical teams in the recruitment and data collection processes. Their unwavering commitment has culminated in the achievement of the recruitment target, marking a significant milestone for the AI-Mind study. Participants have now started with their follow-up visits at clinical sites, some already embarking on their fourth visit.

Launch of the AI-Mind platform

Central to the AI-Mind project are two digital tools: the AI-Mind Connector and the AI-Mind Predictor, which will be integrated into a cloud-based diagnostic support platform. The AI-Mind Connector will identify dysfunctional brain networks (e.g. synaptic malfunction and loss of connectivity which characterise signs of dementia) and the AI-Mind Predictor will assess dementia risk using data from the Connector, advanced cognitive tests and genetic biomarkers.

Massive work has been done to develop the AI algorithms for the AI-Mind Connector and Predictor and on the interactive visualisation tools. With anticipation running high among partners, 2024 marks the transition into a new phase as algorithms are applied to AI-Mind data. This crucial step will not only validate the efficacy of the developed tools but also pave the way for their integration into clinical practice.

Ethical reflection on the use of AI-based dementia risk prediction in the clinical setting

Whilst AI is increasingly being used in many areas of people’s everyday lives, the successful use and ongoing development of this kind of technology is highly dependent on patients and doctors finding it trustworthy and being willing and able to use and understand it. In collaboration with AI-Mind partners, Alzheimer Europe conducted a rapid review of the literature about ethical and social implications of this specific topic. Alongside this review, they organised a series of interviews, focus group discussions and a short survey to help ensure that the various ethical, societal and practical issues considered reflect the views, beliefs, assumptions and possible concerns of lay people from some of the groups affected by the use of these tools, and of clinicians, in addition to those of published scholars and AI specialists. This led to the development of a comprehensive strategy for the ethical and trustworthy communication of AI-based dementia risk prediction to people with MCI in the clinical setting.

A successful General Assembly meeting in Amsterdam

This year, the AI-Mind project enjoyed a successful General Assembly in March in Amsterdam, marking yet another significant milestone in its journey. The meeting provided a chance to gather all partners and collaborators who work on the project to reflect on progress and discuss future activities. The meeting coincided with Brain Awareness Week, making the event an excellent opportunity to raise awareness of the importance of brain health. One of the highlights of this year’s General Assembly was the panel discussion featuring young researchers from the project, underscoring the project’s commitment to fostering interdisciplinary collaboration and involving the next generation of researchers.
The meeting was held at the iconic Nemo Museum – the Studio, where AI-Mind is promoted with the “Living Longer” exhibition. Running until January 2025, the exhibition explores strategies for maintaining long-term health. AI-Mind has contributed to this exhibition, showcasing a cap designed for screening brain connectivity using the electroencephalogram (EEG) method. This exhibit not only raises awareness about the project but also raises awareness of dementia and scientific advancements.

Effective outreach

AI-Mind has made significant strides in public outreach and engagement. The new year commenced with an array of positive developments, including the publication of three papers, all available in full open access, in alignment with the European Commission’s Open Science policy. The AI-Mind protocol paper has been published in the journal Frontiers in Neurorobotics, representing a great milestone in the project’s research journey. Crucially, it lays the foundation for future scientific contributions by providing insights into the background of the AI-Mind study and the potential impact of the project on dementia risk assessment. In another paper published in Frontiers in Neuroinformatics, authors shed light on the innovative methodologies being employed within the AI-Mind project. Most recently, our researchers unveiled a compelling paper in the Journal of Alzheimer’s Disease showing a significant impact of dementia risk predictions on quality of life and highlighting the importance of caution when sharing information about expected MCI disease course.

The AI-Mind project has been very well represented at international and national events in the past several months. The most recent public-facing activity of the project came at the Alzheimer Europe Conference which took place in Helsinki in November 2023. AI-Mind had a booth in the exhibition area, several oral and poster presentations and a dedicated session entitled “The Potential of Artificial Intelligence for Dementia Risk Prediction”. The session attracted over 70 participants and featured four thought-provoking presentations from experts in the field. Please note that these valuable presentations are accessible to a global audience on the AI-Mind YouTube channel.

Finally, the AI-Mind consortium has grown with the inclusion of four new partners, further enriching its expertise, becoming even more representative of the European landscape. With continued collaboration and dedication, AI-Mind is poised to not only achieve its objectives but also make an impact on the field of dementia prevention. By leveraging the power of AI, the project stands at the forefront of efforts to address the growing challenge of early risk prediction.

A few words from Ira Haraldsen, the AI-Mind Project Coordinator

“With 2024, our project has entered a pivotal stage, with the consortium collectively focusing efforts on advancing towards our goals. Our primary focus now is to optimise the AI-Mind platform, refine algorithms and ensure efficient dissemination. AI-Mind data are now being processed, with the plan to disseminate findings at upcoming international presentations, marking a significant milestone. Looking ahead, it is crucial to acknowledge the research achievements while remaining open to post-project improvements for the long-term dementia prevention goals.”

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Malta launches new national dementia strategy

The National Dementia Strategy for the Maltese Islands 2024 – 2031, titled ‘Reaching New Heights’, was launched on 21 February 2024, building on the first national strategy, which ran between 2015 and 2023. In this article, Minister for Health and Active Ageing, Dr Jo Etienne Abela and Parliamentary Secretary for Active Ageing, Dr Malcolm Paul Agius Galea, tell us more about the new strategy.

Outline of strategy

The plan spans the period of the next seven years, setting out a vision for how people with dementia may live as well as possible, and the necessary societal, policy, and service adjustments needed to facilitate this. The policy document identifies priority areas that will help people with the condition and those who help them advance through dementia. The objectives to be achieved through the action areas include:

- Reducing the risk of developing dementia by taking precautionary measures, such as increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression
- Obtaining an early diagnosis to enable individuals to make advance care and legal planning while they are still able to make important decisions
- Instilling a positive approach and empowerment, focused on helping persons with dementia and their families to live well with the condition
- Improving education and training to develop a dementia-capable workforce with skills to deliver high-quality services and support
- Strengthening seamless integrated person-centred care across all settings
- Advancing towards better dementia prevention, diagnosis, treatment, and care by implementing dementia research.


Minister for Health and Active Ageing, Dr Jo Etienne Abela

The National Strategy for Dementia 2024-2031 was launched with the theme “Reaching New Heights”. This strategy aims to improve the quality of services and the quality of life for people living with this condition in the Maltese Islands. This document was produced after a public consultation which was published between October and November last year.

We explained the government’s vision for dementia care. This strategy is a continuation of the first national strategy and builds on the progress made during the latter’s implementation.

Priority areas were identified in order to help us channel our resources and efforts,
Dementia poses a growing concern in Europe, including Malta, with recent data ranking it as the fourth most common cause of death. Furthermore, projections indicate a significant increase in the number of people affected by dementia by 2050. Coping with dementia can be emotionally challenging for families, who often feel isolated and uncertain about how to deal with the condition. Empathy is an indispensable aspect of dealing with dementia, as it provides validation and connection for patients. Empathy entails understanding and sharing the emotions of others, seeing the world from their perspective and putting oneself in their shoes. For individuals living with dementia, empathy is not just a desirable trait but a lifeline, providing validation and connection in a reality that can feel disjointed and confusing.

Advocacy and awareness-raising are fundamental in combating the myths and stigma surrounding dementia. Education campaigns, media outreach, and other grassroots initiatives are necessary to raise awareness of the condition and help people better understand its effects. By sharing personal stories and uplifting the voices of those affected, we can humanise dementia and transform it from a remote concern to a shared responsibility that demands our attention and action.

Creating a supportive and inclusive environment for individuals with dementia requires a multifaceted approach that encompasses policies, initiatives, and practices that address their unique needs and challenges. By implementing these policies and initiatives, communities can create environments that foster dignity, respect, and meaningful participation for individuals living with dementia while also providing support for their caregivers and families.

Several key initiatives can help create a more dementia-friendly society. One of these is providing accessible transportation services that suit individuals with dementia by providing clear signage, designated seating areas, and training staff in dementia awareness and support techniques. Another way to create a supportive environment is to encourage the development of housing options that cater to the specific needs of individuals with dementia. This can include assisted living facilities with dementia-specific care units or modifications to existing homes to improve safety and accessibility.

Establishing programs that provide training and support for individuals with dementia who want to remain in or re-enter the workforce is also crucial. This can be achieved by offering flexible work arrangements, job coaching, and assistance in navigating workplace challenges related to cognitive impairment.

Finally, it is crucial to implement policies and programmes that support caregivers of individuals with dementia. These can include respite care services, counselling and support groups, and financial assistance programmes to alleviate caregiving-related burdens.

The recently established Dementia Care Directorate was crucial in the launch of the National Dementia Strategy in February, which aims to achieve tangible results over the next seven years. The strategy seeks to create a supportive and inclusive environment for individuals with dementia...
and their caregivers, recognising individuals with dementia as full members of society who are deserving of dignity, respect and inclusion. By promoting a rights-based approach that empowers individuals with dementia to live fulfilling and meaningful lives, the strategy aims to improve the lives of individuals with dementia and their caregivers in Malta. In conclusion, dementia is a significant public health challenge that requires collective action to address. Empathy, awareness-raising and advocacy are all vital in combating the myths and stigma surrounding dementia. Creating a supportive and inclusive environment for individuals with dementia requires a multifaceted approach that encompasses policies, initiatives, and practices that address their unique needs and challenges. To this end, the National Dementia Strategy provides a roadmap for achieving these goals and improving the lives of individuals with dementia and their caregivers in Malta.

Dr Anthony Scerri, Vice-Chair, Malta Dementia Society shares the organisation's view of the new strategy

The second National Dementia Strategy for the Maltese Islands 2024-2031 “Reaching New Heights” was officially launched on the 20th of February 2024 by the Dementia Directorate within the Active Ageing and Community Care, following a period of consultation during which stakeholders could send suggestions to the public consultation document that was presented in October 2023. During the summer months of 2023, the Strategy Advisory Committee met to discuss the strategy’s vision and develop the action areas and objectives. It is commendable that the Strategy Advisory Committee was composed of a person living with dementia, an informal caregiver, health care professionals, academics, policymakers and representatives from the Malta Dementia Society. This ensured that the voices of the major stakeholders were included when developing and prioritising the action plans. A qualitative interview with a member of the Strategy Advisory Group who is living with early onset dementia was carried out to gain an understanding of the experience of living with dementia in Malta. These experiences have been documented in the strategy as quotes to put a human perspective to the principles, action areas and objectives discussed in the strategy.

The second strategy is a continuation of the first Dementia Strategy written by Professor Charles Scerri, Chair of the Malta Dementia Society. Much has been done during the timeframe of the first dementia strategy (2015-2023). To note was the development of the Dementia Intervention Team, the increase in the number of Dementia Activity Centres, and the setting up of the Dementia Directorate within the Ministry of Health and Active Ageing. The latter development ensured that all public services directly related to dementia care are coordinated by a central entity, thereby reducing fragmentation and overlapping of resources.

The six action areas of the second dementia strategy follow those set in the first strategy and seek to raise awareness and understanding of dementia, provide timely diagnosis, reduce dementia risk, promote initiatives to living well with dementia, ensure workforce development, develop integrated person-centred dementia services and increasing research & information systems. These action areas are aligned to the other National Dementia Strategies and the World Health Organisation’s Global Action Plan on the public health response to dementia (2017-2025). What is of note when compared to the first strategy, is that the second strategy includes ‘risk reduction’ as another action plan in line with the latest evidence on risk reduction and dementia prevention. Another important focus of the second strategy is the consideration of the needs of specific groups of persons living with dementia such as persons living with early-onset dementia, persons with learning disability and dementia, LGBTIQ+ persons with dementia and migrants living with dementia. The latter category of persons will increase over the coming years, in view of population growth associated with the high influx of non-Maltese citizens residing in Malta, which is making the Maltese Islands increasingly a multi-cultural community.

The strategy consists of 41 specific and time-barred objectives based on local and international evidence. Each objective has a clearly identified group of stakeholders who are responsible for the implementation of the objective during a specified timeframe. Whilst the way these objectives are written help in ensuring that they are achievable, their implementation heavily depends on effective communication with all stakeholders. As suggested in the strategy an Inter-Ministerial Committee led by the Ministry of Health and Active Ageing could be created to oversee its implementation. However, private and non-governmental organisations, such as the Malta Dementia Society, should also be given more opportunity to lead one of more of these objectives. Nevertheless, since the strategy does not clearly explain how the action areas will be funded, securing funding is possibly the biggest challenge for its successful implementation.
Alzheimer Europe progresses with EU elections campaign 2024

Since launching on 15 January 2024, Alzheimer Europe has been working with member organisations on its EU elections campaign 2024. In this article, we highlight the progress made on the campaign, as well as looking at the European Parliament Reception held on 19 March, at which a number of existing Members of the European Parliament (MEPs) signed the Dementia Pledge 2024. The figures in this article are those as of the end of May 2024.

Campaign to date

Since the launch of the European Elections Campaign in January 2024, the support for all three branches of the campaign (the Helsinki Manifesto, public Call to Action and the Dementia Pledge) has progressed rapidly, with many stakeholders endorsing our call to make dementia a policy priority at the European level.

Alzheimer Europe’s member organisations have been proactive in their efforts to support the campaign, sharing the campaign details with their networks, encouraging their members and the public to sign up to the Call to Action, whilst engaging with candidates, MEPs and political parties to gather support for the Dementia Pledge 2024. It has been pleasing to see many members develop their own resources and tools to raise awareness of their campaigns, with some examples featured on these pages.

Since the launch of the campaign, the Manifesto has been made available as a printed booklet, to support its dissemination. The Manifesto has gained broad support, with a total of 73 organisations and research consortia now endorsing it, from organisations at a local level up to European-level organisations.

Alzheimer Europe’s public Call to Action, which demands that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto, now has more than 6,200 signatures, with the majority of signatures coming from Italy, Sweden, Spain, Poland, Portugal and Slovenia.

For the final strand of the campaign, the Dementia Pledge 2024 has gathered 188 signatures, from a mix of existing MEPs and candidates. From the existing MEPs, this includes some who were not previously members of the European Alzheimer’s Alliance (EAA).

Additionally, Alzheimer Europe was especially pleased to see that the European People’s Party (EPP) Manifesto for the European Parliament elections 2024 contains a commitment to develop a European dementia plan. This commitment aligns with our long-standing call for the development and implementation of a European dementia strategy and reflects one of the key calls from our Helsinki Manifesto.
Alzheimer Europe hosts European Parliament Reception

As part of its campaigning activities, Alzheimer Europe invited MEPs and representatives of a range of different organisations to join us on the evening of 19 March 2024, in the Members’ Salon in the European Parliament in Brussels, at an event hosted by MEPs Milan Brglez (Slovenia), Deirdre Clune (Ireland), Tilly Metz (Luxembourg) and Sirpa Pietikäinen (Finland).

Jean Georges, Executive Director, Alzheimer Europe welcomed around 80 guests to the event, including MEPs, with representatives from national member associations, members of the European Working Group of People with Dementia, the Alzheimer Europe Board and staff members, and industry representatives. He outlined the priorities of the Helsinki Manifesto and invited MEPs to sign the Dementia Pledge. He also welcomed the three host MEPs in attendance, Milan Brglez, Deirdre Clune and Tilly Metz who each addressed the room, sharing their perspectives on the importance of the campaign and of prioritising dementia both at national and EU level.

During the reception, there was an opportunity for MEPs in attendance to sign a large-scale version of Alzheimer Europe’s Dementia Pledge 2024 and to say a few words. Additionally, MEPs had the opportunity to meet representatives of our national member associations, people living with dementia and carers of people with dementia, to hear first-hand what matters most to them and how policymakers can help prioritise dementia.

Attendees were also able to take copies of both the Helsinki Manifesto and Dementia Pledge to support activities related to the campaign.

The MEPs who signed the Pledge during the European Parliament reception were:

- Barry Andrews MEP (Ireland)
- Petras Aušrevičius MEP (Lithuania)
- Dominique Bilde MEP (France)
- Milan Brglez MEP (Slovenia)
- Deirdre Clune MEP (Ireland)
- Marie Dauchy MEP (France)
- José Gusmão MEP (Portugal)
- Stelios Kympouropoulos MEP (Greece)
- Tilly Metz MEP (Luxembourg)
- Matjaž Nemec MEP (Slovenia).

Next steps in the campaign

Following the European Parliament elections between 6-9 June 2024, Alzheimer Europe’s wider EU campaign will continue until the end of the year. The Helsinki Manifesto will remain open to new endorsements and will form the basis of Alzheimer Europe’s engagement with elected MEPs and other decision-makers at an EU level. Additionally, the Call to Action will continue to be open to signatures.

Alzheimer Europe will work with member organisations to support them to follow up with MEPs who signed the pledge (thus joining the EAA), identifying committee assignments of MEPs, as well suggested themes for them to raise during the hearings of the Commissioners-designate who have responsibility for health, research and social affairs portfolios.

The campaign and its efforts to prioritise dementia will culminate with a European Parliament Dementia Day on 10 December 2024, during which Alzheimer Europe will coordinate awareness raising activities and key issues to be addressed in the coming term of the Commission and Parliament. Alzheimer Europe will encourage its members to meet with EAA members on this day to discuss prioritising dementia and to coordinate messages on social media, in an effort to raise the profile of dementia and demand it be prioritised as a policy issue.

Demensförbundet highlighted the campaign in their magazine...
Highlights from the European Parliament Reception
EU legislation to establish European Disability and Parking Cards adopted

A Directive establishing the European Disability Card and the European Parking Card for persons with disabilities was announced in the EU Strategy for the rights of persons with disabilities 2021-2030. Following successful negotiations between the Council and the Parliament, the legislation has been adopted. Alzheimer Europe spoke to European Commission Director (Social Rights and Inclusion), Katarina Ivanković-Knežević, tells us more.

Background

Every citizen of the Union has the fundamental right to move and reside freely within the territory of the Member States as laid down by Article 21 of the Treaty on the Functioning of the European Union. Article 18 of the UN Convention on the Rights of Persons with Disabilities also recognises the rights of persons with disabilities to liberty of movement and to freedom to choose their residence on an equal basis with others.

Despite significant progress over the past decades, persons with disabilities still face barriers to their full participation in society, including to exercising their right to free movement and accessing services in all Member States. One of the underlying reasons is the absence of mutual recognition of disability status among Member States.

When persons with disabilities travel to or visit other Member States, they are usually required to show a proof of disability when they want to benefit from preferential conditions offered to persons with disabilities by service providers. However, the acceptance of national disability cards and certificates of non-residents is limited across the EU and takes place on a voluntary basis.

Another obstacle to free movement of persons with disabilities is the fact that when travelling by car in the EU, they have difficulties in using their EU parking card for people with disabilities. This card was set up by Council Recommendation 98/376/EC and nowadays is affected by the national divergences in the implementation and format, which lead to non-recognition of cards. Member States have also experienced problems with fraud and forgery of the parking cards, as the format is usually quite simple and easy to forge.

This is why the Commission, in line with the Strategy for the Rights of Persons with Disabilities 2021-2030, has proposed the initiative on the European Disability Card and the improved European Parking Card for persons with disabilities. This initiative builds on the experience of the EU Disability Card pilot project that took place in eight Member States (Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania, Slovenia) and on the EU parking card.

European Commission proposal

To ensure uniform implementation and mutual recognition, the European Commission proposed a binding act in September 2023 – a Directive of the European Parliament and of the Council establishing the European Disability Card and the European Parking Card for persons with disabilities. The Directive will apply to Union citizens and their family members (whose disability status is recognised by the competent authorities in the Member State of their residence), as well as to persons accompanying or assisting persons with disabilities. This would include personal assistants.

The aim of the Directive is to facilitate the free movement of persons with disabilities by the mutual recognition of their disability status when travelling to another Member State for short stays; and granting them access to benefits and preferential conditions reserved for persons with disabilities on equal terms and conditions as those provided to persons with disabilities in the visited Member State. Therefore, the Directive is creating two cards based on the EU common templates: the European Disability Card and the European Parking Card for persons with disabilities.

European Disability Card

The European Disability Card will serve as a proof of disability status within its scope across the EU. Its holders will have access to the same special conditions and preferential treatment as residents of the country they visit with respect to a large variety of services, activities and facilities. The areas providing the most preferential conditions are transport, cultural, leisure and sports events and...
activities. These conditions vary across Member States, and can include free entry, reduced prices, priority access, personal assistance, braille or audio guides, mobility aids, etc.

While respecting national competences to assess and recognise disability status, the Directive applies to a wide range of services, activities and facilities, in the context of a short stay. They include services in the EU internal market, passenger transport services, other activities and facilities. In this way the scope of the Directive goes beyond the scope of the pilot project, which is an important achievement.

The Directive does not apply to benefits in the area of social security that are already regulated by other EU acts. Other exceptions to the scope include services that are provided for the long-term inclusion, habilitation or rehabilitation of persons with disabilities and special conditions or preferential treatment to access services provided to persons with disabilities in consideration of their individual needs and upon the fulfilment of additional criteria, based on an individual assessment or on a decision to entitlement to specific services.

**European Parking Card**

The European Parking Card for persons with disabilities will ensure that its holders have access to the preferential parking rights and facilities of the country they visit, such as: extended parking space, reserved parking places, reduced parking fee, access to restricted traffic zones.

The Directive is meant for short stays, of up to 3 months, but Member States have to apply its provisions for card holders participating in an EU mobility programme, for the duration of that programme. Member States may also decide to apply the provisions of this Directive for periods longer than a short stay for other card holders visiting or staying in their territory.

The Directive provides for uniform formats for both cards, which will ensure mutual recognition. The cards will be issued in the physical version and the digital version (that will be optional for the parking card). Both formats will include security features, such as a QR code, to prevent fraud and forgery and enable verification of the validity of the cards.

To provide and share information, the Commission will set up a dedicated Union webpage for the European Disability Card. It will contain a link to the national website of each Member State. The Union webpage should be available in all official Union languages, international sign language and the national sign languages of Member States as well as in accessible and easy-to-read formats.

In October 2023 the Commission proposed an additional Directive to extend the main Directive to third country nationals with disabilities legally residing in a Member State. This will help Member States ensuring that they are treated the same as EU citizens (and their family members).

Following intense negotiations in January and February 2024, the European Parliament and the Council have reached an agreement on both proposals. The approval process should be finalised shortly after the formation of the new European Parliament, following the elections on 6-9 June 2024.

Details on both of the Cards are available at: [https://ec.europa.eu/social/main.jsp?langId=en&catId=1139&furtherNews=yes&newsId=10763](https://ec.europa.eu/social/main.jsp?langId=en&catId=1139&furtherNews=yes&newsId=10763)
Alzheimer’s disease affects approximately 100 million people worldwide.¹ It imposes a severe physical, psychological and emotional burden upon people living with the disease, their family members, care partners, and society.

By investing in research and development, we hope to support people living with Alzheimer’s disease to enjoy more independence and meaningful relationships with loved ones for as long as possible.

Novo Nordisk is proud to contribute to and improve our shared understanding of Alzheimer’s disease.

In its first meeting of 2024, the Group met online to discuss a range of dementia policy developments, including the place of dementia in the EU’s health and research programmes, implementation of new initiatives at a national level and relevant work of the World Health Organization (WHO).

On 27 March, the European Group of Governmental Experts on Dementia held an online meeting to discuss national, European and global developments in dementia policy, the first of two meetings scheduled for 2024. At the meeting, 23 European countries were represented, with representatives also from the World Health Organization (WHO), the Organisation for Economic Cooperation and Development (OECD), the European Commission’s European Health and Digital Executive Agency (HaDEA) and DG Research and Innovation (DG RTD), and Alzheimer Europe.

The WHO highlighted a recent publication which aimed to quantify the disease burden of disorders affecting the nervous system (including dementia), using data from the Global Burden of Disease Study 2021. Additionally, updates were provided on progress relating to the global action plan on dementia, as well as the intersectional global action plan on epilepsy and other neurological disorders.

The EU’s forthcoming Joint Action on Dementia (JADE Health) was discussed, which aims to integrate best practices across Europe through pilot initiatives, to complement and reinforce existing policies and programmes. There are 39 participants from 18 EU countries, who will be involved in 38 pilot projects, covering a range of themes including prevention, awareness raising, early diagnosis and improved service pathways.

An overview was provided of some of Alzheimer Europe’s recent work, including the Dementia in Europe Yearbook 2023 and Dementia Monitor publications, as well as its election campaign. Additionally, the forthcoming 2024 Alzheimer Europe Conference (8-10 October) was highlighted, with the next meeting of the Group proposed to align with the conference.

The Netherlands presented on their global Defeating Dementia Conference, held in October 2023 in the Hague, Netherlands. During this, the Group provided feedback on proposals to establish a “Group of International Government Experts on Dementia”, based on the model of the European Group.

The European Commission shared the second Horizon Europe Strategic Plan 2025-2027, as well as providing an overview of the recently-launched EU-supported coordination and support action on Brain Health, which would provide the basis for the future Brain Health Partnership.

Members of the groups then shared updates from their national contexts, including Malta outlining of its new national dementia strategy, whilst Scotland shared the first of its delivery plans for its new 10-year vision for change. Austria highlighted the development of its Dementia Quality Register, whilst also highlighting the ongoing work on the country’s 2024 Austrian Dementia Report. Germany updated on work taking place as part its strategy, including building a pathway of action and access for services and supports, whilst also drawing attention to the Dementia Partners project of the German Alzheimer association, which has been extended.

Ireland outlined that as part of its strategy, a model of care for dementia had been developed, setting out best practices for the entire care pathway of a person with dementia. The approach includes targets and a three-tiered diagnostic model whereby GPs can refer people to memory clinics or a specialist memory service.

Ukraine highlighted the effects of the war in the country, including the large displacement of people disrupting social contact and increasing stress, as well as increasing depression and decreasing mental health. The country is developing a national action plan on non-communicable disease to achieve the UN sustainable development goals, as well as developing policies to improve the quality of life in people with dementia. In Flanders, a campaign “everyone counts” aims to reduce stigma, whilst work is underway to implement the new strategy in the country, including training ambassadors as reference persons for people with dementia in care centres.

The Czech Republic shared work on system preparedness for innovative dementia treatments. Expert meetings were organised to prepare for the approval of new treatments, specifically in relation to the forthcoming decision of the European Medicines Agency (EMA) on Lecanemab. Given the expected cost, the government is starting to discuss reimbursement and how to ensure system capacity for the treatment both on a diagnostic and personnel perspective.

This subject was further discussed amongst the group given its wider relevance for European countries. In particular, the group discussed the capacity needed within healthcare systems to be able to administer the treatment and monitor on an ongoing basis. Some countries shared that working groups to discuss the matter were already established, to address issues relating to capacity, reimbursement etc. Additionally, raising awareness and understanding amongst both the public and professionals was seen as essential, given the expectations for a new treatment.

The Group is scheduled to meet in person on 7-8 October 2024.
People with dementia as carers

We often read about what it is like to live with dementia and about people with dementia as the recipients of care from family members, but people living with dementia are also sometimes carers themselves, for close family members.

Petri Lampinen and Lieselotte Klotz, both of whom are current members of the European Working Group of People with Dementia, share their experience of caring for a parent, while Helen Rochford-Brennan, former member and former Chairperson of the group, shares her experience of caring for her husband.

"Caring for others and the power of love"

Petri Lampinen (Finland) writes about caring for his father

A person living with dementia can also be a family caregiver for a loved one. That is exactly what has happened to me. I am my father’s informal carer; I do not get paid to help my father. I do it out of love for him and that is enough for me!

There are a great many informal family caregivers in my home country, Finland.

However, I think I’m a bit less common because I have dementia (frontotemporal dementia, FTD). Fortunately, this has not been an obstacle to the service system. I have been considered equally to other people.

I have told the officials in my father’s affairs that I have become familiar with the health care system over the past few years. So, I can manage things properly. At one time, in the initial stages of my illness, I had to do a lot of work for the services available. My caregiver role is limited to matters related to health care; my brother takes care of my father’s financial affairs. We have agreed on good terms about these matters. From the point of view of coping, this sharing of things is a helpful solution. I absolutely do not want to take care of my father’s financial affairs because I know how my FTD affects my ability to function (imprudence) and to manage these matters carefully. When it comes to healthcare, however, I’m a good choice, even though I say it myself.

At what point did I become a carer? About six years ago, I noticed a challenge with my parents’ ability to function. At that point, despite their objections, I contacted a service counsellor for the elderly. I agreed with him on the upcoming service needs assessment. It did not take exceptionally long for them to get a positive decision regarding the home care they were about to begin. I felt tired and relieved at this point. After a few home care visits, my parents were also happy with the change. We humans often fear change and the loss of our independence; I guess that is what this point in life was all about.

The most difficult moments I have experienced during my time as a caregiver were four years ago. My mother’s condition and behaviour quickly began to change. My father kept these things from me, and even the home care workers did not notice these changes in their daily lives. My father was 86 years old at the time, and he was struggling. Finally, he had the courage to tell me openly about their situation at home. I started making surprise visits to them, so I could better understand the situation. At times, the situation was so challenging that we had to call an ambulance immediately. I even spent one Christmas night, with my mother and wife in the hospital emergency room. However tough, this nonetheless left a beautiful memory!

Shortly after that Christmas, my mother passed away. I was able to lighten the load for my father at that difficult time, by taking care of funeral arrangements with the support of my wife. My father had taken care of my mother 24/7 for the past two years. Due to the death of my mother, he was now
“allowed” to get sick. I started going to the shops and cleaning up for him. I jumped at every phone call and feared the worst. He started to have falls at home, and as a result, he suffered two serious broken bones that led to surgery. He began to fear for his safety in everyday life. Short, daily homecare visits and constantly changing nurses were not enough to ensure his safety.

A younger person with a memory disorder and their family may have many family caregivers, just like our family. I am my father’s informal caregiver and my wife is both my informal caregiver and her parents’ informal caregiver. "Petri Lampinen"

I was at a meeting of the European Working Group of People with Dementia (EWGPWD) in Luxembourg when, in the middle of the meeting, a physiotherapist from the rehabilitation department called me and said that my father could no longer live safely at home. The doctor and nurse had also agreed. When I got home, I discussed the matter with my brother and father. After a little persuasion, my brother and I convinced my father to become a resident at a round-the-clock unit. We had to wait quite a long time for a place and some months later, during a meeting of the EWGPWD in Brussels, I was informed that my father would move to a care unit within three days.

So, while I was being a diligent participant during our meeting days, fortunately, my brother was able to immediately transfer the most important belongings to our father’s new place of residence and when I got home, I emptied and cleaned his apartment with the support of my wife. That summer was physically tough for me, because osteoarthritis in my knee flared up a lot during that time. I could only sleep for short periods, then.

We all experienced a wide range of emotions in this new situation. However, there was a sense of security. My father knew he would get help right away if he fell. I do not have to worry about every call anymore. My father has access to social relationships and stimulating activities. He is now 90 years old, and his memory works well for his age. He participates actively in daily activities.

Over the past year, I have been concerned about his hearing. He has been diagnosed with a significant hearing loss in the past. He has been on the waiting list for treatment for a year now, even though the treatment guarantee for non-urgent treatment is six months. I know there is researched data on a link between hearing loss and dementia, which worries me very much. I have called the hospital and tried to uphold my father’s rights. I understand the queues that came with the pandemic, but time passes quickly for my father.

I am pleased with the help I have received from the nurses of the care unit! Cooperation with them works well and they all know about my memory disorder. This has only had a positive effect. Often, they ask me “what event are you going to talk at Petri?” and this makes me feel that we truly have mutual respect and appreciation!

My caregiving role has fitted in well with the decisions I have received. A younger person with a memory disorder and their family may have many family caregivers, just like our family. I am my father’s informal caregiver and my wife is both my informal caregiver and her parents’ informal caregiver.

All that I am writing, here, is about caring for others and about strong love. We live in hope and gratitude for each other, in this moment!

“Dementia is a thief”
Lieselotte Klotz (Germany) writes about caring for her late mother

When I remember our mother today, who passed away at the age of 89, I think of a long life that we spent together. I remember many events, experiences and stages of life - both beautiful and sad. There were moments of effort and lightness, of anger and joy. But in all these memories remains the image of a woman who was at the centre of life for as long as she could be. She enjoyed being independent, was always present and was loved and appreciated by many.

In the last 15 years of her life, however, it became increasingly difficult for my mum to remember. She was often disorientated, sometimes desperate and sometimes aggressive. At first she only forgot small everyday things, but unfortunately the disease progressed inexorably until she could only recognise a few things. Unfortunately, Alzheimer’s was only diagnosed very late and, as is so often the case, a lot of initiative was required from family carers at all stages of the disease.

Nobody wants to have a dementia diagnosis in the family, and in my family, this has happened three times, including my own diagnosis with Lewy Body Dementia in 2017. I was personally very relieved when we received the diagnoses. Before that, our everyday lives were characterised by uncertainty, misunderstandings, mutual accusations, helplessness and despair.

With the diagnosis, we gradually developed radical acceptance, clarity, knowledge, options for action and the ability to make decisions.

Of course, we have gone through the various phases of crisis management several times in recent years: shock, reaction, processing and reorientation. Dementia also triggers fears in our family in many different ways. Stigmatisation and the prevention of participation in our society are other unloved companions that don’t make it easy for us.

We reached our physical and emotional limits in waves - as a family and as individuals. It was only through contact with the German
It is always better to act together and there is definitely no shame in asking for help. We have also learnt this as a family. For me personally, as someone living with dementia, it is all the more important to encourage those affected. A life worth living and loving is also possible with dementia.

In 20 years’ time, one in four people will probably have someone with dementia in their family or close environment. We must no longer hide dementia. Many people are already burdened with the same level of anxiety and overwhelm, but few talk about it openly. It is always better to act together and there is definitely no shame in asking for help. We have also learnt this as a family.

For me personally, as someone living with dementia, it is all the more important to encourage those affected. A life worth living and loving is also possible with dementia.

Lieselotte Klotz

“Weathering the Storm: Navigating Alzheimer’s while caring for my terminally ill husband”
Helen Rochford-Brennan (Ireland) writes about caring for her late husband

In the hectic landscape of caring, the roles can sometimes be reversed, placing the main thrust on an individual grappling with Alzheimer’s disease while tending to a husband suffering from a chronic terminal illness. I found myself in this situation in 2020 when my beloved husband Sean became extremely ill. This scenario was fraught with its own unique challenges, I depended on Sean to support me with my everyday challenges and now I had to navigate my own cognitive decline while also providing care and support to Sean. As the world contended with the ongoing pandemic, these challenges were further magnified, adding an extra layer of stress and uncertainty to an already demanding situation. It was so difficult to navigate each day which brought new hurdles to overcome. I felt my memory loss, confusion, and cognitive decline were chipping away at my sense of self, leaving me at times feeling disoriented and vulnerable. Yet, amidst these struggles, I was confronted with the reality of Sean’s need of care and assistance. It is difficult to explain the emotional toll on me of witnessing his illness, coupled with my own cognitive limitations, some days it totally overwhelmed me.

Going through this in the midst of a pandemic, where social distancing measures and lockdowns were enforced, the isolation felt by both of us intensified. The support networks of my family which I once relied upon for companionship became inaccessible, our son Martin was overseas unable to travel home, leaving me feeling increasingly alone. The fear of contracting the virus and passing it on to Sean added an extra layer of anxiety, heightening my sense of responsibility and concern.
As days turn into weeks and months blur together, the demands of caring can take their toll. My stress levels rose, my sleep became elusive, and feelings of guilt and inadequacy surfaced. The grief of watching my husband decline, coupled with the frustration of grappling with my own cognitive limitations some days seemed insurmountable. The emotional rollercoaster of caring at times becomes a lonely journey, fraught with uncertainty and doubt.

I was lucky that we received support of a home care for an hour each day from our health service this was a great support to me especially with morning medicines. The importance of having a support system cannot be overstated for people like me. Connecting with someone who understood my unique challenges eased my isolation and it lightened the load. Sadly, there was no support offered to me in dealing with my own illness at this time. I also got the opportunity to trial Alexa for our health service, this was so useful as I was able to get reminders especially medicine times.

Luckily, amidst the backdrop of this challenging journey, Martin’s arrival from overseas served as a beacon of light in the darkness. Witnessing his much-loved dad and mentor fade away was extremely heartbreaking for him and for me to watch. Thankfully, he was able to work from home, dedicating himself to providing support and companionship during this challenging time. His presence was a source of comfort and reassurance for both Sean and I, it offered me a respite from the loneliness and isolation that often accompany caring. Together, we navigated the highs and lows of our shared journey, drawing strength from our bond as a family and finding solace in each other’s presence.

After several months Sean had to receive his cancer treatment at a hospital 105 kilometres from home. We moved to a hotel near the hospital, I drove him daily and we returned home to Martin and my new puppy at weekends, the pain of watching how treatment affected him was horrific. The loneliness and isolation in the hotel room had a daily impact on my cognition and anxiety kept raising its head as I wondered when Sean slept, was he breathing. I googled to see what supports may be online to help me get through this tough time but unfortunately all I found was loads of articles for carers of people with dementia not the reverse as was my position.

Due to Sean’s rapid decline, he was moved into hospital, I continued to stay at the hotel and spend my days with him, Martin came as often as he could, he was being supported by his cousins. It was Christmas time. Palliative Care supported us for Sean’s end of life. Martin and I stayed with him for his final five days, we got four hours sleep each day. It is difficult to watch your loved one pass, but it is equally difficult to see your only child heartbroken. How I wished there were support for people like me. Sean left us peacefully on 27 December, we were then faced with a COVID funeral. In Ireland funerals are a community event however, we could only have 15 people in the church, the community supported us by lining the streets which was so heartwarming, we will never forget.

So, despite the overwhelming challenges I faced, as a person with Alzheimer’s caring for a sick husband, I possessed a resilience and strength that is nothing short of remarkable. My unwavering dedication to my beloved Sean, even in the face of my own cognitive issues, is a testament to the power of love and compassion. Though the road is long and fraught with hardship, I press on, guided by the belief that every sacrifice I made was an expression of my boundless devotion. My last promise to him was I would continue to advocate for the rights of people with dementia, which I have kept.

In the wake of loss, the journey towards healing is a gradual and nonlinear process. Grief may ebb and flow like the tide, but with time and support, it becomes more manageable. I was fortunate I received bereavement counselling from our local Cancer Support group. As a person with Alzheimer’s who has cared for a sick loved one, the memories of our loved ones, lives on as a testament to the depth of our love and the strength of their spirit. And though the pain may never fully dissipate, I find solace in knowing that I was there for Sean when he needed me most, offering comfort, love, and companionship until the very end.

I am so grateful for the support I received from my Alzheimer fraternity during this difficult period of my life.

“Despite the overwhelming challenges I faced, as a person with Alzheimer's caring for a sick husband, I possessed a resilience and strength that is nothing short of remarkable. My unwavering dedication to my beloved Sean, even in the face of my own cognitive issues, is a testament to the power of love and compassion.”

Helen Rochford-Brennan
First immersive Alzheimer’s disease simulator in Fortnite

At the start of 2024, the Spanish Confederation of Alzheimer’s and other dementias (Confederación Española de Alzheimer y otras demencias - CEAFA), in collaboration with Momentum Spain, launched a campaign to raise awareness of Alzheimer’s disease among young people: ‘Lost in the world’, the first immersive simulator of a disease in the popular online battle royale-style video game, Fortnite.

According to data provided by Momentum Spain, more than 10 million young people play Fortnite in Spain. Considering the fact that CEAFA realises that young people are the sector of the population least aware of Alzheimer’s disease, this collaboration represents an ideal opportunity to approach them.

‘Lost in the world’ aims to raise awareness and sensitise young people to the daily difficulties faced by people living with Alzheimer’s disease. Players are immersed in an environment designed to simulate the symptoms of the disease.

They experience, through the characters they choose, symptoms such as:

- spatial disorientation: the map constantly changes, and the character gets lost, making it difficult to remember where they are and how they have reached their destination
- memory lapses: the character does not remember or repeats names
- language difficulties: names of objects and places in the game are mixed up
- misplacing objects: the character places objects where they do not belong
- lack of understanding: the character does not respond to the player’s commands in the expected way, reflecting the difficulty people with Alzheimer’s disease may have to initiate and carry out simple tasks.

‘Lost in the world’ not only offers a unique gaming experience, but also seeks to raise awareness about Alzheimer’s disease and promote empathy towards those living with the disease. By immersing themselves in the difficulties and challenges associated with this disease, players develop a deeper understanding of how it affects people’s daily lives and how they can offer support.

A collaborative action with Spanish gamers

To boost the reach of this initiative, Momentum Spain collaborated with six Spanish gamers: @Blachitoo, @Mrkeroro10, @Leviathan, @Irenefields, @Sophia and @Gladoop. The collaboration reached a total audience of 6.8 million followers.

These gamers were invited to play the new map for the first time, without knowing the theme. Some of them were shocked or speechless by what they considered to be “bugs” in the game, which turned out to be representations of the symptoms of Alzheimer’s disease.
All these reactions and experiences were captured in the launch video.

The collaboration with these creators not only aimed to attract the attention of a young audience, but also to create an authentic and honest dialogue about the disease. The campaign helps to break down stigma, promote understanding and motivate young people to get involved in the Alzheimer’s cause.

To access the ‘Lost in the world’ interactive map, players need to enter the code 7230-3324-3779 into Fortnite.

Impact of the initiative

The Spanish Confederation of Alzheimer’s and other dementias (Confederación Española de Alzheimer y otras demencias, CEAFA), spoke about the initiative, highlighting that the simulator aimed to offer players an immersive experience that simulates the challenges and difficulties of people living with Alzheimer’s disease. By integrating this experience into a virtual environment frequented by young people, it contributes significantly to raising awareness and empathy towards those affected by the disease.

As the gaming industry continues to evolve, actions such as this demonstrate the potential of video games to address important issues and generate a positive impact on society.

About CEAFA

The Spanish Alzheimer’s Confederation (CEAFA) is an organisation that gathers more than 300 family associations and represents the interests and needs of more than 4.8 million people in Spain who live with Alzheimer’s disease and other dementias (including family caregivers).

Alzheimer’s disease accounts for more than 60% of dependency in our country and represents an annual cost of EUR 35,000 million.
Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia

A new book on occupational therapy and dementia has been edited by Fiona Maclean, Alison Warren, Elaine Hunter and Lyn Westcott. The book has forewords written by people with lived experience, including Margaret McCallion and Chris Roberts, and by Professor Clare Hocking. The editors tell us more.

“Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia” is a textbook highlighting examples of groundbreaking work by occupational therapists and inter-professional colleagues offering examples of how, and, in what way occupational therapists (potentially others also), can respond to and reflect on, a human rights-based approach to dementia practice. This book draws together and acts as a reference point for the ways in which the profession of occupational therapy can apply the essential occupational justice lens to specific examples of dementia care, evolving from research, policy, practice and education. It is unique as it seeks to shine a light on the importance of valuing the ‘everydayness’ of living with dementia and the significant contribution the profession of occupational therapy can make to support people to live well with dementia, including those who support them. This text book has, at its core, the voice of people living with dementia, emphasising their expertise in living with dementia and how this can shape and inform the knowledge and skill of our future workforce. This book challenges traditional patterns of thinking about dementia practice in occupational therapy with a more contemporary approach based on current theory. It critically reviews opportunities, illustrated by examples, of the ways in which the profession can respond to an occupation-focused, rights-based perspective of dementia care.

How did “Occupational Therapy and Dementia” come about and why did you feel that it was important to publish this book?

Our book came about as a result of the editors connecting at different times in their occupational therapy careers and Fiona bringing us all together through our shared passion for occupational therapy, dementia and the difference we know occupational therapy can make to people’s lives every day. We also had a shared passion to inspire the occupational therapists of today, tomorrow and the future to be leaders, innovators, researchers and rights-based practitioners in dementia. Importantly, as well as our career perspective, we also all brought a very personal perspective of dementia that inspired our thinking, creation and writing of this book. In editing the book, we knew we wanted to have people with dementia and their caregivers to guide and inspire the reader, so it was important for us all to have the voice of lived experience throughout the book. This can be seen from the image on the cover of the book, to the fact they are authors of the foreword, as well as chapter writers.

Can you tell us a bit about occupational therapy?

Occupational therapists work to enable people and communities to live their best lives. They work with people of all ages, focusing on the ways in which time spent influences health and well-being, this could be playing sport, through going to work and/or caring for others. But perhaps most importantly, educational therapists focus on the areas which are identified by people as most important to them, working further to support and enable the person to lead a purposeful, fulfilling life. Irrespective of practice setting, occupational therapists have a vital role to play in public health promotion, including dementia risk reduction across the life span. More widely, the profession consists of experts in advocating the right to occupation (what we want, need, and must do as part of our everyday lives) to empower people living with dementia, and those who support

“Occupational therapy can respond to and reflect on, a human rights-based approach to dementia practice. This book draws together and acts as a reference point for the ways in which the profession can apply the essential occupational justice lens to specific examples of dementia care, evolving from research, policy, practice and education.”
them, to maintain and sustain a positive life for longer. This framed our ambition to come together as co-editors of a new publication “Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia”.

**Target audience**

The editors of the book are all involved in the education of student occupational therapists and targeted the text at that key audience, especially students wanting to understand more about how to work alongside people living with dementia, their families, carers and social networks. Since the book has been launched, it has become clear that it is of interest to a wider readership than this, and that the scope of the chapters have drawn in different readers. The book has been popular among qualified occupational therapists, a range of other professionals and a wide range of people wanting to understand more about what occupational therapists can offer those living with dementia.

**Introducing the editors**

All four editors of the book are experienced occupational therapists with a passion for promoting the valuable contribution occupational therapists can make in supporting people living with dementia and their caregivers. All are involved in undergraduate and post graduate education of occupational therapy students and other health and social care professionals.

Dr Fiona Maclean is Associate Professor of Occupational Therapy at Edinburgh Napier University and Member of the Centre for Mental Health Practice, Policy and Law Research at Edinburgh Napier University. Fiona has a practice background in gerontology, dementia care, completed research exploring the occupation of drinking alcohol in later life and has an interest in translating a rights-based approach to practice.

Dr Alison Warren is Associate Professor and Research Lead for Occupational Therapy at the University of Plymouth. Her professional practice experience has been mainly in the area of dementia care, community mental health and emerging areas of practice. Alison leads the Participation in Every Day Life research group as part of Plymouth Institute for Health research.

Elaine Hunter is the National Allied Health Professional Consultant with a strategic leadership role in partnership with Scottish Government and Alzheimer Scotland and is leading in partnership the integration of Connecting People, Connecting Support (Alzheimer Scotland 2017, 2020) to local practice. Elaine has extensive clinical experience in the field of mental health and dementia.

Lyn Westcott is Consultant Professional Lead for Occupational Therapy at the University of Hertfordshire. Her professional portfolio is in the development and quality assurance of pre-registration degrees in health and social care. She has a practice background in mental health occupational therapy and publication interest in leadership, education and occupational therapy.

**The co-authors**

The contributors to this book offer perspectives on the significance of meaningful occupation in everyday life and reinforce that everyone has the right to occupation in their life. Occupational therapists from around the globe and other professionals working closely with occupational therapists, who also play a crucial role in enhancing people’s lives, provide valuable insights. With a collaboration of over 40 contributors, including those with lived experience, from professional practice, academia, and research, this book provides valuable perspectives and practical, problem-solving approaches. The book has a stimulating and thought-provoking foreword from Professor Clare Hocking (New Zealand) describing the book in the context of occupational justice and inclusion.
The textbook is structured using three key theoretical concepts which often guide how occupational therapists work in practice; person, environment and occupation. These concepts shape the three sections which make up the bulk of the book, with chapters that align to these concepts clustered within each section. In the development stages of the book, an overarching ethos was to ensure that the voices of people living with dementia and their caregivers were central and informed thinking and writing across all chapters. As such, it was important that the opening chapter of the textbook was grounded within the concept of the person.

Chapter 2 has been written by members of the Scottish Dementia Working Group (SDWG) and centres the way in which an occupation identified by our co-authors has supported and enabled a positive life for longer, when living with dementia. It was Lorna’s discussion of her love of embroidery which has been brought to life as the front cover of the book. Chapter 3 also focuses on lived experience, and is written by Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD) and member of the Board of Alzheimer Europe, and his wife and supporter Jayne Goodrick, who provide insight into upholding the rights of people living with dementia and their families.

The mid-section of the book considers the environment which influences both people living with dementia and how this can shape their experiences. For example, the way in which education prepares students of occupational therapy to work with people with dementia (chapter 10), as well as the ways in which access to transport, such as air travel, can be improved to promote inclusion (chapter 7).

The final section of this book considers occupation, which is what people want, need and must do to live purposeful and fulfilling lives. The chapters within this section offer an important contribution to enable therapists to focus their practice on people’s right to occupation, when living with dementia. Several approaches are outlined here such as the opportunity to grow access to post diagnostic support through programmes such as “Journeying Through Dementia” (chapter 15), or “Occupational Therapy Home Based Memory Rehabilitation” (chapter 14). Concluding with an emphasis on the growth, importance, and value our professional research offers to support enhanced rehabilitation outcomes for people with dementia and their caregivers (chapter 17).

Next steps

We brought together a group of inspiring people and have celebrated the launch of the book by developing webinars with the chapter authors. We have written and posted blogs and also presented at the Alzheimer Europe Conference, with Margaret McCallion from the SDWG (Margaret is also Vice-Chairperson of the EWGPWD). While we aimed to inspire our readers to reflect and potentially change their practices, we also hoped it was the beginning of an ever-evolving conversation on the role of occupational therapy in dementia. People with dementia are shaping how we understand the lived experience, challenging us as occupational therapists to be bold in our role, to promote the right to rehabilitation while also increasing access to prevention and early intervention delivered by occupational therapists. When looking ahead, we want our profession to adopt rights, opportunities and reflections (or ROAR) as a framework to shape how we work together as professionals in dementia, whilst at all times integrating the voice of lived experience in everything we do.
Turkey is developing search and rescue methodologies for people with dementia in emergencies and for missing cases

The Disaster and Emergency Management Department of Eskişehir, which is a governmental agency operating under the Turkish Ministry of Interior has designed an Erasmus+ project aiming to develop digital training materials to enhance the skills and knowledge of search and rescue personnel in handling cases involving individuals with Alzheimer's/dementia. Füsun Kocaman, Executive Director of the Turkish Alzheimer Association, shares the details of the project.

The project is centred on enhancing the knowledge and skills of search and rescue personnel, as well as emergency responders, in handling cases involving missing individuals with Alzheimer's and dementia to elevate their professional competence engaged in missing person cases following disasters and emergencies, as well as those arising as emergencies themselves. The project aims to develop innovative digital training resources to facilitate the acquisition of these essential skills. Its primary goal is to promote safety for both search and rescue personnel and individuals within the support network of those affected by Alzheimer's/dementia by enhancing their interdisciplinary competencies in search and rescue operations and Alzheimer's/dementia care.

Turkey was shaken by a major earthquake centered in Kahramanmaraş on 6 February 2023, a second major earthquake occurred again the same day, and another in Hatay was felt on 20 February. It has been reported that more than 50,000 people died and thousands were injured. Partners involved in this important project provided assistance to the affected area. There are many disadvantaged groups including elderly among the survivors of the earthquake, which affected 11 provinces and nearly 15 million people in total.

The project was launched on December 31, 2022 with the partnerships of Turkish Alzheimer Association, Irish Civil Defence, ISAR Germany, ESDP from Spain, Slovenian Alzheimer Association, Hungarian ÖPVE Organisation and Asystee Education Technologies from Turkey.

Research indicates that approximately 70% of individuals with Alzheimer's/dementia wander away from their support network or care settings at some point during the progression of the disease. A study conducted by Koester and Stooksbury revealed that 21% of subjects with dementia of the Alzheimer's Type (DAT) involved in search and rescue incidents succumbed to hypothermia, dehydration, or drowning. It was observed that all individuals who were found within 24 hours of their disappearance survived, whereas only 54% of those who were missing for more than 24 hours survived. This highlights the importance of swift and effective search and rescue operations in such cases.
The ultimate goals of the project are to enhance search and rescue methodologies specifically tailored for individuals with Alzheimer’s/dementia in emergency situations and cases of missing persons to ensure that missing cases of people with Alzheimer’s/dementia are resolved efficiently and in a timely manner, and to empower them, and their support networks, to develop safety skills for independent living.

Through the project, digital educational materials will be created for incorporation into an e-learning platform to enable the acquisition of these specialised skills. Moreover, a personalised e-portfolio system will be implemented to allow beneficiaries to assess and evaluate their progress, thereby strengthening the capacity and readiness of educational institutions for a seamless transition to digital education.

The project’s deliverables, designed to be swift, cost-effective, and easily accessible, will respond to the current and future needs of professionals in the field, fostering innovation in vocational education. By facilitating rapid and user-friendly access to beneficiaries, these outputs will enhance training flexibility and help bridge existing gaps in knowledge. Disseminating project outcomes as digital content on an e-learning platform has already been initiated to facilitate their transferability, increase outreach to diverse beneficiaries, and promote knowledge sharing and accumulation.

The most important activities in terms of development of the methodology of the project outputs with joint learning and sharing of professional knowledge and experience of the participants are “Learning, Teaching and Training Activities” (LTT). During these activities which are done in the territory of each partner, participants get the opportunity to gain different professional skills and knowledge related to the project topics and objectives, developing, and evaluating cross-skills. Education and training programmes with similar and different interdisciplinary cooperation will be prepared in these activities, thus the necessary competencies for the production of project outputs will be provided with cross-learning methodologies allowing achievement of the work package objectives.

The content of LTT activities is organised within the scope of the work package for the participants to share their knowledge and experience, give theoretical presentations on the good practices of the partners on the project topic, developing the common learning and skills of participants in different occupational groups and revealing the methodology of the project results, in order to transfer search and rescue, and intervention methods in disaster and emergency situations.

To-date, very productive LTT activities have been achieved in Spain, Germany, Hungary and Ireland, and at a meeting in Dublin (Ireland) in May 2024, the training material was finalised, and video production for the on-line section of the project. We are looking forward to the final completion of the project through the LTT activity in Istanbul in September 2024.

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Drill, Madrid (Spain), September 2023

Drill, Budapest (Hungary), November 2023

Search and rescue dog
Science behind the headlines: clinical study identifies five biological variants of Alzheimer’s disease

Earlier this year, a team of researchers from the Netherlands published new findings in the Nature aging journal, identifying five different subtypes of Alzheimer’s disease. In our Science behind the Headlines article, we delve into the new study, to find out what it might mean for people living with the disease.

Amyloid and tau have long been cited as the key culprit proteins in Alzheimer’s disease (AD). When Alois Alzheimer presented the case of Auguste Deter to an audience of German psychiatrists in November 1906, he noted the presence of distinctive plaques and tangles in her brain. Almost 80 years later, Glenner & Wong showed that the amyloid beta protein was the main component of plaques in AD. This 1984 discovery was swiftly followed by another seminal moment in AD research: the identification of tau as the primary ingredient in neurofibrillary tangles. Amyloid and tau form a toxic double act in AD. Amyloid plaques reside in the spaces in and around neurons, while tau tangles cluster within. Together, they damage brain cells and impair cognition, leading to memory loss, confusion and other symptoms associated with AD. However, research shows that there are many disease drivers of AD beyond amyloid and tau, which vary between individual patients – ranging from inflammation, to blood vessel damage, and beyond. In addition, while amyloid and tau are established hallmarks of AD, a diverse array of biological processes lead to plaque and tangle formation. Focusing entirely on amyloid and tau means that we miss crucial pieces of the AD puzzle.

Using proteomics to unravel disease mechanisms

In their new study, Betty Tijms (Amsterdam University Medical Center) and Pieter Jelle Visser (University of Maastricht) decided to look beyond amyloid and tau, searching for biological processes affecting the development of AD. “This can be hard to study in patients, because the brain is not easily accessible” Dr Tijms explains. “However, the brain is bathed in cerebrospinal fluid (CSF) and we can use new techniques to measure the protein levels in CSF. This can provide a detailed snapshot of the processes that are ongoing in the brain.”

To extract as much information as possible from precious CSF samples, the research team used a proteomics technique called mass spectrometry. Mass spectrometry allows researchers to “read” the human proteome like a book, producing vast data files that identify and quantify thousands of proteins within analysed samples.

The research team also expanded their analysis to genetic and clinical characteristics, showing that different CSF profiles also had different genetic risk profiles, and clinical characteristics. For instance, the 137 individuals in subtype 1 – hyperplastic brain cells - had the longest average survival time of almost nine years, with over-representation of a TREM2 genetic risk variant.

“Thanks to collaboration and sharing we were able to analyse a large number of high-quality samples and data – and find AD subtypes that would otherwise have been impossible to discover.” Pieter Jelle Visser
In comparison, the 56 individuals in subtype 5 showed evidence of blood-brain barrier dysfunction, and a higher risk of progression from mild cognitive impairment (MCI) to dementia. Whereas subtype 4 was associated with damage in the choroid plexus, the organ in the brain that produces cerebrospinal fluid, but normal tau levels and correspondingly slower progression to dementia.

Together, these findings spotlight the molecular diversity of AD, connecting the dots between genetic risk, CSF proteins, and clinical symptoms.

Data and sample sharing enables new discoveries

The findings also underline the value of data and sample sharing. To derive such accurate, meaningful insights on AD, large numbers of CSF samples were required, together with longitudinal data on clinical parameters, brain imaging and genetic risk factors. “Collecting CSF samples from so many people in a single study is very challenging,” explains Pieter Jelle Visser. “Thanks to collaboration and sharing we were able to analyse a large number of high-quality samples and data – and find AD subtypes that would otherwise have been impossible to discover.” These CSF samples were shared from research participants in four clinical studies: the Amsterdam Dementia Cohort, EMIF-AD preclinAD and EMIF-AD 90+ cohorts, and the EPAD study. Verification of the subtypes required datasets shared from a further 600 participants from six independent cohorts. The individuals involved in the study were selected from a number of cohorts in the EPND (European Platform for Neurodegenerative Diseases) Catalogue, which includes over 70 neurodegeneration cohorts representing over 230,000 research participants across Europe. EPND is creating a technical platform to enable researchers to discover, access and share samples and data. By facilitating cross-cohort studies like this one, EPND aims to catalyse innovations in diagnosis, treatment and care.

Biological subtyping for precision medicine in AD

So, what does this mean for people affected by AD? Firstly, there are potential implications for treatment. In revealing the biological diversity of AD, the study indicates that a “one-size fits all” therapy may not be equally effective for all patients. People from different subtypes may respond more or less well to different types of therapy, due to their unique AD characteristics. The results also provide tentative clues on how to tailor treatments to different subtypes. For example, people with subtype 1 AD have distinct patterns of brain shrinkage linked to changes in TREM2 protein levels – and may therefore benefit from therapies that activate TREM2.

The findings also have potential implications for clinical research on AD. “Clinical trials for AD are currently studying a huge range of different drug targets, but we can see indications in our data that a particular target might only work for a subgroup of trial participants,” notes Tijms. “Testing for different AD subtypes would help us recruit the right participants to trials, by identifying people who are more likely to respond to treatment.”

Finally, the study also charts a path towards improved AD diagnosis. For individuals to benefit from tailored and targeted treatments, a timely, molecular diagnosis is essential. Through their work, Dr Tijms and Prof. Visser show that it is possible to use proteomics and biomarker analyses to achieve more precision in diagnosis. If further research shows that treatments have effects that are specific to certain subtypes, this could pave the way for personalised medicine approaches in Alzheimer’s disease.

Identifying subgroups of Alzheimer’s disease patients that share distinct underlying biological processes will help researchers to develop targeted treatments that are more effective and have fewer side effects.” Betty Tijms

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