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Orazio Schillaci

Italian Minister of Health talks about the future of dementia policy in Italy

Alzheimer Europe hosts lunch debate in the European Parliament on the future of disease-modifying therapies for Alzheimer's disease

Sonata Mačiulskytė reflects on her time as Chair and Vice Chair of the European Dementia Carers Working Group over the past two years

Lisa Katharina Mayer Health Expert at the Austrian National Public Health Institute talks about the comprehensive new Austrian Dementia Report 2025

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Welcome

Maria do Rosário Zincke dos Reis (Portugal), Chairperson, Alzheimer Europe

I am delighted to welcome you the 49th edition of the Dementia in Europe magazine, which coincides with our 35th Alzheimer Europe Conference (35AEC), this year held in Bologna, Italy.

We open our Alzheimer Europe section looking back at our successful lunch debate in June, held in the European Parliament in Brussels, Belgium, at which around 100 people were present. We are grateful to co-hosts, Romana Jerković MEP (S&D, Croatia), Sirpa Pietikäinen MEP (EPP, Finland) and Hilde Vautmans MEP (Renew, Belgium) for their support! Our following two articles mark the closing of two projects in which Alzheimer Europe has been involved, with PatternCog Coordinator Jussi Tohka, and ADIS Coordinator, Holger Fröhlich, providing an overview of the achievements of their respective projects. We then hear from Ini Umoh, from the PROMINENT project, about a recently published paper on clinicians' perspectives on clinical decision support systems in dementia care.

We are delighted to welcome and introduce new members of the European Working Group of People with Dementia and European Dementia Carers Working Group (EDCWG), in the following article, before saying goodbye to Sonata Mačiulskytė, who departs from the EDCWG. Having served admirably as Chair and Vice-Chair during the formative years of the group, she leaves with our heartfelt thanks and will be dearly missed!

Opening the policy section, Lisa Katharina Mayer introduces the comprehensive Austrian Dementia Report 2025, setting out the state of play in the country, with a reaction from Friederike de Maeyers of Demenz Selbsthilfe Austria. Turning to European matters, we then examine the EU's general pharmaceutical legislation, with comments from the European Patients' Forum and the European Federation of Pharmaceutical Industries and Associations. We continue with EU-level work, with an article from Petra Ritter on the use of AI in healthcare, as part of the EU-financed initiative, TEF-Health.

Moving to a global level, Katrin Seeher from the World Health Organization (WHO) provides information on the WHO's Global Action Plan on Dementia, which has been extended until 2031. We then hear from Ricarda Milstein from the Organisation for Economic Co-operation and Development (OECD), who provides insights on data from their forthcoming "Care Still Needed - Policies for Improving the Lives of People Revisited" report. Finally, we close this section with a brief overview of the most recent meeting of the European Group of Governmental Experts on Dementia, who met online in June to exchange knowledge and information.

The first article in our Dementia in Society section begins with our member Alzheimer Iceland, which has been actively supporting people with dementia for 40 years – happy anniversary to them! Staying with our members, we mark some significant personnel changes, in the following articles. We warmly welcome Lena Kock to her position as Chair of our Swedish member organisation Demensförbundet, whilst bidding goodbye to Liselotte Björk – a huge thanks for all her hard work and support! We will also miss Gerjoke Wilmink, who after seven years as CEO of Alzheimer Nederland, will retire in November this year – we are grateful for her years of committed support!

Turning to dementia and the arts, we hear from our colleagues at The Alzheimer Society of Ireland about how people with lived experience were involved in the development of the play "Lost Lear", which was performed at the Edinburgh Fringe Festival in 2025. We then speak to director Bertrand Hagenmüller about the inspiration for his documentary film "Les Esprits Libres" and its objectives.

From the arts to science, we round off this section with the positive and long-awaited news about the European authorisation of lecanemab for the treatment of early Alzheimer's disease, which marks a milestone in the development of disease-modifying therapies.

In our final section, Spotlight on Italy, we hear about the current situation in Italy, the host country for 35AEC – a huge thank you to our Italian associations who made this section possible. We are grateful to Minister for Health, Orazio Schillaci, for taking the time to outline the current policy situation in Italy, as well as sharing some of the government's plans for the future. We then hear from Mario Possenti of Federazione Alzheimer Italia, and Manuela Belardinelli of Alzheimer Uniti Italia, who share the vital work of their respective organisations in supporting people living with dementia and their families. If you are attending the conference this year, be sure to check out their sessions!

We draw this section and the magazine to a close with two moving articles from people with lived experience of dementia. First Frank Parisotto, who lives with CADASIL, shares how he lives with the condition and how small changes in the community can help people with a diagnosis to live well. In our final article, Enea Donnoli gives a touching insight into his experience as a caregiver for his wife, Elea, sharing how life changed for them following the diagnosis. Thank you to both of them for sharing their experiences with us!

I hope you enjoy this edition of our Dementia in Europe magazine and hope to see you at our conference in Bologna, Italy! Happy reading!

Maria do Rosário Zincke dos Reis

Alzheimer Europe hosts lunch debate in the European Parliament

On 3 June 2025, Alzheimer Europe held a lunch debate in the European Parliament in Brussels (Belgium), entitled "Preparing for new Alzheimer's treatments in Europe" attended by national member organisations, civil society representatives, industry partners, policy makers and members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG). The event was attended by almost 100 people, including nine Members of the European Parliament (MEPs).

Three Co-Chairs of the European Alzheimer's Alliance (EAA) jointly hosted the session, Sirpa Pietikäinen MEP (Finland), Romana Jerković MEP (Croatia) and Hilde Vautmans MEP (Belgium). We are hugely grateful to each of them for their support and for welcoming us and our guests to this important event.

The session opened with welcome words from Sirpa Pietikäinen MEP who stated that the "EU must step up! By working decisively together on research, development, and clinical trials, we can lead the discovery of new treatments for Alzheimer's and other memory-disabling diseases."

Romana Jerković MEP then spoke to delegates, saying "Alzheimer's disease is a growing challenge for the European Union. As new treatments begin to emerge, we cannot ignore the persistent issue of late and underdiagnosis. Millions across Europe are suffering in silence and we owe them political focus, investment, and a coordinated response that matches the scale of this crisis."

Hilde Vautmans MEP shared that her interest in Alzheimer's came from her personal experience with her father who passed away with Alzheimer's dementia. She said "Europe must lead the way in transforming Alzheimer's care. With innovative projects and new treatments, we have a unique chance to shift from late reaction to early action: offering patients not just more years, but better ones."

After these introductory words, the first of our three speakers, Sebastiaan Engelborghs (Co-Chairperson, European Alzheimer's Disease Consortium, Belgium) presented "The advent of disease-modifying treatments

Speakers at the event, left to right: Sebastiaan Engelborghs, Miia Kivipelto and Linus Jönsson

Romana Jerković MEP

Hilde Vautmans MEP

Sirpa Pietikäinen MEP

for early Alzheimer's disease in Europe". He provided an update on the role of amyloid in Alzheimer's disease and the development of anti-amyloid treatments. His key message was that, through the registration of the first disease-modifying therapy for Alzheimer's disease in Europe, we are entering a new era, demonstrating that research pays off.

Next, Linus Jönsson (Karolinska Institutet, Sweden) spoke about "Preparing for a new era of precision medicine in Europe – the contribution of the PROMINENT project". His presentation gave an overview of the aims of the IHI-funded PROMINENT project, aiming to develop a digital platform for precision medicine to improve the diagnosis and treatment of neurodegenerative disease and co-morbidities. He emphasised that new diagnostic and treatment advances will improve care for Alzheimer's and other dementias. Decision support tools like those from IHI-PROMINENT will help clinicians apply these innovations effectively, ensuring better outcomes for patients and greater value for society."

The third and final speaker was Miia Kivipelto (University of Eastern Finland, Finland), whose talk on "New opportunities for early detection, prevention and treatment of Alzheimer's disease – the objectives of the AD-RIDDLE project" gave an update on AD-RIDDLE, which aims to develop a toolbox platform concept to enable healthcare systems and practitioners to improve the management of AD and dementia across diverse patient population. She noted that the Alzheimer's disease field is at a turning point. AD-RIDDLE bridges scientific innovation and clinical practice with a flexible toolbox platform featuring validated blood biomarkers, digital cognitive assessments, and tailored lifestyle or pharmacological interventions for early detection and prevention.

Sirpa Pietikäinen MEP thanked the speakers and gave the floor to some of her fellow Parliamentarians in attendance, EAA members Michał Szczerba MEP (Poland), Tomáš Zdechovský MEP (Czechia), Tsvetelina Penkova MEP (Bulgaria), Nikos Papandreou MEP (Greece) and Nina Carberry MEP (Ireland). She provided each of them a moment to address delegates and highlight why dementia is important to them, how they advocate for people with dementia and for national dementia plans in their countries and where gaps exist, at national level and across the EU.

Alzheimer Europe thanks all the co-hosts, speakers, delegates and also its Gold and Silver sponsors for making this event possible. Our next European Parliament Lunch Debate will take place on 2 December 2025. Highlight photos from the event are included on pages 6 and 7.

Highlights from the lunch debate in the European Parliament








EUROPEAN PARLIAMENT LUNCH DEBATE


Alzheimer Europe

Pattern-Cog – Advancing personalised dementia prevention in Europe

As the Pattern-Cog project draws to a close, Alzheimer Europe looks back at some of the highlights, and speaks to the Pattern-Cog Coordinator, Jussi Tohka, about his reflections on the work carried out during the project.

Project overview

Coordinated by the University of Eastern Finland, this three-year initiative brought together six partners from five European countries (Finland, Germany, Luxembourg, Spain and Sweden), namely Jena University Hospital (Germany), Charité – Universitätsmedizin Berlin (Germany), Alzheimer Europe (Luxembourg), Fundación Centro de Investigación de Enfermedades Neurológicas – Fundación CIEN (Spain), and Karolinska Institutet (Sweden).

Pattern-Cog stands for “Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals”. The project's overarching aim was to improve dementia prevention strategies by developing and validating a personalised medicine methodology for the detection of earliest signs of impending cognitive decline to enable early and personalised multidomain interventions.

Background

Effective disease-modifying drugs are not yet widely available, but a multidomain lifestyle intervention (FINGER randomised controlled trial, RCT) has been shown to improve cognition and other related outcomes in older adults with elevated risk for developing dementia.

Findings from FINGER and other multidomain lifestyle trials have made it clear that intervention effectiveness may be dependent on a personalised approach to prevention, in which the first task is to accurately identify people at-risk who are most likely to benefit from an intervention. In addition, it is likely that future intervention strategies will be most effective when applied at the earliest stages of the disease.

Pattern-Cog consortium, General Assembly meeting, Helsinki (Finland), October 2023

There are many personalised medicine studies looking at predicting the transition from mild cognitive impairment (MCI) status to dementia. However, there are virtually no methods to: 1) identify individuals in the pre-symptomatic phase of the disease who will transition to MCI status in the future and 2) assess the prevention potential and impact of personalised interventions. These are the critical blind spots targeted by the Pattern-Cog project.

Innovative methodology

Pattern-Cog introduced a novel approach by creating individualised aging patterns based on data from cognitively healthy individuals. By integrating routine measures such as magnetic resonance imaging (MRI), neuropsychological testing, and risk factors, the project developed a prediction methodology termed "personalised aging patterns." This methodology was developed and validated using existing databases, including a large observational study of healthy aging ("Vallecas Study") and dementia intervention/prevention trials (e.g., FINGER, MIND-ADmini).

Public Involvement

Ensuring that the perspectives of people affected by dementia (i.e. people with dementia and/or their informal carers) were integral to the research process. To this purpose, Pattern-Cog established an Advisory Board composed of members from the European Dementia Carers Working Group (EDCWG). Consultations with this group provided valuable insights into the needs, concerns and worries of individuals at risk, and this feedback was shared with researchers and taken into account in the Pattern-Cog project.

Progress and achievements

Throughout its duration, Pattern-Cog achieved several milestones. First, several well-performing methods have been developed for predicting future cognitive decline in cognitively healthy individuals. Interestingly, the prediction of future MCI status can be done several years in advance combining imaging and cognitive data. Blood biomarkers can further enhance the prediction of cognitive decline and models predicting biomarker status work also for clinical status prediction. Leveraging combined data from several databases, a regional BrainAGE framework has been developed enabling the use of BrainAGE for transdiagnostic purposes. The BrainAGE in the context of dementia intervention trials, the Alzheimer disease polygenic risk score (AD-PRS) and APOE4 genotype in the FINGER intervention cohort have been studied. Results suggest that the possible intervention effect on brain amyloid deposition may rely on genetic risk. Work was also undertaken to prepare the EBRAINS Health Data Cloud for the new Europrivacy Seal, demonstrating GDPR compliance. Furthermore, several human data sets were prepared for sharing via the trusted Health Data Cloud.

Pattern-Cog
Personalised ageing pattern
for early risk detection and prevention
of cognitive impairment and dementia
in cognitively healthy individuals

https://pattern-cog.eu/
https://x.com/PatternCog
https://www.linkedin.com/company/Pattern-Cog

A few words from Pattern-Cog Coordinator, Jussi Tohka

Alzheimer Europe, a partner in the Pattern-Cog project, invited Jussi Tohka from University of Eastern Finland, the project Coordinator, to share his thoughts on the various aspects of the project.

What is a personal highlight of the project for you?

It has been an honour and a true learning experience to lead this consortium of talented and dedicated researchers with diverse expertise. We've achieved exciting results and developed innovative methods. A personal highlight for me was working closely with representatives of patient organisations, something I hadn't experienced before. This collaboration was both fruitful and eye-opening, teaching me how to communicate the potential impact of our research to those with a deeply personal stake in the outcomes.

> "It has been an honour and a true learning experience to lead this consortium of talented and dedicated researchers with diverse expertise. We've achieved exciting results and developed innovative methods."
> Jussi Tohka

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

One of the most striking insights for me was realising that predicting cognitive decline requires different predictors depending on the population and the time window. Risk factors shift over time, and current datasets are often too limited (in terms of the size) to fully capture this variability. Interestingly, the most effective risk reduction strategies may also change over time even for the same individual. This complexity highlights the need for more nuanced, personalised approaches in both research and clinical practice.

There were six partners institutions in Pattern-Cog. How valuable was this collaboration for the project?

The collaboration was central to the success of Pattern-Cog. The discussions during our meetings were amazing, and I learned a great deal from our partners. Predicting MCI and dementia is a complex challenge, and this project helped me understand how much the best predictive approaches depend on the specific population and goals. Before this project, I underestimated this variability, something I believe is still overlooked in much of the artificial intelligence research in neurodegeneration.


Jussi Tohka

After three productive years, Pattern-Cog is now finished. What are the plans for its future?

Personally, I'm committed to doing everything I can to ensure the consortium's work continues. Several smaller national projects have already grown out of Pattern-Cog, and our collaboration will carry on through those initiatives as we work toward securing broader support.

Acknowledgement

This project was supported through the following funding organisations: Finland Research Council of Finland (RCF); Germany, Federal Ministry of Education and Research (BMBF); Germany, Federal Ministry of Health (BMG); Luxembourg, National Research Fund (FNR); Spain, National Institute of Health Carlos III (ISCIII); Sweden, Swedish Research Council (SRC), under the frame of ERA PerMed.

ADIS: Immune and sleep markers point to earlier Alzheimer's diagnosis

ADIS stands for "Early Diagnosis of Alzheimer's disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances". The project was funded through the EU Joint Programme - Neurodegenerative Disease Research (JPND). JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. The ADIS project ran for a period of three years with a budget of EUR 1.3 million, distributed among seven collaborators.

Holger Fröhlich

Interview with Project Coordinator Prof. Dr Holger Fröhlich, Fraunhofer SCAI, Germany

In one sentence, what has ADIS tried to prove?

ADIS was looking into new ways to support an earlier diagnosis of Alzheimer's disease and to better understand the interplay between sleep, peripheral immune system and cognitive impairment.

What makes the ADIS data set (including blood, sleep, cognition and digital tasks) different from other Alzheimer's disease studies at the moment?

The ADIS data has a unique depth relative to the number of enrolled patients. To our knowledge, this was the first Alzheimer study, that explored the peripheral immune system at the single cell level using most recent omics technologies (scRNAseq and TCRseq) with such a large number of patients. Our data provides unique insights into the role of the immune system in the development of the disease at an extremely high resolution. At the same time, we have highly interesting data on sleep and cognition, which was assessed via modern digital technologies (smartwatch and app). While other studies have investigated similar devices as well, none of them have been able to combine these data with high resolution biological data. That means, ADIS is unique in its possibility to study the interplay between sleep, peripheral immune system and cognitive impairment. A better understanding of this interplay could open new possibilities to treat patients (e.g. via check-point inhibitors developed by our partner ImmunoBrain) and to support an earlier diagnosis.

Fraunhofer SCAI looked after data management. How do you ensure the data from 75 patients is in accordance with the FAIR (Findable, Accessible, Interoperable and Reusable) principles?

We integrated our data into the ADataViewer data catalogue (https://adata.scai.fraunhofer.de/). This searchable data catalogue displays an overview of the different data modalities in ADIS and their presence in other AD studies. For cognition tests, there is also a mapping performed at the individual test level. Moreover, ADataViewer, directs interested researchers to the contact point, where they can apply for data access.

You also ran the project's AI work. Where did machine-learning add real value that classic statistics could not?

Classical statistics is highly important, and traditional hypothesis tests played a key role in our data analysis to understand differences between diagnostic groups on the level of single variables. However, hypothesis tests are limited to the analysis of selected variables and average trends. In contrast, machine learning focuses on predictions on the level of the individual patient using many variables and data points. In our project, we applied such techniques to various data types, such as actigraphy and single-cell RNA sequencing. Moreover, we used advanced AI approaches to learn in a data driven manner how sleep disturbances, immune system related measures, cognition and brain pathophysiology are connected and thus influence each other.

Agent-based models sound abstract. In practical terms, how might they help doctors spot diseases earlier in the future?

Agent-based modelling is a forward-looking concept to simulate the behaviour of a system, in our case the immune system. Our partners from Tel Aviv University applied this approach to simulate the response to a new drug against Alzheimer's disease developed by our partner ImmunoBrain. Their simulation was able to identify which patients are likely responders to the drug. Hence, agent-based modelling could support doctors in their decision, which patient should receive a drug.

> "ADIS is unique in its possibility to study the interplay between sleep, peripheral immune system and cognitive impairment."
> Holger Frohlich

Are there any early signals from the immune or sleep data that excite you?

We could nicely show that with data acquired from a consumer smart watch it is possible to detect rather accurately that people are not healthy. Patients can easily wear such a smart watch at home. If an algorithm then detects that a person is probably not healthy, this could motivate people to visit a doctor earlier. This could then support an earlier diagnosis, specifically, if there are diagnostic methods that can easily be applied outside specialised memory clinics. Blood-based biomarkers like p-tau217 are now becoming increasingly available, but mainly in memory clinics. Moreover, their accuracy in detecting patients in early stages of the disease is not 100%. Hence, there is still a need for low-cost biomarkers that could ideally be applied at the GP level.

Our analysis shows that there is a strong connection between sleep disturbances and changes in the immune system in the blood of patients. Hence, markers related to the immune pathways, which we identified in our work, could fill this gap. In the future they could be developed into assays that support AD diagnosis in an early stage at the GP.

ADIS involved universities, a hospital, tech firms and patient advocates in five countries. What did this cross-border mix achieve that a single-centre study could not?

ADIS was at its core a data analysis and modelling related project, with AI playing a central role. However, the focus on Alzheimer's disease requires a strong interdisciplinary mix of people, including experts from other areas like neurology, biotechnology, and patient advocates. None of the involved partners had all the required expertise in house, therefore, we needed an according consortium.

Data privacy matters. How do you balance open science with strict GDPR rules for sharing pseudonymised health data?

Data privacy does matter. However, without analysis of real patient data there is no progress in research. Fortunately, the GDPR is research friendly. It allows sharing of pseudonymised patient data for research purposes under strict confidentiality constraints. In addition, we asked patients for their explicit consent to share their data with the consortium members, and we are extremely grateful to all patients who supported our research in this way.

Open science means to make research findings derived from these data publicly available, which is very important to check reproducibility and thus to build trust. However, open science does not imply making patient-level data open. We never share any data of an individual patient, also not in pseudonymised form, without a clear legal basis, i.e. explicit consent or GDPR.

Looking ahead, what needs to happen (scientifically and politically) to turn a research-grade blood test into a tool that memory clinic specialists can use?

This is a long process, which includes:

- checking the reproducibility of our findings with independent data
- development of an assay that could be used by a physician
- development of an accompanying algorithm
- validation via a clinical study
- development of a business model
- regulatory approval
- negotiation of reimbursement possibilities.

Population-wide screening is controversial. Where do you draw the line between smart early testing and over-testing?

Getting tested is a very personal decision. The idea behind projects like ADIS is to give people a possibility to test a potential health problem, not to force them. It is always better to have freedom of choice.

Last one: if you could fix one bottleneck in Alzheimer's disease research tomorrow, what would it be?

From my point of view, one of the biggest bottlenecks in research is still the scattered data landscape with various studies that measure different aspects of the disease. Each of these datasets represent a highly selected patient subgroup, not the world-wide disease population. Therefore, it is not always clear whether findings from one study can be generalised. We need to get a more holistic understanding about the overall disease population in all its facets if we want to progress.

Another challenge is the translation of findings in research projects like ADIS into real world applications from which patients can really benefit. Unfortunately, this is financially and from a regulatory point of view far more difficult in Europe than in other areas of the world.

Raquel Sanchez-Valle

"Throughout the study, we worked hand-in-hand with our Advisory Boards, people living with various dementias, individuals keen on brain health or at risk, and carers, to shape every step. Their clearest instruction on consent was to strip the paperwork back to plain, everyday language, keep it brief, and add uncluttered visuals so each person can grasp the essentials and decide for themselves." **Raquel Sanchez-Valle, Neurologist at the Hospital Clínic de Barcelona**

adis

https://linktr.ee/ADIS_JPND
https://www.adis-project.eu

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PROMINENT project publishes paper giving clinicians' perspectives on clinical decision support systems (CDSS) in dementia care


Ini Umoh

In this interview we talk with Dr Ini Umoh, a medical doctor and health economist with a strong commitment to advancing access to health innovations that improve patient outcomes and health systems. She has a master's degree in health economics, policy and management from Karolinska Institutet, Stockholm (Sweden) and her research is driven by a passion for evidence-informed decision-making that supports strategic efforts to assess and scale innovative health technologies.

Could you start by sharing some background on what motivated you to study clinicians' perspectives on clinical decision support systems (CDSS) in dementia care?

A digital system is being developed to enhance clinical decision-making for patients with dementia and Alzheimer's disease by using multimodal data from different patients to predict disease progression and outcomes. This is the goal of the PROMINENT project. The end-users of this system are the clinicians managing this condition. We wanted to co-develop the system with the end-users, and to do that, we sought their opinions through a recently published study.

What were the specific aims of your study, and how did you define its scope to capture the needs of clinicians?

The study set out to answer two main questions: Firstly, what do clinicians want these tools to be able to do? We focused on what features are most useful to the clinicians. Secondly, what makes or breaks whether these tools will be used? It investigated the real-world challenges of rolling out these systems in clinics. Is the tool easy to use? Do doctors trust its accuracy? To make sure the study really reflected what clinicians need, we mapped the scope around the actual clinical journey. This means basically looking at the key decision points they face, from diagnosis to treatment as well as follow-up. We also built upon a previous study with similar objectives, but we made sure to fill in any gaps by adding themes not covered previously.

Could you briefly describe how you designed and conducted the survey, including participant recruitment through the European Alzheimer's Disease Consortium as well as inclusion criteria?

The survey was designed to be straightforward and practical; it was a digital questionnaire with about 65 items, covering topics such as diagnostic tools, treatment decisions, and what would make the digital platform usable in a real-world clinical setting. In order to reach out to participants, we contacted the European Alzheimer's Disease Consortium, which has a great network of memory clinics and specialists across Europe. We specifically invited clinicians like neurologists, geriatricians, psychiatrists, basically specialists actively working with patients affected by dementia. We only included responses from those with direct clinical experience in dementia care in order to keep our results focused.

Over half of the respondents had no prior experience with CDSS. Were you surprised by this finding, and what does it suggest about current adoption levels in Europe?

I was not entirely shocked by this finding. It just showed the gap between technological development and what's being used in day-to-day clinical practice. Variation across countries and institutions might be a reason for the patchy adoption. There is also the issue of trust where, if the tools are not user-friendly or beneficial, clinicians are unlikely to incorporate them into their already busy routines.

The results underscored the importance of data accuracy and ease of use for clinicians. Why do you think these factors stood out so prominently?

Clinicians are at the front lines of patient care, so it makes perfect sense that their top concerns are data accuracy and ease of use. When you are dealing with complex conditions like dementia or Alzheimer's disease, small errors in patient data can have consequences, like misdiagnosis and a missed treatment window, especially with the pre-requisites of a disease modifying therapy (DMT). So naturally, they want to feel confident that any tool they are using is giving them reliable, evidence-based information.

Then, there is also ease of use. Clinicians already have packed schedules and a lot of pressure. If a tool is clunky, takes too long to navigate, or does not fit into their workflow, it is not going to be used. Our results highlight that a clinical decision support system has to be accurate and intuitive to be truly helpful.

How do you see these tools improving day-to-day clinical workflows, patient outcomes, and overall dementia care in future?

These tools have the potential to transform the way dementia care is managed on a day-to-day basis. For starters, they can streamline clinical workflows by helping clinicians make faster, more informed decisions, whether it is by identifying early signs of Alzheimer's disease, assessing if a patient is eligible for a new treatment, or predicting how quickly someone's condition might progress. That kind of support reduces the mental load on clinicians and makes consultations more efficient.

From a patient perspective, it means more personalised care. These tools can analyse patient-specific data like cognitive tests, imaging or biomarkers, and offer tailored recommendations. That could lead to earlier diagnoses, more timely interventions and ultimately better outcomes.

In the bigger picture, as these tools become more integrated into practice, they can help standardise care across regions, reduce unnecessary variation, and improve communication among healthcare teams.

With new DMTs emerging, how might CDSS integrate with these treatments, and what role could they play in identifying candidates for therapy?

With the arrival of new DMTs for Alzheimer's disease, clinical decision support systems are becoming more relevant than ever. These therapies often require early and accurate diagnosis, plus a clear understanding of who may be at risk of adverse treatment effects, based on specific criteria such as the presence of the ApoE4 gene.

A CDSS can really step in as a smart assistant. It is able to pull together all the relevant patient data and help identify patients who meet the criteria for a specific DMT. It can also highlight contraindications or potential risks, which supports safer prescribing.

As the number of therapies grows, the complexity of treatment decisions will also become more challenging. These tools are therefore aimed at helping with navigating complex decision-making processes.

What do you view as the main barriers to widespread CDSS adoption, and how can these challenges be overcome through research, policy, or clinical practice changes?

As a medical doctor, I know that clinicians are cautious by nature. They need to know where the recommendations are coming from, what data was used, what algorithms are running behind the scenes. If they don't understand the underlying principles, they won't rely on the tool(s). Therefore, it is crucial that the systems should be explainable and transparently designed and involve clinicians from the development phase onwards.

Furthermore, there is the issue of integration and familiarity, if a CDSS doesn't integrate smoothly into the existing workflows, and the clinicians are unfamiliar with the tool, then the likelihood of use will be smaller. From a research and policy standpoint, we need to push for standards that make interoperability easier. On the clinical side, proper onboarding and training would help build confidence and encourage adoption.

A coordinated effort across research, policy and clinical practice is needed to make CDSS an integral part of dementia care.

Based on your findings, what areas of research should be prioritised next, to advance the use of CDSS in dementia care?

I think that there is a lot of value in real-world validation studies, because clinicians want to see solid evidence that these tools improve decision-making, patient outcomes, or workflow efficiency in day-to-day settings. These studies of CDSS should be conducted in diverse clinical environments and with measurements of outcomes like diagnostic accuracy and impact on treatment decisions.

If there is one central message you hope diverse stakeholders (clinicians, researchers, policymakers, and the public) take away from your work, what would it be?

My takeaway message is that: "Technology requires collaboration for it to be an effective solution". For CDSS to succeed, it has to be built around the real needs of clinicians, tested in practice, supported by policy, and trusted by the public.

Prominent
PRECISION MEDICINE

🌐 https://www.ihi-prominent.eu/
✱ https://linktr.ee/IHI_PROMINENT
Link to the study:
https://doi.org/10.1159/000544801

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European Working Group of People with Dementia and European Dementia Carers Working Group begin new mandates and elect Executive members

The membership of both the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) have been renewed and both groups officially began their new mandates after the Annual General Meeting (AGM) of Alzheimer Europe on 4 June 2025.

The new European Working Group of People with Dementia

As of 1 July 2025, the European Working Group of People with Dementia (EWGPWD) has voted in its Executive members, with Kevin Quaid (Ireland) being re-elected as the group's Chair and Gerda Van Tongerloo (Netherlands) elected as the new Vice-Chair. Many congratulations to them both and a big thank you to the group's former Vice-Chair Lieselotte "Lilo" Klotz (Germany) for her excellent work in this role over the past year. Lilo will remain as a member of the group.

For more information about the group, see: https://www.alzheimer-europe.org/about-us/european-working-group-people-dementia

Farewell to departing group members

Alzheimer Europe would like to express its gratitude to outgoing EWGPWD members Chris Roberts (United Kingdom – England, Wales and Northern Ireland), Margaret McCallion (United Kingdom - Scotland) and Minna Kinnunen (Finland), for their important contributions and we wish them well. They will be sorely missed! The group also lost Nigel Hullah (United Kingdom – England, Wales and Northern Ireland), who sadly passed away suddenly, earlier this year.

The members of the new group

The EWGPWD is now composed of the following 15 members, five of whom are new to the group:

Kevin Quaid, Chair

Kevin Quaid lives in Ireland with his wife, Helena. He lives with Parkinson's disease and Lewy body dementia. He is a co-founder of Lewy body Ireland and is Chair of the Irish Dementia Working Group. He was nominated to the EWGPWD by The Alzheimer Society of Ireland. Prior to becoming the group's Chair in 2024, he was Vice-Chair from 2022-2024. As the group's Chair, he is an ex-officio member of the Board of Alzheimer Europe.

> "Having a working group of people with dementia is vital because it's the voice of the lived experience. We are experts in what it's like to have our disease. Who better to listen to than an expert? More and more people are getting diagnosed each and every day. Now is the time for action!" Kevin Quaid

Gerda Van Tongerloo, Vice-Chair

Gerda Van Tongerloo lives in Zeist (Netherlands) with her three dogs. She was diagnosed with Vascular Cognitive Impairment in 2017 and is an active member of the working group of people with dementia of Alzheimer Nederland and a member of Alzheimer Nederland's Social Advisory Board. She is also a co-researcher in Brain Power, a research group of the University of Applied Sciences Utrecht, a member of the DEEP UK Network of Dementia Voices, and a participant and evaluator of projects from the Expertise Centre for Dementia and Technology of the Eindhoven University of Technology. Gerda was nominated by Alzheimer Nederland to join the EWGPWD in 2024 and was voted the group's Vice-Chair in 2025.

> "As a member of the EWGPWD, I speak up for those who can't. My aim is to explain what everyday life with dementia is like and to advocate for a dementia-friendly society." Gerda Van Tongerloo

Phillip Angrave (new member)

Phil Angrave lives in Kent (England) and has 40 years' experience of working as a registered nurse in a variety of clinical management and academic settings. He was diagnosed in 2021 with dementia with Lewy bodies when aged 58. He retired in 2023 and has been a passionate advocate for people living with dementia at an early age. He is a member of the Department of Health and Social Care Dementia Programme Board, the Young Dementia Network - Research and Evidence workstream and the Young Dementia Network Steering Group. Phil was nominated by Alzheimer's Society.

Stuart Dougall (new member)

Stuart Dougall lives with his wife in West Lothian (Scotland). He spent 36 years working with the prison and police services before his diagnosis of young onset Alzheimer's dementia in 2022, when he joined the Scottish Dementia Working Group (SDWG). He is involved in a wide variety of work with the SDWG, including research activities, developing dementia related supports and communication projects. He has also taken part in many studies and research opportunities in relation to dementia. Stuart was nominated by Alzheimer Scotland.

Kjell Ehn

Kjell Ehn lives with his wife, Eva, in Nyköping (Sweden) and has two adult children, Jonas and Sofia. He was diagnosed with Alzheimer's dementia aged 61. Among many other hobbies, he enjoys writing and is the author of a column in the quarterly magazine of the Swedish dementia organisation (Demensförbundet). In 2024, Demensförbundet nominated Kjell to the group.

Jan Runar Eliassen

Jan Runar Eliassen is married to Marion and has five children. He was diagnosed with Alzheimer's dementia, aged 45. In 2023, NRK, Norway's national broadcaster, started a series similar to the BBC's "Dementia Choir". Jan Runar joined the production aiming to raise awareness, especially around younger people being affected by dementia. He is also a member of the Norwegian working group for people with dementia, an ambassador for the Norwegian Center on Healthy Ageing, and a member of the steering group of young people with dementia in Norway. The Norwegian Health Association nominated him in 2024.

Hafsteinn Ágúst Friðfinnsson (new member)

Hafsteinn Ágúst Friðfinnsson is from Reykjavík (Iceland) but lives in Mosfellsbær, a town close to the capital. He and his wife Kolbrún have two daughters and one son. Hafsteinn is living with Lewy body dementia and shortly after his diagnosis, he joined Alzheimer Iceland and attends Seiglan (daily service provided by Alzheimer Iceland) regularly. He was nominated by Alzheimer Iceland.

Katya Genadieva (new member)

Katya Genadieva is 66, lives in Bulgaria and has limited cortical atrophy. She is married and has one daughter. She worked as a general nurse and a then in the field of mental health, before she retired. When she was working in mental health, she fought for the rights of her patients and now, she hopes to help make improvements in the lives of people with dementia. She was nominated by Alzheimer Bulgaria.

Jost Hamschmidt, Switzerland (new member)

Jost Hamschmidt is 59 years old and lives with his wife and their two sons in St. Gallen (Switzerland), while their daughter is studying abroad . In 2021, he was diagnosed with young onset Alzheimer's dementia and through an association called "mosa!k" for people with young onset dementia, he was introduced to Alzheimer Switzerland. He was nominated by Alzheimer Schweiz Suisse Svizzera (Alzheimer Switzerland).

Erla Jónsdóttir

Erla Jónsdóttir is from Reykjavík (Iceland), but lives in Garðabær. She and her husband Emil, who is a member of the EDCWG, have two daughters and four grandchildren. Erla was diagnosed with early onset Alzheimer's disease in 2020 and immediately joined Alzheimer Iceland's working group of people with dementia. She was nominated by Alzheimer Iceland in 2020.

Lieselotte (Lilo) Klotz

Lilo Klotz is from a small town near Cologne (Germany) and currently lives in Hennef (close to Bonn). She lives with Lewy body dementia and has two daughters and one son. She is a passionate sailor and spent her career mainly in the IT sector. Since her diagnosis, she volunteers at Deutsche Alzheimer Gesellschaft (DAlzG) in Berlin. She was nominated to the group by DAlzG in 2022 and served as Vice-Chair from 2024-2025.

Angela Pototschnigg

Angela Pototschnigg lives in Vienna (Austria) and has been living with cognitive impairments since 2015 and now has dementia. She is an ambassador for inclusion and the rights of people with dementia and since 2022, has been on the board of Demenz Selbsthilfe Austria. She was nominated by Alzheimer Austria in 2018.

Shelagh Robinson

Shelagh Robinson is living with Alzheimer's dementia and volunteers for the Alzheimer's Society. She is passionate about good support at the time of diagnosis, and good end-of-life care. She was nominated by Alzheimer's Society in 2022.

Věra Ryšavá

Věra Ryšavá lives in Kostelec nad Černými lesy, a small town near Prague (Czechia). She worked for 25 years in the children's department of a library in Prague and was also a cultural worker at the zoo. She is now retired and lives with Alzheimer's dementia. Věra was nominated by the Czech Alzheimer Society in 2022.

The new European Dementia Carers Working Group

European Dementia Carers Working Group
ALZHEIMER EUROPE

As of 21 July 2025, the European Dementia Carers Working Group (EDCWG) has voted in its Executive members, with Trevor Salomon (United Kingdom – England, Wales and Northern Ireland) being re-elected as the group's Chair and Roslynn Vella (Malta) elected as the new Vice-Chair. Many congratulations to them both and a big thank you to the group's former Vice-Chair Sonata Mačiulskytė (Lithuania) for her excellent work in this role over the past year. For more information about the group, see: https://www.alzheimer-europe.org/about-us/european-dementia-carers-working-group

Farewell to departing group members

Alzheimer Europe would like to express its gratitude to outgoing members Barry Northedge (United Kingdom - Scotland) and Sonata Mačiulskytė (Lithuania) for their important contributions and we wish them all the best for the future.

The members of the new group

The EDCWG is now composed of the following 15 members, two of whom are new to the group:

Trevor Salomon, Chair

Trevor Salomon lives in London (England). He stepped away from his job in 2011 to devote time to his wife Yvonne who was diagnosed with young onset Alzheimer's dementia when she was 57 years old. Trevor was nominated to the EDCWG by Alzheimer's Society in 2022 and held the position of Vice-Chair from 2022 to 2024, when he was voted in as Chair.

> "A unique aspect of the EDCWG is the desire to work together to improve the lives of carers and to use our voices for the greater good of people impacted by dementia. I accept though that putting ideas into action across Europe is inevitably linked to adequate levels of funding and resources." Roslynn Vella

Roslynn Vella, Vice-Chair

Roslynn Vella lives in Malta. Some ten years ago, she came to the realisation that her mother, Alice, had young onset dementia at the age of 58. Roslynn, her father and brother are Alice's carers. Roslynn was nominated by the Malta Dementia Society in 2022 and became the group's Vice-Chair in 2025.

> "The carers working group brings a unique voice embedded with knowledge and personal experiences from different countries, with a common goal to improve and shape policies, services and research. Being a member of the group, actively contributing and advocating for the best interests of our families, is both an honour and a great responsibility." Trevor Salomon

Bill Alexander (new member)

Bill Alexander retired eight years ago and lives near Stirling (Scotland). His late wife, Christine, was diagnosed with mixed dementia in 2019 and sadly passed away just before Christmas 2024. She was a member of Scottish Dementia Working Group and Bill joined the National Dementia Carers Action Network. He was nominated to the EDCWG by Alzheimer Scotland.

Peter Banda

Peter Banda is from Slovakia but lives in Graz (Austria). In 2018, his mother was diagnosed with Alzheimer's dementia and experienced a rapid disease progression.Peter was nominated by the Slovak Alzheimer's Society in 2022.

Patrick Crosbie

Paddy Crosbie lives in Dublin (Ireland). He was a carer for his late husband Derek, who was diagnosed with young onset Alzheimer's dementia at the age of 58. Derek passed away in November 2021. Paddy has been involved in the Dementia Carers Campaign Network (supported by The Alzheimer Society of Ireland) since it was founded in 2013. He was nominated to the EDCWG by The Alzheimer Society of Ireland in 2022.

Sylva Dneboská

Sylva Dneboská is from Prague (Czechia). When her husband Miloš was diagnosed with Alzheimer's dementia, she became his carer for more than seven years until he passed away in 2022. Sylva was nominated by the Czech Alzheimer Society in 2022.

Chris Ellermaa

Chris Ellermaa is from Tallinn (Estonia). Her journey as caregiver lasted more than six years, while she supported her mother who was diagnosed with Alzheimer's dementia. Chris was nominated by Elu Dementsusega (NGO Life with Dementia) in 2022.

Emil Emilsson

Emil Emilsson lives in Garðabær (Iceland) with his wife, Erla, who was diagnosed with young onset Alzheimer's dementia in 2020 at the age of 63. She and Emil joined Alzheimer Iceland and the Icelandic working group of people with dementia. Erla is also in the EWGPWD. In 2024, Alzheimer Iceland nominated Emil to the EDCWG.

Annick Germeys

Annick Germeys lives in Hasselt (Belgium). She has a son and a daughter and works as a project manager in a regional hospital, whilst also being carer to her husband Geert, who has young onset Alzheimer's dementia. Alzheimer Liga Vlaanderen (Flemish Alzheimer's Association) nominated Annick in 2024.

Zornitsa Karagyozova

Zornitsa Karagyozova is originally from Sofia (Bulgaria). She is married and has two sons. She has a Law degree and works as a legal advisor in a private company. Her journey as a carer began in 2020, when her father was diagnosed with Alzheimer's dementia. Zornitsa was nominated by Alzheimer Bulgaria in 2022.

Hatice Sertaç Süslü

Hatice Sertaç Süslü is from Istanbul (Türkiye). When her mother was diagnosed with Alzheimer's and vascular dementia, she joined the Turkish Alzheimer Association. Sertaç was nominated by the Turkish Alzheimer Association in 2024.

Peter Thörngren (new member)

Peter Thörngren lives close to Gothenburg (Sweden). He works full-time for a Swedish private engineering company and has been his wife's primary carer since her first symptoms five years ago. She was diagnosed with Alzheimer's dementia two years ago at the age of 59 and recently moved into a care home. Peter was nominated by the Swedish Dementia Association, Demensförbundet.

Liv Thorsen

Liv Thorsen is from Gjøvik (Norway). She is carer to her husband Kjell, who lives with Alzheimer's dementia and they have five children and 11 grandchildren. As a psychiatric nurse and teacher, she worked in patient and relative education, including dementia carers. Liv is the Chair of their local dementia organisation and a local politician. She was nominated by the Norwegian Health Association in 2022.

Olivera Vasilevska Danev

Olivera Vasilevska Danev lives in Skopje (North Macedonia). She is married, has one daughter and a dog. She works as a project manager and public procurement specialist in tender procedures. Together with her father and brother, she cares for her mother who has Alzheimer's dementia. She was nominated by the Institute for Alzheimer's Disease and Neuroscience (IAN) in 2024.

Christina Zioga

Christina Zioga lives in Thessaloniki (Greece). She is a medical doctor currently working as a consultant cytopathologist. She cares for her mother who has Alzheimer's dementia and has been an active member of several non-profit organisations and volunteers with the Hellenic Union of Search and Rescue. In 2024, Christina was nominated by Alzheimer Hellas.

Sonata Mačiulskytė reflects on her time giving a voice to carers of people living with dementia in Europe

After two years as Chairperson and one year as Vice-Chairperson, Sonata Mačiulskytė left the European Dementia Carers Working Group (EDCWG) in June 2025. We asked Sonata to look back over her time as the first ever Chairperson of the group and to share what it meant to her to be in a leadership position for the first years of the EDCWG.

Sonata Mačiulskytė

You joined the European Dementia Carers Working Group (EDCWG) in 2022 when it was first launched. What were your reasons for joining and what were your expectations? Were these expectations met?

When I joined the EDCWG in 2022, I felt both honoured and motivated. Having cared for my mother with Parkinson's and later dementia for nearly a decade, I knew first-hand how isolating and challenging the experience of caring can be, especially when access to support, diagnosis and information is limited. My main reason for joining was to use my personal and professional experience to ensure the voice of carers is heard at the European level and to help shape policies and research that truly reflect our realities.

My expectations were that this group would become a space where carers from across Europe could come together, share our diverse experiences, and make impact on Alzheimer Europe's activities, ensuring they truly reflect carers' priorities and needs. I hoped we could move beyond being "shadows" in the dementia journey and claim our own space in advocacy, research and awareness.

Looking back, my expectations were not only met but exceeded since the group has achieved far more than I could have anticipated: we have become a visible, active, and respected voice for carers within Alzheimer Europe, participated in numerous projects and events, and supported each other both personally and through our contribution to Alzheimer Europe activities.

First ever in-person meeting of the EDCWG, Brussels, March 2023

You served as the group's first ever Chairperson from 2022 to 2024 and then as Vice-Chairperson from 2024 to 2025. What did it mean to you to hold these positions and could you share one or two personal highlights from the past three years?

Serving as the first Chairperson was both a privilege and a great responsibility. It meant being entrusted to guide a unique, multinational group of people through the formation of a new "home" for dementia carers at the European level. My personal aim was always to create an environment where every member felt empowered to contribute and where diverse voices were valued.

A key highlight for me was witnessing our group's impact grow so rapidly. In just over a year, we contributed to advisory boards for research projects, shaped policy documents,

> “To the Alzheimer Europe team: “Thank you for believing in us, for giving us space, and for supporting our vision. I am proud of what we have achieved together, and I am confident that the EDCWG will continue to make a difference for carers and families across Europe.”

EDCWG at the 34th Alzheimer Europe Conference in Geneva, October 2024

provided testimonials, participated in conferences, and recorded campaigns to raise awareness ahead of the European Parliament elections. Another personal highlight was seeing members support one another through difficult moments, showing that our group became a true support group.

What do you think have been some of the EDCWG’s biggest achievements so far and what do you hope the group can achieve in the future?

Some of the group’s biggest achievements include:

- Making carers visible as a distinct and essential group within Alzheimer Europe and across national organisations
- Contributing to research and policy projects, and position papers
- Providing regular testimonials and video campaigns, amplifying the voices of carers across Europe
- Inspiring the formation of similar groups at the national level, as our example encouraged other countries to organise dementia carers’ working groups.

For the future, I hope the group will continue to grow in its influence, deepen collaboration with the European Working Group of People with Dementia, and have an even greater impact on research and policy, especially regarding access to support services, recognition of carers’ needs, and reducing inequalities between countries. I also hope the group can further support the mental health and wellbeing of carers, who are often at risk of burnout and isolation.

The group was formed to ensure, together with the European Working Group of People with Dementia (EWGPWD), that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia and carers, and to contribute towards research projects in the context of Public Involvement. Do you think these goals are being achieved?

Yes, I believe these goals are being achieved, and we can see real progress. EDCWG has had an active advisory role in many projects, shaped organisational documents, and ensured that carers’ experiences and needs are represented alongside those of people living with dementia. The group’s work is now an integral part of Alzheimer Europe’s agenda and public involvement activities, and there is genuine collaboration with the EWGPWD, culminated in a joint plenary session at the 2024 Alzheimer Europe Conference in Geneva. Of course, there is always more to do, especially in ensuring ongoing support and meaningful involvement at every stage of research and advocacy.

As a passionate advocate for the rights of carers of people living with dementia, what are your plans for further work in this area?

Over time, I have become more cautious in using the words “advocate” and “advocacy.” I sometimes feel that my activities are too modest to truly deserve these terms. In recent years, I have focused on deepening my knowledge in the field of brain health, benchmarking myself internationally, and building my professional community. I now see the greatest value in integrating my personal experience and voluntary work with Alzheimer Europe into my professional career. For me, this is the most meaningful way to use all that I have learned and experienced. Going forward, I expect to be less visible in the public arena and instead concentrate on making real changes for real people, quietly but effectively, in my everyday work.

As you leave the group, do you have any words you would like to share with your colleagues in the EDCWG and the team at Alzheimer Europe?

To my fellows in the EDCWG: “Thank you for your openness, solidarity, and courage; Working with you has been a personally very enriching experience and our shared laughter (and even tears) have made us stronger.”

Austria’s Dementia Report 2025: Insights, progress, and the path ahead

Lisa Katharina Mayer

In May 2025, the Austrian National Public Health Institute (Gesundheit Österreich GmbH, GÖG) published the "Austrian Dementia Report 2025" on behalf of the Austrian Federal Ministry of Labour, Social Affairs, Health, Care and Consumer Protection. Lisa Katharina Mayer, Health Expert at the Austrian National Public Health Institute, tells us more about the report, with Friederike de Maeyer, Chairwoman, and Johanna Püringer, Deputy Secretary of Demenz Selbsthilfe Austria, sharing their thoughts on the report.

Background

The Austrian Dementia Report analyses changes and reflects on developments since the implementation of Austria’s national dementia strategy “Living Well with Dementia,” building on it while addressing emerging challenges and outlining approaches to strengthen sustainable and inclusive support systems.

With approximately 169,000 people currently living with dementia in Austria and projections reaching nearly 290,000 by 2050, the report presents an interdisciplinary framework for advancing dementia care. Its recommendations address medical and social support, prevention, inclusion, public health, and system governance.

A collective knowledge effort: Contributions from over 80 experts

Over 80 experts from across disciplines, research and practice (spanning health and care professions, social work, public health, technology and digital innovation) contributed to the report. This wide-ranging input strengthens its relevance across sectors and scientific foundation. As a result, the following main thematic areas were developed:

- National and international developments: Overview of current strategies, trends, and insights in dementia care, including Austria’s international engagements.
- Epidemiology and demographics: Analysis of current and projected prevalence, age trends and regional variations.
- Prevention and health promotion: Presentation of risk and protective factors, evidence-based measures, and overarching social and political strategies.
- Early detection and diagnosis: Screening methods, the importance of differential diagnosis, and the role of primary care and interdisciplinary approaches.
- Therapy and interventions: Current developments in pharmacological and non-pharmacological treatments, psychosocial and rehabilitative approaches.
- Design of the living environment: Public awareness, promotion of social and cultural participation, innovative care models, urban and community planning, as well as technological support and digitalisation.
- Informal and family caregivers: Support and relief services for caregiving relatives and close contacts.
- Support, assistance and care: Overview of existing care structures, key challenges, and innovative approaches in support and long-term care.
- Structural framework conditions: Summary of financial support services, legal safeguards for people with dementia and their families, as well as macroeconomic effects and strategies for sustainable financing.
- Care-related aspects in marginalised and underrepresented groups: Challenges by people from marginalised or underrepresented populations e.g. individuals with migration background, intellectual disabilities, people with young-onset dementia, LGBTIQ+ individuals and those living alone.

New topics and developments since 2014

Since the first report, significant progress has been made in policy coordination and public awareness. The 2025 report introduces new themes such as dementia prevention in the context of public health, structured integration of digital tools, and expanded recognition of informal caregivers. Social participation, cultural accessibility, and tailored responses for marginalised populations receive increased attention. The report identifies dementia as a major public health issue and highlights several key contributing factors such as the rising number of affected individuals and caregivers, increasing health and long-term care expenditures, unequal access to services, and the broader implications for equity and workforce policy. Dementia prevention is addressed through modifiable risk factors, while systemic responses call for coordinated approaches across sectors.

Participatory contributions

The report integrates perspectives from people with dementia, informal caregivers, and family members, including contributions from self-representative groups and civil society organisations in the form of authored articles. Additionally, it includes a chapter which focuses on the situation and needs of caregivers, underscoring the dual burden of care and the importance of adequate support structures.

Limitations of the report

Identified limitations include the absence of standardised data collection across federal states and the lack of an operational dementia registry. Additionally, more research is needed on the long-term use of digital tools and the situation of people with dementia living alone. Challenges remain in scaling successful local projects and addressing workforce shortages. Further data collection and focused research will be needed to develop tailored responses for marginalised groups.

Strategic recommendations and future directions

The report also highlights specific priority areas under the broader themes of caregiving, technological innovation and social equity. These include, for example, the implementation of a dementia registry, the strengthening of participation and social inclusion of people with dementia, as well as:

- Fostering interdisciplinary collaboration across health and social care professions is considered essential for sustainable support structures. The report recommends expanding access to dementia-specific training and continuous professional education to facilitate this cooperation.
- Supporting informal caregivers, who are predominantly women, remains a critical concern. The report calls for better access to mental health services, respite care, and financial and social protections to alleviate the burden on families.
- Scaling successful regional models is highlighted as essential for national system improvement. The report points to initiatives such as the “Demenzservicestellen” in Upper Austria, offering low-threshold, post-diagnostic support, as good practice examples. These local services combine counselling, coordination and accessibility, and can serve as a blueprint for broader implementation across Austria.
- Advancing technological innovation is highlighted as a major opportunity to support autonomy and inclusion. Smart home systems, digital tools, and telemedicine are cited as promising developments, particularly for rural or underserved areas. However, the report also underscores the need to ensure equitable access and improve digital literacy.

Austria’s efforts align with broader international frameworks such as the WHO’s Global Action Plan on Dementia and initiatives by Alzheimer Europe. This alignment allows Austria to contribute to and benefit from shared learning across European systems.

Several pertinent questions are also addressed, such as: How to implement a dementia registry without overburdening care staff? How can urban pilot models be adapted for rural areas? How can technological progress be integrated in ways that are inclusive of older people’s preferences and capabilities? Ensuring sustainable financing especially in workforce and infrastructure remains an overarching issue.

Towards a sustainable and inclusive dementia policy

The Austrian Dementia Report 2025 does not propose a fundamental shift in dementia policy but supports the ongoing development of existing approaches. It recognises the progress made through the national strategy, pilot initiatives, and local models, while highlighting areas where coordination, resources, and implementation structures still require improvement. Central to this is a resource-oriented view that values people’s abilities, not just their needs. Autonomy, participation, and person-centred care are not abstract goals but practical guiding principles that require ongoing coordination, monitoring and support at every level.

Rather than redefining the role of dementia policy, the report clarifies its direction aligning existing efforts, addressing persistent gaps, and supporting long-term system development within a cross-sectoral public health framework – building on what exists, strengthening what matters.

The full report (in German) is available at: https://jasmin.goeg.at/id/eprint/4699/ or scan the following QR Code:

National Dementia Strategy – “Living well with dementia” (2015)

Launched in December 2015 and based on the findings of the first Austrian Dementia Report in 2014, this strategy set the direction for Austria’s long-term dementia policy. It was developed through a nationwide participatory process coordinated by Gesundheit Österreich GmbH (GÖG) and includes seven objectives. Guiding principles of the strategy: inclusive, resource-oriented, evidence-based, participatory.

- Full strategy (English PDF): Living Well with Dementia (2015) https://www.demenzstrategie.at/fxdata/demenzstrategie/prod/media/Demenzstrategie_Englisch.pdf
- Strategy website: https://www.demenzstrategie.at/
- Ministry website: https://www.sozialministerium.gv.at/en/Topics/Care/Dementia.html
- Contact for further information: demenz@goeg.at

Friederike de Maeyer, Chairwoman, and Johanna Püringer, Deputy Secretary, of Demenz Selbsthilfe Austria, share their thoughts on the report.

Friederike de Maeyer

Johanna Püringer

Dachverband
Demenz
Selbsthilfe
Austria

Austria's Dementia Report 2025 offers a detailed 324-page analysis of dementia care, far more extensive than the first report issued in 2014. The core aim is to provide a founded overview of the current care and living situation of people living with dementia and their families and to guide the next steps in Austria's national dementia strategy, "Living Well with Dementia". Key goals include improving quality of life, supporting participation and securing equitable access to services.

The report covers demographic trends, regional disparities, risk factors and care needs. It calls for coordinated action across sectors to meet growing demand. Core focus areas include prevention, early diagnosis, medical care, support services and social inclusion. In contrast to 2014, the report now addresses digital support tools, dementia-specific palliative care, and the needs of younger people with dementia. New attention is also given to marginalised groups due to gender, culture or migration. Language barriers, cultural misunderstandings and discrimination are identified as key challenges.

> "Austria's Dementia Report 2025 sets important goals, but implementation gaps remain. Expanding dementia-friendly communities, social participation and carer support are critical if Austria wants to improve life with dementia."

The report calls for culturally sensitive, low-threshold and tailored services. Dementia-friendly regions and the concept of "Caring Communities" also make an important contribution to social participation. These approaches enable inclusive living spaces in which people living with dementia can actively participate in social life. New concepts of supported housing, raising awareness in the neighborhood and local social networks help people stay involved in society.

Despite many positive ideas, there are still major gaps in practice. Post-diagnostic support remains regionally limited. Since there is no cure for dementia in sight and drug therapies are only aimed at delaying the disease and alleviating the symptoms, self-help groups are a a vital form of support in coping with the disease and are becoming increasingly important. The groups act as social networks focusing the resources and abilities of people with dementia.

However, despite great efforts, the necessary structures are lacking, the support programmes provided by self-help groups is largely based on voluntary commitment and without stable funding. This shortage is increasingly jeopardising the sustainable work of self-help initiatives, because only public engagement can ensure participation, support and visibility for people with dementia and reduce the stigma. But to find good solutions, we also need political framework conditions.

Although Austria offers various support services, many of these fail to reach carers due to lack of coordination or simply poor visibility. As a result, many family carers face daily challenges without meaningful support.

Angela Pototschnigg, expert on experience (supported by Johanna Pueringer), was able to emphasise the enormous importance of self-help, self-advocacy and public involvement in a national and international context from her personal perspective in chapter 8.4 of the report. She also highlighted the role of personal assistance in self-advocacy, but also as a necessary prerequisite for living well with dementia. In summary, Austria's Dementia Report 2025 sets important goals, but implementation gaps remain. Expanding dementia-friendly communities, social participation and carer support are critical if Austria wants to improve life with dementia.

EU general pharmaceutical legislation reaches trilogue stage

On 17 June 2025, the European Parliament, the Council of the EU and the European Commission held their first trilogue meeting on the reform of Europe's general pharmaceutical legislation. In this article, we look at the intention behind the reforms, with contributions from Solène Jouan of the European Patients' Forum (EPF) and Nathalie Moll of the European Federation of Pharmaceutical Industries and Associations (EFPIA), on their organisations.

Background

On 30 March 2021, the Europe Commission published its Roadmap for revising the general pharmaceutical legislation (GPL), setting out the broad parameters of its intention to amend legislation governing the approval, marketing and supply of medications in the EU.

On 26 April 2023, the European Commission adopted a proposal for a new Directive and a new Regulation, to revise and replace the existing general pharmaceutical legislation. The reforms mark the most substantial changes to EU pharmaceutical legislation in two decades. The stated aim of the revision is to:

- Ensure timely and equitable access to safe, effective, and affordable medicines
- Enhance the security of supply and availability of medicines
- Make Europe an attractive region for the research, development and production of medicines
- Make medicines more environmentally sustainable
- Address antimicrobial resistance (AMR) and the presence of pharmaceuticals in the environment.

The reform also proposes a strengthened framework for scientific and regulatory support from the European Medicines Agency (EMA), particularly for medicinal products that address unmet medical needs, such as anti-microbials. The reforms will also impact on the EMA's committees and patient representation within these.

The European Parliament adopted its position on 10 April 2024, whilst the Council of the EU adopted its position on 4 June 2025. The institutions positions vary on a number on conditions, including those relating to:

- Regulatory data protection and marketing protection
- Orphan market exclusivity
- Launch conditionality around access and supply of medicines
- Transfer exclusivity vouchers.

The reform proposals are now subject to negotiations in the trilogue, a process which is expected to take a number of months. Further information on the reform of the GPL is available at: https://health.ec.europa.eu/medicinal-products/legal-framework-governing-medicinal-products-human-use-eu/reform-eu-pharmaceutical-legislation_en

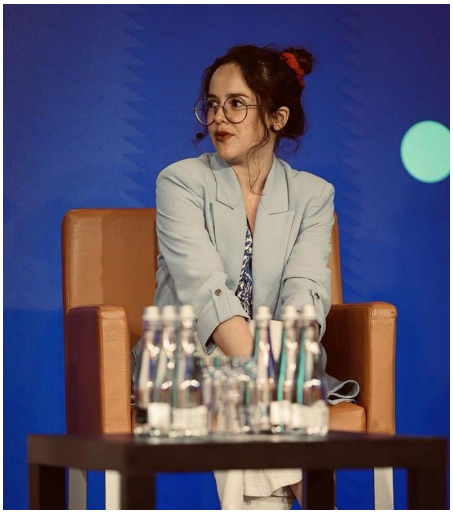
Solène Jouan, Policy Officer, European Patients' Forum (EPF), sets out the organisation's view on the reform of the GPL

EPF has been involved in revising the EU GPL from the start, as the revision will significantly impact patient communities. The rules that govern how medicines are authorised have far-reaching implications: they influence how patients are involved in the regulatory process, how research and development is shaped, and how medicines are accessed, including during critical shortages. It is therefore crucial to ensure that the patients' voice is heard and that the revised rules work for patients. Because, ultimately, pharmaceutical rules should meet the needs of those who will benefit from approved medicines: the patients.

EPF European Patients Forum

Patient involvement

But why do we need a new framework, and why are we, at EPF, committed to ensuring that the patient community has a voice in the negotiation process? Given that today's patients face challenges that didn't exist when the current legislation was adopted more than 20 years ago. Since then, healthcare has evolved dramatically.


Solène Jouan

We are seeing breakthroughs in science and technology, a rise in chronic and complex diseases, increasing antimicrobial resistance, and growing pressure on health systems. But the legal framework has not kept pace.

The revision of the GPL must ensure that medicines deliver real, tangible benefits to patients, not just in theory, but in practice. Equally important is the issue of access. In today's geopolitical context, we should see and understand that solidarity within the European Union is more crucial than ever. The future text to be adopted needs to put this topic and solutions at the forefront, prompting us to consider how, as a Union, we can ensure that all patients, regardless of where they were born and where they live in the EU, have timely and equitable access to essential treatments, which is a major issue today.

Keep Patients Voting

Patients aren't observers – they're experts.

Their insights shape safer, better, more effective medicines. They must have voting rights at the European Medicines Agency.

Take action!

“Keep Patients Voting”

One of our strongest concerns is the erosion of patient involvement in the proposed legislation. We are closely following discussions around how patients are included in EMA decision-making. Unfortunately, the direction of travel is worrying. In particular, we regret that key provisions have been significantly weakened compared to the original proposal from the European Commission and the position of the European Parliament adopted in April 2024. The Council's position, adopted in June 2024, includes the removal of the voting rights in the Committee for Medicinal Products for Human Use (CHMP), the number of patient representatives reduced in the Pharmacovigilance Risk Assessment Committee (PRAC), as well as failing to consult patients when drawing up the EU's list of critical shortages and critical medicines.

However, the attractiveness of the European continent should not only be based on its capacity for innovation but also on its rigorous involvement of patients in the regulatory process for medicines and consistently throughout the lifecycle of medicines. Reducing patient involvement or removing voting rights would not only undo decades of progress, but it would also send a damaging signal that patient perspectives are no longer valued in decisions that directly affect their lives. From our own experience and that of our members involved in several EMA committees, as well as from numerous academic studies and EMA reports, we know that regulatory decisions informed by the patient perspective are crucial. They enhance the quality of EMA opinions, provide a deeper understanding of patients' needs, and strengthen the EU's public health system, ultimately leading to better health outcomes for all. That's why we have launched with other patient organisations and advocate the “Keep Patients Voting” campaign to call on the EU Institutions to recognise and protect the meaningful and robust involvement of patient representatives during the trilogue negotiations between the European Commission, Parliament and Council.

> “The attractiveness of the European continent should not only be based on its capacity for innovation but also on its rigorous involvement of patients in the regulatory process for medicines and consistently throughout the lifecycle of medicines.”

To conclude, this revision of the pharmaceutical legislation represents for us at EPF a once-in-a-generation to make Europe's pharmaceutical system more equitable, resilient, and centred on public health. If we fail to embed meaningful patient involvement now, we risk falling short of the legislation's promise. If we succeed, we will have taken a major step toward a Europe that delivers on its commitment to health for all.

Nathalie Moll, Secretary General, EFPIA, shares the organisation's position on the proposed reforms and relevance for new Alzheimer's medications

The revision of the EU general pharmaceutical legislation must support investment if Europe is to lead the way in Alzheimer's research. The history of Alzheimer's disease (AD) research is a story of perseverance, commitment and hope. The research community has faced numerous frustrating setbacks over the past few decades. Nevertheless, industry's commitment can be seen in the ongoing quest to tackle unmet medical needs. European researchers and patients have a common goal: we want to be at the forefront of clinical research globally, ensuring that novel therapies are developed and accessible here in Europe. The revision of the general pharmaceutical legislation (GPL) is an opportunity to restore Europe's place at the heart of clinical research.

The legislation was last addressed in 2004. Since then, Europe's share of global research and development (R&D) has declined amid fierce competition from the US and China. In fact, Europe has lost a quarter of its share of R&D investment and its share of industry sponsored global clinical trials has almost halved. This has resulted in 60,000 fewer clinical trial places for Europeans across all disease areas.

These trends are what prompted Mario Draghi (the former Prime Minister of Italy who authored an influential report on European competitiveness and the future of the European Union) to warn that, unless Europe takes concrete steps to catch up with its global peers, we face an era of continued decline. A strong and predictable intellectual property system is the foundation on which innovation is built: it encourages and protects investments which are essential to the future of dementia research. It is also vital, economically, that Europe is positioned as a global leader in an increasingly competitive world.

Boosting research

Modernising the GPL is a chance to strengthen, rather than erode, Europe's intellectual property framework. This is crucial in areas like Alzheimer's disease, where the risks are high, and the rate of failure is significant.

However, the European Commission's proposals for the GPL would weaken Europe's intellectual property (IP) framework, making investment, the opportunity to participate in clinical trials, and access to cutting edge treatments less likely. The European Parliament and the Council have also had their say, but there is a real risk that the EU could reduce the number of years of regulatory data protection available – at a time when competitors are doing all they can to become more attractive to investment.

For Alzheimer's disease, early diagnosis is critical. Currently, in Europe, products that combine treatments with diagnostics have no single pathway to authorisation. The treatment will be assessed by the European Medicines Agency and often the diagnostic component by a national regulator.

The revision offers a chance to introduce a streamlined assessment pathway, enabling a single scientific advice process for these products. And that makes a real difference when developing innovative treatments for complex diseases like Alzheimer's.

A pivotal moment

Discussions are now at a crucial phase, with talks underway between the European Commission, Parliament and Council. Getting this right is essential for patients – who benefit from participation in clinical trials as well as from potential new therapies – as well as university hospitals and research-driven companies. It's an exciting time in Alzheimer's research.


Nathalie Moll

Novel therapies have emerged in the past few years and considerable progress has been made in both the development and approval of new treatments. For the first time in history, we are facing the possibility of treating Alzheimer's disease, not just for its symptoms, but also for the underlying pathology per se, at least in its earliest stages. The pipeline of AD treatments is rich. As of 1 January 2024, there were 164 clinical trials for AD assessing 127 drugs.

Treatment means time

Slowing cognitive decline will mean for people living with AD more 'functional' time in which the disease interferes to a lesser degree with daily activities, making it possible to enjoy life and be more independent, including spending time with family and friends, working, reading books, watching movies and travelling. Every year of independence gained is a year of intense home-based or nursing home-based care avoided, with obvious cost savings for both healthcare services and families. We all want to discover innovative medicines that meet the needs of people living with Alzheimer's disease. Developing a future-proof legislative framework which makes Europe more attractive in a competitive environment is the best way to turn this ambition into reality.

efpia

TEF-Health: advancing the implementation of trustworthy AI in healthcare

With full application of Europe's flagship AI regulation expected in 2026, healthcare innovators are facing new requirements for transparency, data governance and oversight. In this interview, we speak to Petra Ritter, coordinator of TEF-Health, about how this EU-financed initiative is bridging the gap between AI innovation and clinical implementation.

Artificial Intelligence (AI) is increasingly shaping healthcare, from diagnostics and drug development to surgical robotics and digital patient monitoring. Yet the deployment of these technologies in real-world clinical environments remains slow, in part due to strict regulatory requirements and the absence of pan-European testing infrastructures.

Aiming to bridge this gap, the European Commission, along with Member States and 128 partners from research, industry, and public organisations, launched EUR 220 million worth of investment in four sectoral Testing and Experimentation Facilities (TEFs) for AI, in June 2023.

One of these is TEF-Health, which is dedicated specifically to AI and robotics in healthcare. With a budget of approximately EUR 60 million, co-financed by the EU and seven Member States, TEF-Health brings together hospitals, research institutes, SMEs, certification bodies and tech developers across Europe. Its mission is to test and validate AI systems under real-life conditions, ensuring they are safe, trustworthy, and compliant with the EU's regulatory framework for AI.

Central to this framework is the Artificial Intelligence Act, the EU's first comprehensive legislation on AI. The AI Act, which came into force in August 2024, introduces a risk-based approach to regulating AI systems, requiring particularly rigorous oversight for "high-risk" applications. "High-risk applications" are AI systems that could significantly impact health, safety, or fundamental rights, such as those used in medical diagnostics, critical infrastructure, law enforcement, and employment decisions. These systems must meet strict requirements for transparency, data governance, human oversight, and compliance before entering the EU market.

The AI Act is being rolled out gradually, with full application for medical devices expected from August 2027 onwards. TEF-Health plays a key role in helping developers prepare for this shift by offering access to testing environments and certification support aligned with the AI Act's provisions. This means that for developers working on AI in dementia diagnosis, brain modelling, or rehabilitation robotics, TEF-Health offers a bridge between innovation and clinical implementation. More information on TEF-Health is available at: https://tefhealth.eu/home

The Coordinator of TEF-Health, Petra Ritter (Johanna Quandt Professor for Brain Simulation at the Berlin Institute of Health), outlines the project's goals and structure

What is TEF-Health?

TEF-Health is one of four sector-specific testing facilities launched by the European Commission under its Digital Europe Programme. TEF-Health, as the name suggests, focuses on healthcare. The idea is to provide developers - particularly startups and SMEs - with a realistic, secure environment where they can test AI and robotics technologies before bringing them to market. This is a more urgent need than ever, because under the AI Act, all AI-based medical technologies in the EU will soon need certification. TEF-Health is designed to support that process by providing access to testing infrastructures, regulatory expertise, and certification support.

What does that mean in practice and what kinds of technologies are being tested?

Something important to understand is that TEF-Health isn't focused on fundamental research. Instead, we focus on technologies that are already at Technology Readiness Level (TRL) 6 or higher – in other words, we aim to increase market readiness from the stage of working on prototypes.

We're seeing a wide range of technologies being tested: AI systems that help with diagnostics, such as brain imaging analysis; software for patient monitoring; robotics in surgery and rehabilitation; and even digital twins for modelling the brain. Many of these are relevant for dementia care. For example,

Petra Ritter

AI-based tools can help with early detection of cognitive decline, or robotic assistants can support people with dementia living in nursing homes.

Although these technologies might be designed to meet different needs, all of them face similar challenges: they need to be validated clinically, and they need to be certified from a regulatory perspective. This means testing them under real-world conditions, with real hospital workflows and clinical datasets, in a way that meets legal, regulatory and ethical requirements. This is where TEF-Health comes in: we are providing testing and validation services, and establishing standardised protocols and codes of conduct, to support innovators in bringing their products to customers and patients.

What does the TEF-Health network look like?

To support AI innovators across the EU, we have built a collaborative network with expertise in both national and European requirements for trustworthy AI. TEF-Health has set up seven nodes in Germany, France, Sweden, Belgium, Portugal, Slovakia and Italy; two associated nodes in Finland and Czechia and also involves the pan-EU structures EBRAINS AISBL.

TEF-Health is coordinated by Charité - Universitätsmedizin Berlin and currently includes 52 partners from nine countries, including research institutes, hospitals, small and large tech companies, standardisation organisations. Each site offers different services. For example, some focus on robotics, others on cloud infrastructure or legal consulting. Through a central platform, developers can search available services and apply for access, with subsidised rates during the initial five-year period. Right now, our platform includes 342 services from 31 organisations in 9 countries, and to date we have launched two calls for price reductions on these services. Selected SMEs and startups from EU member states will receive state aid support in the form of discounts on certification and validation services from the platform.

How is this relevant to dementia?

While TEF-Health generally supports a broad range of healthcare AI and robotics use cases, brain health is one focus area – besides cancer, cardiovascular and intensive care. At the Berlin Institute of Health, we've developed a secure cloud infrastructure that supports high-performance computing and privacy-respecting access to patient data, which is ideal for brain simulation and digital twins. These technologies are important in modelling neurological diseases like dementia. We can offer testing for algorithms that simulate brain activity or predict cognitive outcomes. And by working within a secure environment, we can comply with data protection laws while still enabling meaningful analysis.

Why is testing with real, individual-level data so essential in this field?

Because brains are incredibly complex, and average values don't help us. You can't test a dementia diagnostic tool using anonymised, averaged datasets: the variability between individual patients is just too high. You need real, individual-level data, of course handled responsibly and ethically, to see whether an AI system is accurate and reliable. That's one reason we built TEF-Health: to provide a secure, legally-compliant and clinically relevant setting where such testing is possible.

What's the process for a company or research group that wants to use TEF-Health?

We've created a database of around 340 test services across our sites. Developers can go online, browse services by category, and submit a request. Then we do a matchmaking process, which connects them with the right test site and helping them navigate legal and technical requirements. Services include infrastructure, data access, interoperability checks, and even certification preparation. And right now, everything is offered at reduced rates thanks to EU co-financing of TEF-Health.

Does TEF-Health also support developers preparing for the AI Act?

Absolutely. The AI Act is coming into force gradually, and from 2027 onwards, AI-based medical devices will need to comply. That includes having proper documentation, risk assessments, and often, third-party audits. TEF-Health supports companies in preparing for these new elements, working with notified bodies, standardisation agencies, and regulators to provide the necessary testing and documentation. We see ourselves as a link between developers and the regulatory environment – and as a pathway to support patient access to innovative, AI-powered tools that can improve diagnosis, treatment and care.

What is the long-term vision for the programme?

TEF-Health's unparalleled network of pan-European institutions, partners and services makes it unique. TEF-Health represents clinical testing environments, cross-border cooperation, real-world data access, and regulatory integration - all in one. And it's not just for big tech companies. We want to empower smaller developers, researchers, and care innovators to bring trustworthy, effective AI tools into practice. Especially in areas like dementia, where innovation can significantly improve the patient journey, TEF-Health can make a real difference.

The EU funding covers the first five years, but we've designed TEF-Health to be sustainable. Under the AI Act, Member States are expected to set up permanent regulatory sandboxes. We hope TEF-Health will form the basis for a Europe-wide infrastructure that remains available beyond 2028, in the form of a European Digital Infrastructure Consortium (or EDIC). This would ensure continued support for AI innovation long into the future – so patients can access new diagnostic, treatment and care innovations much faster.

> "AI innovations for dementia diagnosis, treatment and care must be tested and validated to ensure accuracy, safety, and clinical relevance. TEF Health offers the secure, real-world environments essential for validating and certifying these advanced tools, so patients can access them faster."

European Group of Governmental Experts on Dementia meets online

In its first meeting of 2025, European Group of Governmental Experts on Dementia met to discuss the latest policy developments related to dementia, at national, European and international levels.

On 10 June, the European Group of Governmental Experts on Dementia met online to discuss developments, publication and projects, with relevance for dementia policy, as well as to exchange knowledge and information. The Group meets twice per year, with meetings organised and secretariat provided by Alzheimer Europe.

In total, 18 European countries were represented at the meeting, in addition to representatives from the World Health Organization (WHO), WHO Europe, the European Commission's DG Research & Innovation (DG RTD) and Health and Digital Executive Agency (HADEA), the Organisation for Economic Cooperation and Development (OECD), the EU Joint Action on Dementia (JADE) and from Alzheimer Europe. Representatives from national ministries, including Austria, Belgium (Flanders), Czechia, Denmark, Estonia, Finland, France, Germany, Iceland, Ireland, Hungary, Netherlands, Norway, Poland, Slovenia, Sweden, Switzerland and the United Kingdom (Scotland) were also present.

During the meeting, findings from a survey which had been distributed to the group were discussed, which indicated that members of the group wanted to explore topics such as disease-modifying therapies, the evaluation of dementia strategies and risk reduction/prevention.

The JADE project was introduced, highlighting its aim to address the challenges posed by dementia and improve the quality of care for people living with the condition. Members learned that the project involves 46 entities across 17 countries, with 44 pilot actions underway, involving around 7,500 participants. The work is divided into ten work packages, six of which focus on technical areas such as early detection, person-centred care models, vulnerable groups, stigma, prevention and equitable access.

The representative from DG RTD provided an overview of the forthcoming European Partnership for Brain Health, which will commence in 2026 and run for ten years. This partnership will consolidate existing initiatives, including the EU Joint Programme – Neurodegenerative Disease Research (JPND), the Human Brain Project etc., into a single ecosystem, with the aim of promoting innovation in diagnosis, prevention and treatment.

Alzheimer Europe introduced findings from the SHARE (Survey of Health, Ageing and Retirement in Europe) project they are leading, which focuses on understanding dementia risk reduction and prevention strategies across European countries. Using data from survey responses, the project will assess how modifiable risk factors for dementia are distributed both within and between countries. Preliminary findings show significant variation across countries and between sexes, with certain risk factors being more prevalent among women (e.g. depression, loneliness) and others more common in men (e.g. smoking, diabetes).

Opening the session on national developments, the representative from Sweden introduced the country's new national dementia strategy, "Everyday Counts" (2025 -2028), setting out four overarching goals: individualised care; stronger focus on prevention and intersectoral collaboration; ensuring staff work based on scientific evidence or proven experience and better support for informal carers. The strategy also emphasises the importance of early diagnosis, the use of assistive technologies and rehabilitation to maintain the abilities of the individual over time.

The Scottish Government provided an update on the progress of its 10-year dementia strategy, "Everyone's Story", which was launched in 2023. A two-year delivery plan is underway, containing seven key action areas, including the development of a dementia index to identify how people with dementia access health and social care services

The Dementia Expertise Centre in Flanders spoke about the implementation and monitoring of their third dementia plan (2021–2025), noting that political continuity had helped sustain momentum for work in the region. As Flanders prepares for its next strategy, feedback was sought from members on monitoring and evaluation frameworks.

From Austria, an update was provided on the Dementia Report 2025 (also covered in our article on pages 20-22), outlining developments and gaps in dementia policy and practice over the past decade, addressing topics including diagnosis, therapy, care systems, social participation and the needs of underrepresented groups.

The German Government provided an update on the country's national dementia strategy which runs until 2026. It brings together 86 state and non-state stakeholders and contains four action areas, 27 goals and 167 measures. By the end of 2024, half of the measures were completed, with most others in progress, showing strong advancement towards full implementation.

The next meeting of the Governmental Expert Group will take place in person, on 5 and 6 October 2025, coinciding with the 35th Alzheimer Europe Conference in Bologna (Italy).

Strengthening the global response to dementia: Extension of the WHO Action Plan to 2031

At the 78th World Health Assembly in May 2025, the Global Action Plan on the Public Health Response to Dementia 2017-2025 was extended until 2031. In this article, Katrin Seeher, Mental Health Specialist, World Health Organization (WHO), tells us more.

Katrin Seeher

Dementia affects over 55 million people worldwide, a number expected to rise sharply in the coming decades. In response to this growing crisis, the World Health Organization (WHO) adopted the Global Action Plan on the Public Health Response to Dementia 2017–2025, which envisions a world in which dementia is prevented, and people living with dementia and their caregivers are supported to live with dignity, respect, autonomy and equality.

The action plan outlines seven strategic areas: dementia as a public health priority; dementia awareness and friendliness; risk reduction; diagnosis, treatment, care and support; support for caregivers; information systems and research and innovation. It sets global targets and recommends actions for Member States, WHO and other stakeholders to guide national and international efforts toward realising its vision.

Despite these efforts, a progress report submitted to WHO's governing bodies in 2025 revealed that the world remains far from achieving the plan's objectives. Alarmingly, low- and middle-income countries (LMICs), where most people with dementia reside, are particularly struggling to mount an effective response. These countries face systemic challenges, including limited health infrastructure, insufficient funding and a lack of trained personnel, which hinder the implementation of dementia strategies.

WHO Member States took decisive action during the 78th World Health Assembly in May 2025. They extended the global dementia action plan until 2031, aligning it with the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031. This extension reflects a renewed commitment to addressing dementia as a global health priority and acknowledges the need to close the implementation gap.

In addition to extending the timeline, Member States requested the WHO Director-General to submit progress reports to the 80th World Health Assembly in 2027 and the 82nd in 2029. These reports will be integrated into the broader reporting framework of WHO's Comprehensive Mental Health Action Plan 2013–2030, ensuring that dementia remains a central focus within global mental health and neurological strategies.

The extension of the action plan presents a timely opportunity to build on recent advances in policy, service delivery, data systems and research. For example, growing evidence on modifiable risk factors such as physical inactivity, smoking, poor diet and social isolation, can inform targeted prevention strategies. Innovations in digital health and telemedicine offer new avenues for improving diagnosis and care, especially in underserved regions. A recent WHO report, Dementia in Refugees and Migrants: Epidemiology, Public Health Implications and Global Responses, also highlighted the urgent need to consider vulnerable populations, such as refugees and migrants, who face unique and compounded barriers to dementia care. Moreover, increased global attention to brain health provides a platform for integrating dementia into broader health and development agendas.

However, realising the vision of the extended action plan will require more than technical solutions. It demands political will, sustained investment, and inclusive partnerships across sectors and countries. LMICs, in particular, need tailored support to develop and implement national dementia plans, strengthen health systems and build workforce capacity. International collaboration will be essential to share best practices, mobilise resources, and ensure that no country is left behind.

The extension reinforces the importance of a human-rights-based approach to dementia. People living with dementia and their caregivers must be meaningfully involved in shaping policies and services that affect their lives. Promoting dignity, autonomy and social inclusion is not only a moral imperative, it is central to achieving equitable and effective public health outcomes.

The decision to extend the global action plan until 2031 marks a critical juncture in the global fight against dementia. It offers an opportunity to accelerate progress, address disparities, and work together as a global community to ensure that all people affected by dementia can live well and realise their full potential. The coming years will be pivotal, and success will depend on our collective resolve to turn vision into action.

Care still needed: Updated OECD report outlines latest trends in dementia care across Europe

In 2018, the Organisation for Economic Cooperation and Development (OECD) published "Care Needed: Improving the Lives of People with Dementia", on the state of care for people with dementia. In this article, Ricarda Milstein, Soohyun Kim and Ana Llena-Nozal of the OECD, share some of the work undertaken to update this report, which will be published in early 2026, and provide the latest data on the current state of services for people with dementia.

Background

Across the OECD, populations are ageing, with the increase particularly pronounced among the oldest age group. The share of people aged 80 and above is projected to almost double from 4.9% to 9.6% from 2023 to 2050. As dementia is especially prevalent among older people, an ageing population will lead to an increase in people experiencing a set of symptoms of cognitive decline, such as memory loss, which interferes with one's daily life, social activities and relationships. Countries with older populations, such as Japan and Germany, already face this issue, and the overall OECD countries will see an increase in people with dementia by 50% over the period from 2021 to 2040 (Figure 1).

The increase in dementia puts financial pressure on health systems, societies and individuals. In 2019, the global burden of dementia was estimated to amount to USD 972.3 billion in high-income countries (Wimo et al., 2023[2]). Around half of these costs are incurred by informal care providers who are often first in line to care for people with dementia. Across 11 European countries, the average annual hours of informal care due to dementia ranged from 163 hours in Sweden to 1,051 hours in Czechia. The financial burden to households varied accordingly between almost EUR 2,700 in Sweden and around EUR 15,500 in Germany, resulting from out-of-pocket costs and informal care costs.

Countries have recognised increasing challenges that dementia poses to their health and long-term care systems. A recent OECD analysis finds that at least 24 out of 29 OECD countries have dedicated stand-alone dementia plans aimed at improving the prevention, diagnosis, and care delivered to people with dementia, while eight countries have more than one dementia framework in place. Around half of the countries have updated their strategies over the past seven years. Greece, Canada and Ireland have joined the group of countries with a dementia plan, and Costa Rica and Japan have passed laws on dementia care and awareness. Austria, Germany, and Switzerland are currently undertaking updates, alongside Poland, which is planning to release its first national dementia strategy in 2025. The recent changes in national strategies highlight a more comprehensive understanding of dementia that addresses its risk factors and call for broader societal adaptations to improve the lives of people with dementia.

Prevention of dementia remains a promising but challenging area.

Around 45% of dementia cases are subject to modifiable risk factors, such as early childhood education, chronic disease management, and addressing visual and hearing impairment (Livingston et al., 2024[5]). Prevention has been difficult to translate into real-life gains, with many


Ana Llena-Nozal


Ricarda Milstein

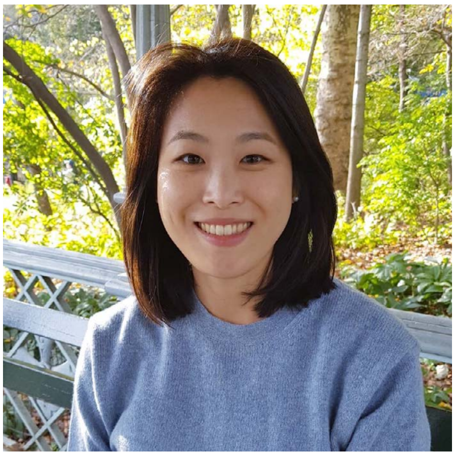
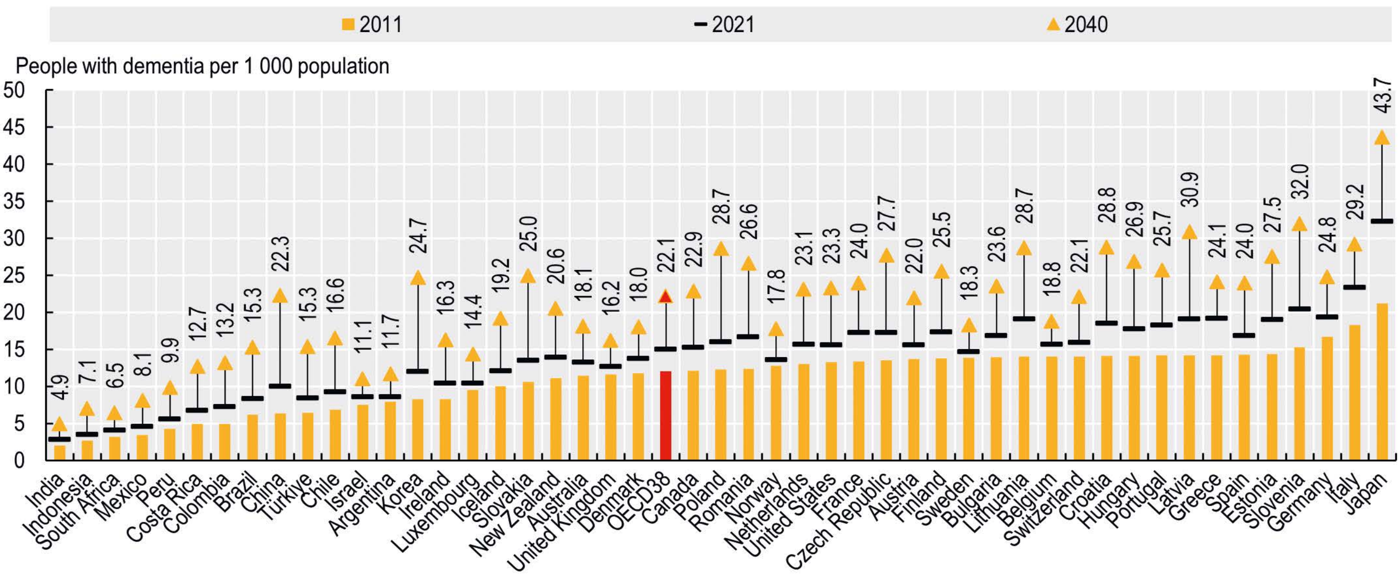

Soohyun Kim

Figure 1: Estimated prevalence of dementia, 2011, 2021, and 2040



Note: Estimates for 2021 and 2040 are forecasts using a reference scenario.
Source: Institute for Health Metrics and Evaluation (IHME). Used with permission. All rights reserved. Global Burden of Disease Study 2019. For more information, see OECD (2023[1]).

randomised control trials showing only modest improvements. However, there are some interventions that have been found to benefit cognition in older people with an elevated risk of dementia, such as the multidomain lifestyle intervention FINGER which is used in several OECD countries. Furthermore, OECD countries invest in public health campaigns promoting healthy lifestyles, for example, Germany's national action plan "IN FORM" to increase physical activity, alongside campaigns like "Alcohol? Know your limits". Sweden and Australia focus on sharing information and raising awareness, while the Netherlands and Canada invest in research on modifiable risk factors.

Early detection and diagnosis can help delay the worsening of dementia but progress in early diagnosis is still limited.

At least 23 OECD countries have diagnostic guidelines in place to support healthcare workers in recognising symptoms and in harmonising and streamlining diagnostic pathways. Financial incentives in England and the United States have helped reduce the gap between estimated and diagnosed rates of dementia. Across the OECD, the GP remains the main point of contact, but some countries have broadened the type of healthcare workers who can diagnose dementia. Denmark has just made financial support available to scale up diagnostic capacities, and the Netherlands now possess a widespread network of memory clinics available across the country.

Treatment of dementia has shown limited innovation and integration within the health systems.

Over the past decade, OECD countries have become increasingly aware of non-pharmacological interventions and their potential benefits (e.g. cognitive stimulation therapy), while avoiding using anti-dementia drugs in early to moderate dementia unless it is absolutely necessary. However, mixed scientific evidence and a lack of reimbursement schemes limit the integration of non-pharmacological interventions into dementia care practices, further limiting user access and experience. Meanwhile, recent progress in Alzheimer's medications has raised new hope for treating dementia. Although these new drugs aim to slow down the progression, their notable side effects, limited clinical use, high cost and implementation burden prompt countries to exercise caution in adopting them into healthcare systems.

Support for dementia carers continues through care coordination and management, as well as informal carer training and support.

Care coordination and special care management can reduce dementia carer confusion and burden in the post-diagnosis period. Currently, dementia care coordinators and case management are available in 14 and 16 countries out of 28 OECD countries, respectively. Across the OECD, 84% of countries (32 out of 38) offer policies that aim to support, inform and empower informal caregivers in their roles. This includes helplines, such as Korea's 24-hour counselling and outbound case management through the National Dementia Helpline. Specific training for formal long-term care workers remains sparse across the OECD. Dementia cafés, that are available in several countries, such as France, Czechia, Hungary, and the United Kingdom, offer a place for people to meet and interact, and training and guidance to specific groups, such as policemen, firefighters and shopkeepers, as well as the wider audience, which is offered in 18 countries, such as Austria, Canada and Estonia, help prepare people for more frequent interactions with people with dementia.

Alzheimer Iceland celebrates its 40th anniversary!

This year, Alzheimer Iceland celebrates 40 years of work and pays tribute to the many people who have made this possible, including all those living with dementia and the pioneers who have worked with and for them over the past four decades. Guðlaugur Eyjólfsson, Director of Alzheimer Iceland, tells us about the celebrations.

Guðlaugur Eyjólfsson

Alzheimer Iceland for 40 Years

The fact that an association like Alzheimer Iceland has been active for 40 years is a significant achievement. It is the result of extensive work, to which many have contributed.

The beginning

In 1985, a group of carers decided to form a group to meet with the authorities and urge them to act for what was, at the time, a silent, forgotten group – people living with dementia. This led to the establishment of a formal association with the aim of safeguarding the interests of people with dementia, strengthening cooperation among carers through educational meetings, publications, and more. Raising awareness among authorities, healthcare professionals, and the public about the challenges faced by people living with dementia and their carers and ensuring them the care and social support needed in a modern society.

Day centres and support

A year later, in March 1986, the first day centre for people living with dementia was opened, partly thanks to the strong efforts of Alzheimer Iceland. The goal was to reduce social isolation among people living with dementia, maintain their independence, and promote participation in daily activities. Also to relieve pressure on carers, monitor daily health, boost self-confidence, and alleviate distress and feelings of helplessness.

Around the same time in 1986 Alzheimer Iceland also started offering counselling and participation in support groups which is still a vital part of the service Alzheimer Iceland provides today. There was a significant lack of accessible information about dementia for families and for those involved in nursing and caring for people with dementia until 2002 when Alzheimer Iceland began publishing dementia-related material and launched the website https://www.alzheimer.is/.

In 2020, the Ministry of Health issued a five-year action plan for services for people with dementia. A review of that action plan is now underway and will cover the period from 2025 to 2030. Alzheimer Iceland is actively participating in this review.

Seiglan

In 2021, Alzheimer Iceland opened a day centre called Seiglan, which means "Resilience", intended for people who have been diagnosed with a dementia-related condition that is at the stage of mild cognitive impairment (MCI), from the time of diagnosis until there is a need for more specialised services. Seiglan operates according to the philosophy of occupational therapy. This professional approach is rooted in the belief that engagement in meaningful activity is essential for all people. Throughout history, human life has been shaped by the need to engage in purposeful activities and participate in society. Research has shown that when individuals are unable to engage in meaningful activities, their health and well-being can suffer.

By creating opportunities for people to participate in such activities and strengthen their social connections, we increase the

A concert to celebrate the 40th anniversary was held on 16 March 2025

A special screening of the documentary film "Human Forever" was held on 10 April 2025

likelihood of achieving greater balance and well-being in their lives. The support provided at Seiglan is guided by each person's interests, abilities, wishes, and needs. The goals of Seiglan are to slow the progression of the disease by supporting individuals in setting goals that increase daily activity, enhance overall quality of life, and strengthen their sense of identity, maintaining physical, cognitive, and social functioning, promoting independence and increased engagement and providing opportunities for social interaction and encouraging communication.

Celebration of 40 years

Alzheimer Iceland is organising several events throughout the year to celebrate this anniversary, while at the same time raising awareness about dementia in society, encouraging public discussion, and highlighting the services provided by Alzheimer Iceland.

The first event was an anniversary concert on 16 March. It was a wonderful evening filled with joy. Many well-known Icelandic performers took part and donated their time. All proceeds went to Alzheimer Iceland. The two big TV news channels in Iceland came and did a live news segment from the concert.

On 10 April, we organised a special screening of the amazing documentary film “Human Forever”, in which the 24-year-old humanitarian and activist Teun Toebes is on a mission to improve the quality of life for people with dementia. It was especially gratifying to welcome Jonathan de Jong, the film’s director, to Iceland. He spoke about the making of the film and its purpose, and his passion for the project was truly palpable. We hope the film encourages us all to reflect on how, as a society, we want to care for people living with dementia. Most importantly, we must remember that at the heart of it all are human beings. As the title of the film says, we are all “Human Forever”.

> “This year, we reflect and remember all those who have lived with dementia and the pioneers who have worked for the association over the years. They laid the foundation on which we stand today.”

During Easter, Alzheimer Iceland partnered with one of the biggest Easter egg producers in Iceland and the biggest supermarket and produced 40th anniversary Easter eggs. The eggs sold out and the initiative was a big success.

On 24 May, Alzheimer Iceland held the “Purple bench walk“, for which we walked together in Hafnarfjörður and Höfn to raise awareness about dementia. Purple benches can be seen in many places around the country, and their purpose is to raise awareness of, and encourage discussion about dementia, which represents an important step toward reducing stigma in our society. The walk started at the purple bench in each location and was part of our 40th anniversary celebrations. In Hafnarfjörður, the walk ended with a birthday cake at the office of Alzheimer Iceland.

On 20 September, the main celebration took place as Alzheimer Iceland hosted an anniversary conference. At the conference, the association patron, Björn Skúlason (the spouse of the President) and the Minister of Health, Alma Möller, spoke. Well-known

Purple benches can be seen in many places around Iceland, to help raise awareness of dementia

40th anniversary Easter eggs

experts also reflected on achievements over the last 40 years and looked to the future. After the conference, the anniversary was celebrated with a reception where guests toasted this milestone.

Alzheimer Iceland today

Discussion about dementia in Iceland is steadily increasing, which helps reduce stigma surrounding the condition. Great progress has been made over the past 40 years, but more work remains to be done. Today, the role of Alzheimer Iceland is still to safeguard the interests of people with dementia and their carers and to raise awareness among policymakers, healthcare professionals, and the public about the daily challenges faced by individuals living with dementia and their families.

Today, Alzheimer Iceland provides a counselling service for individuals and families on site, via telephone or through online meetings. The association actively promotes public discussion through education and publications, including educational meetings and maintaining a strong online presence via its website and social media.

Alzheimer Iceland is stronger than ever and will continue to increase awareness about dementia and work in the interests of people living with dementia and their carers as long as it is needed.

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Lena Kock takes the helm at Demensförbundet in Sweden


Lena Kock

In May 2025, Lena Kock took up the position of Chairperson at Demensförbundet, Alzheimer Europe's national member association in Sweden. She replaced Liselotte Björk, who stepped down to take on a new challenge elsewhere. We spoke to Lena Kock about her new role and asked Liselotte Björk to share a few words about her time as Chair.

What made you decide to take the position as Chairperson at Demensförbundet?

I accepted the role as Chair because I have, for a very long time, worked with and for people and families living with dementia, to help ensure they can continue to live their lives despite the illness. I also accepted the role because I see an opportunity to continue influencing, developing, and being part of the efforts to create the conditions necessary for living as well as possible throughout life.

I also accepted the assignment because I am incredibly proud to be part of the Swedish Dementia Association (Demensförbundet), with all its fantastic local associations that provide support and make a real difference close to home for those affected. The local associations are the heart of the federation's work, and together we make an impact and create change throughout the year, all across our country.

What are your main hopes and aims for the future of the organisation?

My main hopes and goals are to help make a difference close to those living with dementia, to contribute to advocacy efforts nationally and locally here in Sweden, but also internationally through our collaboration with, among others, Alzheimer Europe.

My goal is for politicians and decision-makers to understand the "value" of getting involved early in the disease and of providing the whole family with various forms of support, for example, by offering a dedicated contact person within the healthcare system, sharing suggestions for meaningful daily activities that can bring strength and joy, and offering social connection in peer support groups for both the person with dementia and their family.

Another goal is to help decision-makers understand the difference between being diagnosed at a younger age compared to later in life. The grief may be similar, but the challenges differ greatly. A younger person may have to stop working, their partner might need to continue working and be less available, and sick leave often leads to financial strain. Everyday life becomes much more difficult with reduced income, stressful conversations with the social insurance office, and more.

It is not uncommon for families affected by dementia to still have children living at home, children who are deeply impacted in their daily lives, school experience, and friendships. I want to do all I can to highlight these challenges and advocate for change. Of course, it is also my goal to contribute to moving research forward toward solving the mystery of dementia. And on the way there, we must be present and supportive in the everyday lives of affected families, both young and old!

Do you have a few words to share with your predecessor, Liselotte Björk, regarding her time in this role?

Liselotte, you have done a fantastic and extensive job during your three years as Chair. Through numerous internal and external connections, you have clearly communicated what the association stands for and aims to achieve. You have paved the way for the Swedish Dementia Association to take even greater steps toward a dementia-friendly society and to be part of solving the mystery, together with others. A heartfelt thank you, Liselotte, for your warm dedication and hard work. Best of luck with your new assignments!

A few words from departing Chairperson Liselotte Björk

After three interesting and developing years as the chair of Demensförbundet, I chose to hand over the role for the upcoming term before the congress in May. I am proud that during these years we have increased the visibility of the Demensförbundet and thus also increased the opportunity to influence for better conditions. We have tried new ways to disseminate information, for example, through open webinars on various current themes that we have carried out, they have been very appreciated and reached


Liselotte Björk

a wide group among both the public and professionals. In the work with the new dementia strategy, we have been active in highlighting the challenges and needs of our members. We have also started an effort to update our texts and imagery to ensure that everyone feels included. I wish the new board and staff at Demensförbundet a big and warm good luck with the work ahead. In a time of great challenges, our organisations are needed more than ever so that our issues do not come last.

Demensförbundet has an important role in Sweden representing individuals with dementia and their relatives. Through all the local associations around the country and the engagement found there, there is a unique opportunity to be close to where the needs are, we can offer personal support and spread knowledge about what it means to live with dementia both at local and national levels.

I also want to extend a special thank you to Alzheimer Europe, the wonderful collaboration has contributed strength and drive. It has truly been a pleasure to collaborate, with always friendly and accommodating staff regardless of the issues at hand. The exchange between our European organisations provides inspiration to see new opportunities in our work. Sweden is now represented in both EWGPWD and EDCWG, which I am very happy about.

My commitment to people living with dementia and their relatives will not end. I believe many of us who work in our field recognise that it is not just a job, it is more than that. I am now looking forward to having a bit more time for family and friends, but I also look forward to contributing to professional development at the company Seniorglädje, which offers social services for the elderly. I will also continue with lectures and a podcast that I run with a friend.

I believe that knowledge brings understanding and can pave the way for a dementia-friendly society. Warm greetings to all of you who continue to make a difference for everyone affected by dementia, whether you are someone living with dementia, a relative, or a person who has chosen to get involved. Together, we can enable more people to participate and feel a sense of community in our society.

Demensförbundet

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Gerjoke Wilmink reflects on her time at the helm of Alzheimer Nederland

After seven years as CEO of Alzheimer Nederland, Gerjoke Wilmink is stepping down from her position in November 2025. We asked Ms Wilmink to look back over her time at Alzheimer Nederland and to share what it has meant to her to be in this leadership position at such a large and influential organisation, working for people with dementia in the Netherlands and collaborating with colleagues across Europe.


Gerjoke Wilmink

You have been the CEO of Alzheimer Nederland for over seven years. What were your reasons for taking the position and why have you decided to step down?

My dear mother was diagnosed with Alzheimer's dementia and passed away nine years ago. As a result, I had a close personal experience with dementia. I saw the impact. Not only on my mother, but also on all her loved ones. For me it was a very sad period in which I realised that we weren't the only ones suffering from the loss of a loved one with dementia. In the Netherlands we have more than 300,000 people with dementia and 800,000 family caregivers.

I really wanted to work for a better quality of life for all those people and of course for a future without dementia. Alzheimer Nederland was and is the organisation that puts its heart and soul into those goals. It was great to be able to lead this organisation for over seven years. I have seen it grow enormously, both in size and impact.

Now the time has come for me to retire. I do so with both pain in my heart and peace of mind. Patricia Kerckhoff, with whom I co-managed Alzheimer Nederland for the past two years, will have a very good successor in Professor Wiesje van de Flier.

Can you share some highlights from your time in charge? What do you think has been the biggest achievement of Alzheimer Nederland during that period?

We have achieved a tremendous amount in recent years.

When I started in 2018, we spent EUR 5.3 million annually on scientific research. In 2024 it was already EUR 14.3 million. The expectation is that we will increase our annual investment in research significantly in the coming years. In our allocations, we also invest heavily in research talent. We very much want to keep as many qualified researchers as possible in the dementia field. I was delighted to see that no fewer than 300 Dutch dementia researchers attended a scientific conference co-organised by us at the end of 2024! After all, a lot of research is still needed, not only fundamental research to find medicines or other solutions, but also research focused on diagnostics, prevention, care, and quality of life.

So much is still possible after the diagnosis of dementia. It is very important that people with dementia continue to participate in society for as long as possible. We have shown that, in no less than three seasons of the TV series "Restaurant Misverstand" (The restaurant that makes mistakes). The premise of this series is that 12 people with dementia run a restaurant, under the direction of a chef. The TV programme has helped to further break the taboo surrounding dementia.

Another great result of the past years, from my perspective, is that almost 700,000 people have completed an online training

on our website, about how to interact well with people with dementia. This is a very important step towards achieving a dementia-friendly society.

We have also played an important role in the development and implementation of the National Dementia Strategy in the Netherlands. Right now, there looks to be a green light to give the strategy a follow up for the years 2026-2030. We work closely with the Dutch Government, but also ensure we provide constructive criticism when needed.

How would you describe the benefits of the collaboration between Alzheimer Nederland and Alzheimer Europe?

It is enormously important to look beyond our borders. After all, dementia does not stop at the border. Together with FVA (France) and AFI (Germany), Alzheimer Nederland participates in an international scientific advisory board that reviews proposals for basic scientific research.

Alzheimer Europe offers much more besides. I greatly admire all the staff who, under the leadership of Jean Georges, get a tremendous number of activities done! We especially welcome the work that has been done in setting up both the European Working Group of People with Dementia and the European Dementia Carers Working Group. Thanks to all these initiatives we can make a big impact with our lobbying in Brussels, or with European agencies like the EMA, which also has an impact at national level.

Alzheimer Europe is an important network for us to follow European developments. I always loved to go to the annual conferences of Alzheimer Europe and see so many new initiatives, so much creativity and so many people committed to the field of dementia!

For me, it was a real highlight when the congress was organised in The Hague in 2019. I was closely involved in the meeting that was organised in that context for and by people with dementia. An eye opener for me was a workshop on the effect of music on people with dementia. It was surprising for me not so much regarding the fact that music can have a big effect but rather in discovering the music preference of the participants. Not a sweet song from the dusty archives in sight, but instead music and rock songs by the likes of James Brown and Meatloaf. How I danced along!

What are your hopes for the future of Alzheimer Nederland? Do you have a few words of wisdom for your successor?

I hope and expect that my successors will continue to build on an even stronger organisation. By 2040, there will be more than half a million people with dementia in the Netherlands. Professional care will not grow with them, nor will the number of informal caregivers. It is therefore important that we work to ensure that people with dementia need fewer years of intensive care than is currently the case. I believe that this is possible if society becomes more dementia-friendly. A society in which people with dementia can simply continue to participate. Alzheimer Nederland should continue to play an important role in that work. This can be done by continuing to invest in dementia-friendly neighbourhoods in which there is a good connection between the built environment, social context and care.

In addition, the role of research funding remains vital. Alzheimer Nederland is the largest private funder of dementia research in our country and, with government cuts, possibly the largest funder overall, in years to come. That's a big responsibility. In doing so, it is good to always keep an eye on the infrastructure of research. Is it in order?

It is also good to look at new promising developments. I am very hopeful about the possibilities of gene therapy. But we should also cherish the possible positive effects of existing vaccinations or medications, as recently revealed by research into the effects of the shingles vaccine.

How does the future look for you? Do you plan to continue any work in the area of dementia?

Retirement for me does not mean that I am not going to do anything anymore. I have always been socially active in other fields in addition to my main job, serving on various boards and on the Advertising Code Committee. Although I will miss Alzheimer Nederland, I also look forward to having more time to dedicate to that. I will remain active in the health domain and there will always be a link for me, with the area of dementia.

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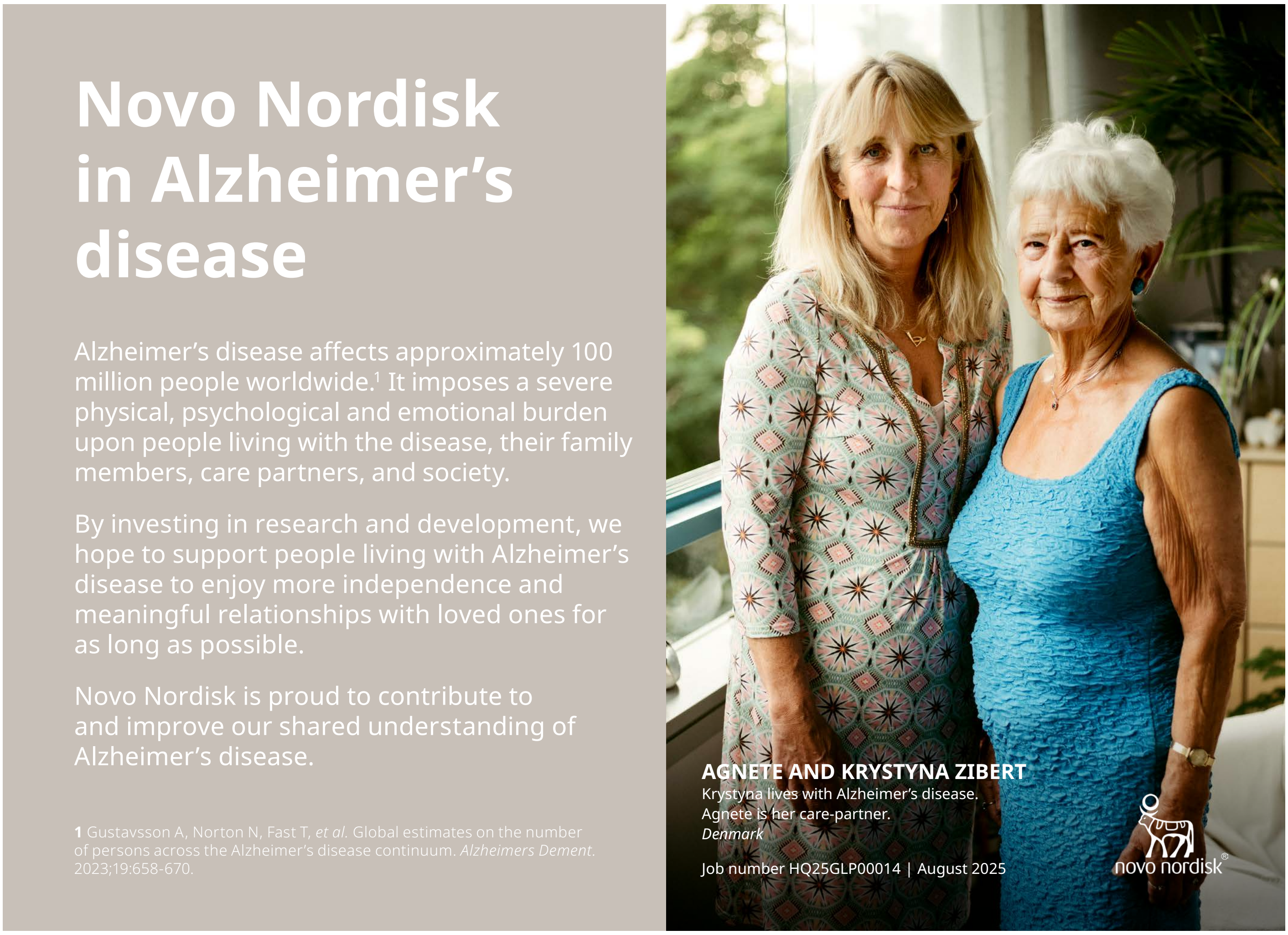

Lost Lear: Setting the stage for authentic dementia representation

The ground-breaking play “Lost Lear”, written and directed by Dan Colley, and produced by Matt Smyth, offers a unique portrayal of dementia through the eyes of Joy, a woman living with the condition. In collaboration with the Dementia Carers Campaign Network (DCCN), an advocacy group supported by The Alzheimer Society of Ireland, the play explores memory, identity, and care. Niamh Burke, Communications Officer Lead at The Alzheimer Society of Ireland, tells us more.

Niamh Burke

The portrayal of dementia – whether through the arts, news media, documentaries, or other formats – can shape perceptions and dispel stereotypes. On the flipside, it can perpetuate harmful beliefs and reinforce negative narratives. Ultimately, how dementia is depicted plays a key role in tackling stigma, shaping public understanding of what it means to live with it, not only for the person with the diagnosis but also for the carer.

This presents a conundrum. According to the World Health Organization, over 55 million people worldwide are living with dementia, with nearly 10 million new cases diagnosed each year. It’s impossible to fully capture what it’s like to experience the condition as everyone's story is their own.

Paddy Crosbie, a member of the Dementia Carers Campaign Network (DCCN), who cared for his husband Derek, who lived with young-onset dementia and passed away in 2021, points out: "The one thing I wish more people understood, is just how individual the condition is for each person, as someone said: ‘When you meet one person with dementia, you meet one person with dementia’.”

Not to mention that representation, particularly in the arts, is subjective. But when treated with care, it can create a space for more truthful and emotive storytelling. Susan Crampton, Vice-Chair of the DCCN and a carer for her late mother Anne, who lived with mixed vascular and Alzheimer's dementia until her passing in 2017, believes that dementia and caring are often presented in the media as facts and statistics, conveyed in medical terms.

"The reality of being affected by dementia is something very emotional and personal, and this is where the arts come in to help bring those feelings to a wider audience" she says. "When creative people listen, they can represent a complex set of emotions in a way that a set of facts can't."

So, how can one (where possible) portray the condition both accurately and respectfully, in a way that feels authentic to the audience, when exploring dementia through storytelling?

Involving people affected by the condition is a good place to start, which is exactly what Lost Lear did. Written and directed by Dan Colley, and produced by Matt Smyth, the award-winning play depicts dementia through the eyes of Joy, a woman living with the condition. Exploring themes such as memory, identity and care, the production sees Joy relive her past as a young actor rehearsing for Shakespeare’s King Lear. Her carers, trying to maintain her reality, cast her estranged son in the play. His resistance disrupts her fragile world, causing a clash of realities.

Paddy Crosbie with his late husband Derek, who lived with young-onset dementia

Máire-Anne Doyle pictured with her late father Brian, and their dog Missy

Susan Crampton and her late mother, Anne

Premiering at the Dublin Theatre Festival in 2022, Lost Lear was developed with insights and guidance from the DCCN – an advocacy group which aims to be a voice for carers in Ireland. The creators also engaged with the Irish Dementia Working Group (IDWG) during the early stages of the process, along with other groups.

Drawing on lived experience

Colley, an acclaimed Irish playwright, said that the workshops with the DCCN, which is supported and resourced by The Alzheimer Society of Ireland, were "hugely influential" recalling them as generous, honest and emotionally complex spaces.

"We talked a lot about what it means to care for someone whose reality no longer matches your own. The carers spoke about compromise, humour, exhaustion, but also love. Their stories helped shift the piece away from abstraction and into something lived."

Listening to these stories, Colley learned how caring can create a new-found connection – an idea he and the team revisited time and time again, thinking about how their characters might find something positive in their future relationship. According to Colley, dementia is often framed in the arts as a "tragedy or disappearance, a fading out. There's more to it than that."

Theatre is well placed to explore "altered realities and slippery subjectivities"; the disorientation that can occur during the condition. "My hope is to reflect the normality of dementia as just one of the many strangenesses of the human experience with its own textures, rhythms, absurdities and truths" he says. The consultation process itself was thorough. Colley updated the advocates as the play developed and asked for feedback.

Máire-Anne Doyle, a member of the DCCN, describes her experience working with Colley and the Lost Lear team as "magic," equating their eagerness to learn more about dementia and hear from those affected with giving her "so much hope." Máire-Anne cared for her father Brian, who passed away in 2020 after living with vascular dementia.

Members of the Dementia Carers Campaign Network (DCCN) pictured with playwright Dan Colley (second from right)

Given that dementia is so complex, it's natural that Colley felt a strong responsibility to represent it accurately, which led him to closely collaborate with people with lived experience. "We didn't want to reduce dementia to metaphor or turn it into a narrative device. We wanted to listen carefully, make space for contradictions, and show the dignity and humanity that persists, even when memory doesn't" he says.

This collaboration also gave the Lost Lear team the courage to explore deeper aspects of dementia. "Because we had developed meaningful relationships with dementia advocates – people we trusted to tell us if something felt wrong or in bad taste – we were able to go places in the play that I'd have been reluctant to explore on my own" says Colley.

One of the places he is referring to is a narrative choice that we wouldn't typically associate with dementia: comedy. "Without those conversations with carers, where we laughed together about the strange places dementia brings you, I wouldn't have had the confidence to include humour. And the piece would have been poorer and less reflective of the real life of a carer because of it."

Challenging stereotypes

The advocates said they were listened to throughout the process, which was important to them. While acknowledging that playwriting is fundamentally imaginative, Susan believes their involvement "fed" into the creative process, by bringing carers' emotions to the forefront of the narrative.

She says Lost Lear moves away "from the stereotypical representation of a person living with dementia as someone passive and feeble." Instead, it portrays the complexity of the relationship between the carer and the person they care for: "Two people physically living in the same world but, in their minds, often worlds apart. The carer can be as bewildered and confused by what is going on as the person living with dementia." Susan says.

Máire-Anne felt that the production revealed many facets of the dementia journey, mainly around acceptance, particularly for the family members. She referred to Joy's son in Lost Lear, describing "the feeling of loss of control and letting go" that comes on "the road of the long goodbye to the parent one knew and loved."

Telling one story

Did Colley learn anything new or unexpected through drawing on the lived experience? "Yes, almost everything" he says. "One major shift was realising that dementia isn't a vanishing point: it's a phase of life.

Many people with dementia described it as a complicated, challenging period, but also one full of life, relationships, even joy. That perspective changed how we approached Joy's character. She isn't just a vessel of loss: she's still active, still performing, still trying to exert agency, even as her world becomes more unstable."

Another key realisation for Colley: "When you've met one person with dementia, you've met one person with dementia." This echoes Paddy's earlier point about the uniqueness of the condition. He explains that the team had to "let go" of trying to represent every individual experience – something that would be impossible. This shift made way for the creative process, allowing them to focus instead on the story that matters in Lost Lear: Joy's.

The production, which raises key questions about caring, the ethics of white lies, and how we understand and communicate with those living with dementia, doesn't shy away from conveying Joy's inner world, using projections, green screens, live video, and puppetry to capture her ever-changing reality as past and present collide. The puppet, Colley explains, is used to externalise her disconnection from her body, with the form of the show reflecting the fragmented nature of her experience.

On his inspiration for the innovative production, Colley says the seed was sewn during a visit to his grandmother's care home. He describes a corridor "dressed up like old Irish streets" complete with "shopfronts, signage, a whole replica streetscape" which aimed to provide comfort to those with dementia by evoking a familiar time and place.

"I remember finding it strangely eerie. It didn't resonate with my idea of who she was, but it was clear someone thought it might help her feel at home" the playwright says. "That unease, that gap between what I could see and what she might be experiencing, lodged itself in my mind. I started to wonder: 'Can we ever truly understand another person's reality? Could could theatre, with its invitation to suspend disbelief, be a space to explore that question?'"

Seeing the person, supporting the carer

Colley then set out to find answers to those questions, a quest that has paid off. Lost Lear has received widespread praise, with national publications in Ireland describing it as "beautifully executed and boldly imaginative" and "a powerful, tender portrayal of dementia that manages to be both heartbreaking and hopeful." The production has also been recognised across Europe for its emotional depth, and its sensitive and innovative approach to portraying dementia on stage.

Having been featured on both Irish and international stages, Lost Lear continues to invite audiences into Joy's world, recently appearing at the Traverse Theatre during the 2025 Edinburgh Fringe – the largest arts festival in the world, where it won a Fringe First Award for outstanding new writing. Many are watching.

What do carers wish others better understood about supporting someone with dementia?

Susan wishes people understood that it's not so much the tasks, like washing and dressing, which can be difficult for carers, but the "constant responsibility, the challenge of not always knowing how to be kind, how to be understanding and the strength and patience" it takes to keep going when the person with dementia changes and behaves in ways that are hard to understand. "Storytelling, she says, can bring this experience to life, illustrating a carer's emotions and responses to these difficult situations."

Lost Lear brings audiences into Joy's fragmented reality, blurring past and present in a powerful depiction of dementia

For Máire-Anne, there is a hope that people open up and are heard – and that we see beyond dementia: that the person living with it still matters. It's something her dad told her, quoting a line from a film about a woman with Alzheimer's: "I am still me."

Carers are often overlooked during the dementia journey, with the focus tending

A glimpse into Lost Lear, a powerful and innovative stage production inspired by lived experience to shift to the person with the diagnosis. However, the challenges, emotional and physical toll, and sheer magnitude of responsibility that caring brings can't be underestimated.

Máire-Anne emphasises the importance of checking how the family carer is doing (and not just in a passing way) so that they are not "left in the background or caught up in the aftermath of the diagnosis." One strand of the conversation around the depiction of dementia in Lost Lear (and in the arts generally) that mustn't be overlooked is the comfort it can bring.

Paddy, who is also a member of the European Dementia Carers Working Group, says the play came at a time in his life when his grief for Derek "was extremely raw and yet experiencing and watching the play gave me some solace."

Lost Lear

Written and directed by Dan Colley and produced by Matt Smyth, Lost Lear is a moving and darkly comic remix of Shakespeare's play told from the point of view of Joy, a person with dementia, who is living in an old memory of rehearsing 'King Lear'. Joy's delicately maintained reality is upended by the arrival of her estranged son who, being cast as Cordelia, must find a way to speak his piece from within the limited role he's given.

Using puppetry, projection and live video effects, the audience are landed in Joy's world as layers of her past and present, fiction and reality, overlap and dis tort. 'Lost Lear' is a thought-provoking meditation on theatre, artifice and the possibility of communicating across the chasms between us. For more information, click here

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About the IDWG:
https://www.alzheimer.ie/creating-change/ways-to-have-your-voice-heard/irish-dementia-working-group-3/

"Les Esprits Libres" reimagines dementia through theatre, community and compassion

Through an artistic lens, the documentary film "Les Esprits Libres" reimagines dementia through theatre, community and compassion. Alzheimer Europe spoke to the director (and co-writer) Bertrand Hagenmüller about the inspiration for the film and its objective, including what lessons they learned and how society can try to reduce the stigma surrounding dementia (translation provided by Kevin Charras, psychologist and scientific advisor for the film).

With a bold mission to transform the way individuals living with dementia are perceived and cared for, "Les Esprits Libres" (The Free Minds) offers a stirring and original perspective on ageing, memory and human connection. Far from a conventional documentary, the film provides a powerful insight into how theatre and creativity can serve as impactful forms of self-expression, to bring healing, dignity, and renewed purpose to those navigating the challenges of cognitive decline.

Released on 30 April 2025 in French cinemas, "Les Esprits Libres" brings together science, care, and creativity on the big screen. With a unique project embracing both art and life, the film focuses on nine people living with Alzheimer's dementia and their "soignants"(caregivers). Viewers are offered a glimpse into the lives of these people as they live together in a residential-style setting and create performances of improvised theatre, music, and poetry over the course of two weeks. Through these ground-breaking artistic experiences, the story is both uplifting and heart-wrenching. The creative acts allow residents to regain autonomy, build authentic relationships, and reclaim their identities, while exploring the untapped potential to interpret art at different stages of the disease and of life itself.

The documentary presents vulnerable and deeply human moments, reminding viewers that even in the face of memory loss, the essence of the person remains. Challenging this stigma has also led to the publication of a manifesto-style book accompanying the film, entitled "Un autre soin est possible" (Another care is possible).

The creation of the film highlights the limitations of current dementia support and where significant improvement is needed. It opens a broader dialogue around dementia and ageing, encouraging others to be more open-minded, to listen more attentively, to be more respectful, and to remember the importance of personal identity. More than just a film, "Les Esprits Libres" is a call to action emphasising presence, empathy and the enduring power of expression in dementia care.

More information about the film and the manifesto are available on the official website: https://www.lesespritslibres.film/

An interview with director and co-writer Bertrand Hagenmüller

Tell us about "Les Esprits Libres". What was the inspiration behind the film?

I have worked with caregivers and social workers for many years from the perspective of a sociologist. As a result, my films often focus on supporting vulnerable people, whether they are elderly, children or people with disabilities. I have animated philosophy workshops and ethics seminars with carers for over ten years. This has taught me a great deal and motivated my desire to bring these issues to the screen.

"Les Esprits Libres" is the third part of a trilogy on dementia. After having followed caregivers in a special care unit ("Prendre Soin", released in 2019), and then during the COVID crisis ("Première Ligne", released in 2022), I wanted to imagine a third and final part, full of hope and possibilities. A film that could contribute, in its way, to creating


Bertrand Hagenmüller

a public debate about the care of elderly people, and more specifically the care of those living with dementia.

This question then came up: What would a place where we would like to grow old look like? We rapidly imagined a place that was open, intergenerational and, above all, without uniforms. We also wanted a creative atmosphere that could bring people together around a common project, and that is when we thought of theatre.

Why was it important to use theatre as the medium of expression? How did it contribute to the storytelling of the film?

For many years, residents and caregivers of the Villa d'Epidaure (a nursing home in the suburbs of Paris) have been practising improvisational theatre with art therapist Emanuela Barbone, going so far as to organise tours to perform their show all over France.

When I encountered this initiative, it made a big impression on me. Of course, the idea was not to teach Molière or Shakespeare to people living with dementia, but to create acts from improvisations: taking on board the suggestions of others, extending the story they told us, expanding on fictions and oddities. This is a theatrical exercise, but it is also one of the required skills of caregivers, particularly in care facilities for people with dementia. If you say "no" to an idea for a play, the story ends, leaving all the actors powerless.

As it is in real life, when caregivers take the stage as actors, they welcome the person's suggestions and pay special attention to prolonging the relationship. "You have to live in the present", says Françoise, a person living with dementia, in the film. The full sentence here should read: We understand using role-playing and improvisation is a way to stay in touch with others and join them in their present moment. There is no need for the past or the future, just an imperative need to live in the here and now.

While I was making the film, I wanted to push the boundaries between reality and fiction by side-stepping the "raw" form that sometimes characterises documentaries. I wanted to create an almost fictional universe. Since people living with dementia often question the relationship between reality and fiction (for those not living with dementia, their reality may sometimes feel like a fiction), I wanted viewers to be unsure whether they were dealing with theatre or reality.

By highlighting the creativity of people with dementia and their caregivers, what does the film reveal about resilience and human connection?

Creativity is at the heart of daily life in "Les Esprits Libres" through theatre, of course, but also music, dance and poetry. There was a festive spirit, an invitation to play and fantasise. As the French philosopher and musicologist Vladimir Jankélévitch suggests, playing without stakes may quickly become dull and boring. This collective performance fundamentally served the project through another way of living with and caring for others. The show we created together is not an "activity" for patients, but rather the expression of a shared desire and common goal that makes everyone essential.

Thanks to the presence of Mélanie Leblanc, poetry occupies a large place in the Villa, on the kitchen windows, the living room walls, and scraps of paper scattered here and there, the house was literally (and literarily) inhabited by this spirit of poetry. Musicians, led by composer Tom Georgel, were the beating heart of the project. They were on the set, accompanying theatrical improvisations and choreographies, in their rehearsal studio next to the Villa (where residents and caregivers regularly visit them), during the day when piano, cello or guitar resonated in the vast building, but also, and perhaps above all, at the dances organised every evening.

Throughout the project, we kept coming up with creative proposals: photo-language games, performing the invisible, musical walks in the forest. Some came to fruition, others were abandoned for lack of participants. Among these proposals was "the red umbrellas". This is a tribute to Brittany and to Jacques Demy's famous 1964 musical film "Les Parapluies de Cherbourg" (The Umbrellas of Cherbourg). It was a way to affirm that colour is still possible, even when the sky is grey and threatening. But it was also a reference to the temptation of institutions to "put up umbrellas" to protect themselves, by creating enclosed, secure spaces to avoid having to take responsibility for a fall or a runaway... Here, the umbrellas are bright red and they dance in the Breton sky!

> "Using role-playing and improvisation is a way to stay in touch with others and join them in their present moment. There is no need for the past or the future, just an imperative need to live in the here and now." - Bertrand Hagenmüller

> “Les Esprits Libres' is a hymn to empowerment, to people’s full vitality.” - Bertrand Hagenmüller

Far from institutional regulations, closed doors for security, protocols, hierarchies, “power” that feeds on submissive bodies, to paraphrase the French philosopher Gilles Deleuze, “Les Esprits Libres” is a hymn to empowerment, to people’s full vitality. Anne-Marie was motionless and mute before her departure for the manor, but she powerfully comes alive throughout the film.

What is/are the main message(s) from the film which you want to share with viewers?

It may sound simple: an open house, caregivers without uniforms, dancing every evening, meals prepared and shared together, children playing... It all sounds like “ordinary life”, but it is a far cry from what happens in most nursing homes in France and worldwide. This is what the film is about: an experience that should be ordinary, but which in the current context of care in France remains “extraordinary”.

It seems to me that “Les Esprits Libres” can be analysed on several levels. It can be seen as a story, a tale, made up of surprising, funny and moving characters who go together on a crazy adventure. But it can also be seen as a proposal for an in-depth transformation of the current system of care for people living with dementia. A film whose aim is to convey a political message that can be summed up in a few words: “a different kind of care is possible”.

Since the release of the film, what impactful and/or unexpected feedback have you received from viewers?

Of course, much of the feedback from caregivers (and more broadly from those supporting people with dementia) seized on “Les Esprits Libres” as a field of possibilities, a room with a view, a new horizon. I think what touched me most was the way the film was so enthusiastically welcomed by people from so many different social backgrounds, cultures and ages, some of whom were unaware of this condition. Something universal unites us in our desire to highlight another way of living together, and another way of caring for people we believe are vulnerable. People realised that it is not a matter of suffering for some and sacrifices for others, but a matter of rethinking our solidarity as a means to achieve a better way of living together, that consequently benefits everyone.

Based on the themes explored in the film, where do you think policymakers and society can have the greatest impact for improving care and reducing stigma around dementia?

Concomitantly with the release of “Les Esprits Libres” at the cinema we are publishing a book, supported by the Caisse Nationale de Solidarité pour l’Autonomie (the French National agency for autonomy and solidarity) and co-written by Dr Laure Jouatel, a geriatrician and author of a scientific study about the project, Dr Kevin Charras, a psychologist specialised in dementia care and disabilities, and me. It extends an observation shared by the vast majority of people involved in nursing homes, whether they are professionals, families or residents: we need to reform the current system.

Everyone acknowledges the urgency of developing new forms of support and care for older people living with dementia. It is a question of money, of course, but not only that. We need to use our collective imagination to get us out of a paralysed institutional system. Whether it is Dementia Villages, intergenerational accommodations, or mixed facilities, multiple initiatives (although still a minority) are springing up all over France. The therapeutic experience of “Les Esprits Libres” is one such initiative. It puts older people living with dementia back at the heart of the community, and promotes a holistic, individualised and artistic approach (as an alternative to a pharmacological approach). It is a search for hope, a contribution to seeking new ways of coping with cognitive impairments in old age.

The rocky path towards lecanemab approval in Europe

After many high-profile failures, clinical trials of anti-amyloid drugs have marked a turning point for the field, leading to the approval of the first disease-modifying therapies for Alzheimer's disease. In this article, our Director for Research, Dr Angela Bradshaw, looks back at the journey towards approval of lecanemab in Europe.

Angela Bradshaw

The approval of lecanemab in Europe marked a milestone in the development of disease-modifying therapies for Alzheimer's disease (AD). From the outset, we have closely followed and engaged with the regulatory process, highlighting the need for timely, safe and equitable access to disease-modifying therapies for all patients who could benefit from treatment. Here, we chart the regulatory path that led to the drug's eventual authorisation on 15 April this year.

Lecanemab is an antibody treatment that targets amyloid-beta plaques, a hallmark of Alzheimer's disease, aiming to slow disease progression. Marketed by Eisai and Biogen, lecanemab was among the first anti-amyloid therapies to demonstrate a statistically significant effect in modifying the course of early Alzheimer's disease, offering new hope to people with AD and their families.

The regulatory journey of lecanemab in Europe has been marked by reversals of opinion and an eventual authorisation after several layers of negotiation at the European Commission. The journey began with a setback: on 26 July 2024, the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) issued a negative opinion on the marketing authorisation application for lecanemab. The committee's concerns centred on the modest clinical benefit shown in trials such as CLARITY-AD, outweighed by the risk of serious side effects such as amyloid-related imaging abnormalities, linked to brain swelling and microbleeds. At that stage, the CHMP concluded that the evidence did not support a favourable benefit-risk balance for people with mild cognitive impairment or mild dementia due to AD.

This decision prompted a formal re-examination request from the manufacturers. The re-examination process allowed the re-evaluation of clinical data and arguments to address the CHMP's initial concerns. In parallel, Alzheimer Europe published an official statement on the refusal of lecanemab, developed following discussions with our member organisations, working groups and other members of the dementia community. Six key areas of concern were identified in the statement, in which we highlighted the availability of feasible risk management approaches that would ensure that people who could benefit would not be unduly denied treatment as a result of safety concerns.

On 14 November 2024, after reviewing further evidence and a more narrowly defined patient population, the CHMP reversed its earlier decision and issued a positive opinion. The updated recommendation supported the use of lecanemab in a restricted group of patients with confirmed early Alzheimer's disease and with no more than one copy of the ApoE4 gene, given the lower associated risk of side effects in this subgroup. The committee found that in this targeted population, the benefits of the treatment outweighed its risks.

Following this revised opinion, further scrutiny was applied at the request of the European Commission. In February 2025, the CHMP reviewed newly available safety data but found no grounds to alter its November conclusion. This confirmed the committee's position that the drug's safety and efficacy profile was acceptable in the specified patient group.

Jean Georges

"Alzheimer Europe welcomed the EMA's positive opinion on lecanemab. We were encouraged by the considered approach to manage risk, enabling eligible patients to make individual choices with their treating physicians, based on a personal analysis of benefits and risks."

"While this is a watershed moment for the community, it also marks the beginning of a much longer journey to build the necessary infrastructure, ensure equity in access, and support patients and their families in making choices that reflect their values and needs." **Jean Georges, Executive Director, Alzheimer Europe**

The European Commission's Standing Committee on Medicinal Products for Human use (SCMP) authorises medicines approved by the EMA, and in the vast majority of cases, it follows the EMA recommendation for approval. Not so for lecanemab. At its meeting in March 2025, the SCMP was not able to reach consensus based on a qualified majority, voting a 'no opinion' outcome. In view of that vote, the European Commission convened an Appeal Committee meeting, involving representatives from each EU Member State to make a final decision on the marketing authorisation for lecanemab.

Following these developments, we wrote to Olivèr Vàrhelyi, the European Commissioner for Health and Animal Welfare, to express grave concern about the ongoing delays in the approval process. Escalation of an approval decision to the Appeal Committee is unprecedented, occurring fewer than 10 times in over 3,500 procedures since 2013. In our letter, we expressed our grave concerns about the ongoing delays in the review process for lecanemab, emphasising Alzheimer Europe's support for the independent assessment of medicines and the rigorous scientific evaluation conducted by the CHMP. We endorsed the considered approach of the CHMP to manage risks associated with lecanemab, calling for the Appeal Committee to affirm the positive opinion of the CHMP by a qualified majority, enabling Europeans to access this first disease modifying treatment for early Alzheimer's disease.

Minutes from the 7 April Appeal Committee meeting revealed a further "no opinion" outcome. This means that the Committee could not reach a "qualified majority" of 55% of Member States representing at least 65% of the total EU population. As a result, the decision reverted to the European Commission, which retains the authority to adopt or reject the marketing authorisation for lecanemab in the EU, Iceland, Liechtenstein and Norway.

We warmly welcomed, with a deep sense of relief, the European Commission's landmark decision on 15 April 2025, to grant formal marketing authorisation for lecanemab. This long-awaited decision marks a historic turning point, offering, for the first time, a path toward access to a disease-modifying treatment for Alzheimer's disease in Europe.

With the regulatory hurdles overcome, attention now turns to the next phase of implementation. Each Member State must now assess the cost-effectiveness of lecanemab through its own health technology assessment (HTA) processes. These evaluations will determine whether and how the treatment will be reimbursed by national healthcare systems. This is a complex process involving analysis of clinical benefits, healthcare costs and budgetary impact.

While approval of lecanemab represents a watershed moment for the community, it also marks the beginning of a much longer journey: to build the necessary infrastructure, ensure equity in access, and support patients and their families in making choices that reflect their values and needs. With authorisation now granted, the challenge lies in translating regulatory approval into meaningful benefit for people living with Alzheimer's disease across Europe.

TIMELINE

11 January 2023
Eisai announces the submission of a marketing authorisation application (MAA) for Lecanemab to the EMA

26 July 2024
EMA's Committee for Medicinal Products for Human Use (CHMP) recommends refusal of the MAA, citing an unfavourable benefit-risk balance

5 August 2024
Eisai submits a formal request for re-examination to the EMA

14 November 2024
After re-examination, the CHMP issues a positive opinion, approving lecanemab for the treatment of early Alzheimer's disease in patients with one or no copies of ApoE4

31 January 2025
The European Commission asks the CHMP to evaluate new safety data and consider the wording of its risk minimisation measures

28 February 2025
After considering the new safety data, the CHMP reaffirms its positive opinion on lecanemab, with no changes to the wording of risk minimisation measures

21 March 2025
The European Commission's Standing Committee on Medicinal products for Human Use votes on lecanemab, resulting in a "no opinion" outcome. The decision is escalated to the Appeal Committee

7 April 2025
The Appeal Committee considers lecanemab, similarly returning a "no opinion" outcome based on qualified majority voting. The final decision is deferred to the European Commission

15 April 2025
The European Commission grants the EU-wide marketing authorisation for lecanemab

Minister of Health looks to the future of Italy's dementia policy

In the run up to the 35th Alzheimer Europe Conference, we spoke to Italian Minister of Health, Orazio Schillaci, about dementia policy in Italy. In this article, he reflects on the progress made in the country since the introduction of the country's first national dementia plan in 2014, the ongoing work to update the new plan and the vital place of dementia research.


Orazio Schillaci

The Italian Dementia Plan was first launched in October 2014, what have been the most significant developments in dementia policy in that time?

First of all, in recent years, awareness of the importance of investing in prevention has grown significantly in Italy, strengthening the ability to address risk factors, many of which are modifiable, such as obesity, diabetes and social isolation, to reduce the risks of dementia. In Italy, it is estimated that over one million people are affected by neurodegenerative diseases, and nearly 900,000 have a mild cognitive impairment, a condition that may progress to dementia. This prevalence increases with age, and given the progressive aging of the Italian population, a preventative approach is mandatory.

Against this backdrop, I believe that significant progress has been made since 2014. In particular, in recent years, the establishment of the Alzheimer's Fund has enabled tangible actions targeted not only at patients, but also at their families and carers. Furthermore, strategic activities have been pursued, such as the development of guidelines for the diagnosis and treatment of dementia, a thorough analysis of the prevalence of 12 preventable risk factors for dementia, and the mapping of services, to name just a few. These are crucial actions, the result of extraordinary teamwork among all stakeholders involved in various capacities, to ensure increasingly earlier diagnoses and effective care.

What are the next steps Italy's dementia policy? Does the government plan to update the strategy or introduce a new strategy?

This government has already demonstrated its strong commitment to dementia, allocating nearly EUR 35 million to the Alzheimer's Fund for the period 2024-2026 in the 2023 budget law, doubling the resources allocated by the previous government. The commitment is to continue this high level of attention. To this end, the Permanent Dementia Committee, coordinated by the Ministry of Health and the dedicated Observatory of the Istituto Superiore di Sanità, is working to update the current National Plan, which we expect to approve by the end of 2025. The document, aligned with the most recent international recommendations, aims to serve as a valid roadmap for ensuring a more targeted and comprehensive approach to these diseases.

> "The Permanent Dementia Committee, coordinated by the Ministry of Health and the dedicated Observatory of the Istituto Superiore di Sanità, is working to update the current National Plan, which we expect to approve by the end of 2025."

Regarding resources, as is well known, the 2014 Dementia Plan lacked dedicated funding, whereas today we recognise the need for a change of pace and the opportunity to provide structural funding. This would allow for dedicated staff and even more adequate social and health services, promoting sustainable and equitable care for all people with dementia and their families and carers.

Beyond healthcare assistance, what initiatives is the Ministry putting in place to support families and carers of people with dementia, and how does it intend to strengthen the integration between health and social services?

As I mentioned, we are fully aware that this is a condition which also deeply affects all those who live alongside the patient, who requires constant care and attention. Credit must be given to this Government—and in particular to the Minister for Disabilities and the Minister of Labour, who lead the competent Departments—for working, also with the active contribution of associations, so that Italy may soon adopt a national law that recognises, from both an economic and social perspective, the role of carers.

As for health and social care integration, it is undoubtedly one of the key pillars around which the National Recovery and Resilience Plan (PNRR) revolves. I am thinking in particular of the single access points established within the Community Health Centres (Case della Comunità), which represent the place where welfare and healthcare come together. The model we are building is precisely aimed at overcoming barriers and fragmentation between services, moving away from a predominantly hospital-centred system, and bringing care into the patient's home, addressing all of their needs.

What is the role of research (biomedical, social, and technological) in the Ministry's dementia policies? Are targeted investments planned?

For over 30 years, the scientific community has been engaged in research into a pharmacological therapy that can modify the progression of Alzheimer's disease. Significant resources have been allocated in recent decades, allowing for advancements in research, but to date, we still lack a therapy capable of halting the progression of the disease. However, we continue to invest to create new treatment options. The Interceptor project, funded by the Ministry of Health and AIFA (the Italian Medicines Agency), is moving in this direction. Its innovative approach is enabling significant results. Designed to analysing reliable predictive tools to early identify subjects at risk of converting from mild cognitive impairment to Alzheimer's disease, it is demonstrating an accuracy of over 80% in predicting the progression of the disease.

Efficacy trials for non-pharmacological interventions are particularly important in research, as they show promising data in terms of maintaining cognitive abilities and improving the quality of life of patients and caregivers. In this regard, the Ministry, thanks to the 2024-2026 Alzheimer's Fund, is promoting the launch of a randomised controlled clinical trial to evaluate the efficacy and safety of an innovative telerehabilitation device that enables personalised, home-based cognitive stimulation interventions. Furthermore, in the area of cognitive disorders, the Ministry of Health has funded over EUR 37 million over the past five years for 89 research projects, while with the PNRR funds (as part of the EU Recovery and Resilience funds), we have allocated over EUR 24 million to 26 research projects. Research is a lever that must never be stopped.

How does the government ensure that people with lived experience of dementia are involved in the decision-making processes?

The Ministry of Health considers the role of associations to be fundamental. Thanks to their direct knowledge of patients' experiences and potential critical issues during the disease course, they can make a decisive contribution to improving models and making truly informed decisions. It is not by chance that the most representative patient family associations, such as Federazione Alzheimer Italia, are members of the Permanent Dementia Committee, actively participate in all the strategic activities listed above, and will continue to be key players in future project developments.

How is the government working with organisations such as Federazione Alzheimer Italia and Alzheimer Uniti Italia?

The Ministry of Health has established a vital collaboration with both organisations, benefiting not only patients. For example, I cite the national survey conducted with the Alzheimer Uniti Italia Association on the social and economic conditions of family members of dementia patients. This survey provides insight into a healthcare service that we want to make increasingly accessible to patients and beyond. The challenge is to also understand the needs of family members so they don't feel left alone to face a disease that shouldn't be synonymous with isolation.

As the #35AEC is hosted in Bologna (Italy) in October this year, do you have a message for delegates attending the conference?

Absolutely. Thank you for giving me the opportunity to reiterate the importance, already highlighted during the G7 Health Summit in Ancona, of continuing to exchange best practices and evidence to develop more effective measures to reduce the burden of dementia. We must continue working together to support the development and implementation of multisectoral national action plans, adopting integrated approaches to dementia, promoting awareness that many risk factors are modifiable, and developing and disseminating information and resources that contribute to a deeper understanding of dementia, for both the public and professionals. Without forgetting that there is still work to be done to reduce the stigma associated with dementia.

> “We must continue working together to support the development and implementation of multisectoral national action plans, adopting integrated approaches to dementia, promoting awareness that many risk factors are modifiable, and developing and disseminating information and resources that contribute to a deeper understanding of dementia, for both the public and professionals.”

“The strength of not being alone”: Federazione Alzheimer Italia on 30+ years of services and advocacy

Federazione Alzheimer Italia (FAI) was founded on 30 June 1993, by a group of family members with the goal of improving the quality of life for people with dementia and their loved ones. In this article, Secretary General of FAI and Alzheimer Europe Vice-Chair, Mario Possenti, tells us about their work providing vital support and services for people with dementia.

Mario Possenti

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La forza di non essere soli.

Federazione Alzheimer Italia (FAI) is the largest national non-profit organisation in Italy dedicated to promoting scientific research on dementia, supporting people with dementia and their caregivers, advocating for their rights, and participating in the planning of health and social policies. It brings together and coordinates over 40 associations and more than 60 dementia-friendly communities across the country. A member of Alzheimer Europe since 1994, it is the sole representative for Italy within Alzheimer’s Disease International.

Secretary General, Mario Possenti, recalls: “We started when the stigma was very strong. Very few dared to even say the word Alzheimer’s. Since then, we’ve been informing and raising awareness, offering support, building networks, and bringing the voices of those living with this condition to policymakers and institutions. It’s a comprehensive effort reflected in our slogan: *The strength of not being alone*”.

Over the years, through the Pronto Alzheimer helpline, the Federation has responded to more than 170,000 requests for help, offering psychological, legal, social, and occupational therapy consultations, or simply comfort during difficult times. Much has been done to support people with dementia: from promoting the Alzheimer’s Patient Bill of Rights in 1999 to endorsing the Paris Declaration adopted at the 2006 Alzheimer Europe conference, which urged governments to recognise dementia as a health and social priority; to strong scientific collaborations, both with prestigious Italian institutions – such as the Golgi Cenci Foundation and the Mario Negri Institute – and within European projects like the Horizon 2020 programme.

Equally important has been the close work with Italian institutions and the advocacy for concrete policies, first through the Alzheimer Study Commission and, since 2006, through the Permanent Dementia Table at the Ministry of Health. Thanks in part to a petition that gathered over 130,000 signatures, the Federation played a key role in securing the first funding for the National Dementia Plan, with EUR 15 million allocated in the 2021 Budget Law. Today, it is actively involved in shaping new legislation for caregivers and reforming care for non-self-sufficient elderly people.

With the launch in 2016 of the first dementia-friendly Community in Abbiategrasso, the Federation brought to Italy for the first time initiatives aimed at making people with dementia feel welcomed and understood, while raising awareness to fight stigma. Possenti explains: “Through the dementia-friendly Italy project, we are gradually building a more inclusive society. Communities are transforming services, businesses and public spaces into places that are more attentive to the needs of those living with dementia; we’ve also involved schools, pharmacies, markets, cultural institutions and hospitals. This initiative goes beyond simple awareness, it’s a profound cultural shift that includes every citizen”.

FAI faces many challenges. “There is still much to be done to ensure that all people with dementia receive timely care and a complete path of treatment, support and assistance” continues the Secretary General. “Together with the Permanent Dementia Table, we are drafting the new National Dementia Plan: a crucial step to provide Italy with an updated, effective and shared strategy. For this, we are calling for adequate financial investment: the current ‘Dementia Fund’ only covers certain areas. We need to act and we need to do it quickly, because population aging will lead to an increase in dementia cases and, consequently, greater pressure on health and social systems”.

A first version of the new Italian Dementia Plan will be presented at the Bologna Conference during the session “Italian policies on dementia” curated by FAI. Possenti concludes: “We are proud to once again be among the organisers of this event, 30 years after the first Italian edition held in Milan, thanks to the determination and commitment of our founder Gabriella Salvini Porro. We have always worked with Alzheimer Europe to address the global challenges posed by dementia, and on this occasion, we’ve brought together top professionals, researchers, institutions, people with dementia and caregivers, contributing to a record turnout. In this international context, Italy is in the spotlight and has the opportunity to show that it is finally taking concrete steps to improve the lives of people with dementia and their families. As always, we are on the front lines to shine a light on the needs and rights of those living with this condition”.

Alzheimer Uniti Italia approaches 20 years of working to support people affected by dementia

Alzheimer Uniti Italia (AUI) was founded in 2006 by Professor Luisa Bartorelli to provide help for people with dementia and their families. In this article, AUI President, Manuela Berardinelli outlines how the work of the organisation has evolved over the past two decades and some of the challenges faced today.

Manuela Berardinelli

How has the work of Alzheimer Uniti Italia developed over the years?

Today, the association has 38 affiliated associations throughout Italy, is a founding partner of Fondazione Maratona Alzheimer and of Alzheimer Fest, is a member of Alzheimer Europe and actively participates at institutional tables. In all its work, the starting point is to listen to people with lived experience of the condition.

The role of the association has responded to the societal changes. For example, the traditional family in Italy has for centuries provided for the social and care needs that arose, guaranteeing the stability of the system. However, the concept of family the unit has completely changed; often now composed of one or two persons, but sometimes there may be none, e.g. for single-person households. The system is not ready and does not have the tools to deal with this change. Alzheimer Uniti Italia is therefore increasingly important in supporting individuals and families, as an actor striving to achieve social cohesion. Therefore, the association's role has naturally evolved, still based on the values that established it but that seeks to create new models for supporting people and families.

Can you tell us about the key successes of the organisation?

The association has had many successes of which we are proud, including:

- The Dementia-Friendly City Project, which we believe is the greatest success (which we will present at 35AEC). We realised that the cultural change of mentality for how to support people with dementia cannot be detached from the geographic context. Italy is very different from place to place; even in the same region customs are different. Therefore, we have drawn up dynamic (created by the relevant commitee of the Istituto Superiore di Sanità) indicators that can help those seeking to develop a dementia-friendly city.
- The training and promotion of the “Gentlecare method” introduced by Prof. Bartorelli, precisely to provide new answers to new needs, as well as a system of care for people with dementia developed by the Canadian therapist Moyra Jones.
- Associations affiliated with Alzheimer United Italy now have Alzheimer’s Cafés in order to support the person with dementia and provide a reference point for families, formal and informal caregivers.
- Following the earthquake in 2016, we operated a 24-hour helpline for the four regions affected by the earthquake in Central Italy (Abruzzo, Lazio, Marche, Umbria).
- We also developed a handbook for firefighters, in collaboration with Prof. Marco Trabucchi and Dr Valerio Valeriani, to give practical guidance on how to intervene for people with dementia in an emergency and in the immediate aftermath.
- The “holiday for people with Alzheimer's disease” (which we will present at 35AEC) is unique in the way it is conceived: 40 people with dementia, more than half without caregivers, are accompanied by a trained multidisciplinary team who are dressed in normal clothes. Now on its 5th edition, seven days of holiday gives the person a real normality, and has proven to be extraordinarily successful, garnering interest from elsewhere in Italy and Europe.

What are some of the key challenges faced by the organisation in trying to support people living with the condition?

The challenge is to unify care provision so that there is no distinction from city to city in Italy. We have always fought so the collaboration between social and healthcare services, teamwork, training, and providing information to patients and their families ensure that decisions are closely aligned with the real needs of individuals. All this with training, with choices increasingly targeted to real needs. The aim is to improve the quality of life of the person and their family allowing them to live a normal life that is true and not granted.

What does it mean to co-host this year’s Alzheimer Europe Conference in Italy?

It is a great honour for all of us. It means a lot and it is important, above, to understand, to confront and to facilitate the change that is taking place, but that is not yet felt everywhere.

"I am not my disease": Frank's testimony

Francesco Parisotto – known to everyone simply as Frank – is 59 years old and lives with a rare form of dementia called CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy). By his side there is always his wife Fanny, whom he lovingly calls "my better half". Together, they have built a relationship based on love and shared experiences, even when faced with difficult diagnoses.

"In 2015, at just 49, I was diagnosed with CADASIL, a rare form of dementia. I speak about it openly because it's part of me, but I am not my disease: I am a person. A man with ideals, passions, vulnerabilities, and a deep desire to be seen and loved. The diagnosis is part of my life, but it does not define it."

Frank reflects on his journey: his work as a mechanical toolmaker, his civil service with the Alpini corps in Belluno, and over 25 years of dedication to Civil Protection. Then came his encounter with Fanny, the love of his life, and their marriage in 1999. A life built on shared dreams, until illness arrived unexpectedly: first Fanny's diagnosis of multiple sclerosis, then his own diagnosis of CADASIL.

"I could no longer do calculations properly, I would forget appointments and struggled with simple daily tasks. In 2012, my mother passed away after a long illness. Back then I didn't understand, I didn't know. I only realised later, with my own diagnosis: CADASIL is a rare genetic condition that affects the small blood vessels in the brain and can cause mini-strokes and cognitive decline, in addition, it's hereditary. In those years, Fanny and I felt like our world collapsed twice. But we didn't give up."

Frank has developed strategies to cope with situations that may overwhelm him: wearing headphones and listening to music while grocery shopping to block out distracting noise, carrying a note with instructions when going to the laundry, practicing mindfulness to calm himself. Attending an Alzheimer Café is also a great source of support, as it provides a space where he can connect with others living with dementia without fear of making mistakes or being judged.

Frank and Fanny

With deep self-awareness, Frank also gives voice to another essential need for people living with dementia that is often overlooked: the need to be recognised, listened to, welcomed without prejudice. A need that echoes powerfully through a poem he wrote himself, titled Listen to me:

Listen to me / why don't you hear / I scream my pain / No one listens / Listen to me / I feel my life explode / A thousand pieces will scatter / None will settle / None will be remembered / Listen to me

"Often, people see us walking, talking, but they don't imagine the effort, the anger, the confusion we deal with every day". Frank continues: "No one should presume to judge a life they don't know. A diagnosis isn't the end: it's a change and we must learn to adapt. But to do that, we need others: we need empathy, understanding and a dementia-friendly community to support us".

His message is that everyone can and should help create this kind of community, even through small everyday actions: "At the local supermarket, they know me and help me when they see I'm struggling. If I forget my bank card PIN, they break up my purchases into several smaller receipts, so I don't need to enter it. If I forget something, they offer suggestions. Dementia-friendly shops and services can help people with dementia feel safe, yet free."

Having a supportive community means not being left alone: "It's when depression sets in that we truly risk losing ourselves. But if we stay connected, if we talk, if we reach out, we can go on living with dignity, and even with joy".

Frank doesn't hide challenges and dark moments, but he also shares the strength he draws from his relationships - first and foremost with Fanny - and from the ability to express himself: "Today I keep writing, speaking and sharing my story to say that I exist and to help others who are in my situation. To those people I say: you are not alone. Even with a dementia diagnosis, you can still choose, love, take part, and live".

“Life is beautiful”: Enea’s caregiving experience

Enea Donnoli is the caregiver for his wife, Elena, supporting her following her diagnosis Alzheimer’s disease. In this article, he shares with us his experience of when his wife was first diagnosed, his role in supporting her and what matters most to allow him to continue supporting his wife.

On 11 March 2022, one beautiful morning, I woke up and at 1:30 pm I went to Bellaria Hospital in Bologna. The doctor who had been following Elena’s assessments handed me a letter with the post-hospital diagnosis: Young-onset neurocognitive disorder of neurodegenerative nature – Alzheimer’s disease. After a year of tests, at last, a diagnosis! At that time, I knew nothing about this disease, and I couldn’t believe that someone so young (46 years old) could have Alzheimer’s. It all started like this. It was hard to understand, hard to accept. And now, what can I tell you?

It completely changes the life of the person living by your side: her prospects, her moods, her desires. But at the same time, it changes your life too and your future. I find myself crying in the morning, before going to work, so I don’t show weakness in front of my wife, so I can still be her anchor.

I do everything for her: managing her retirement from work after 30 years, trying to get her a disability pension, and creating a new life for her. I was introduced to ARAD, an association in Bologna that supports people with a disability and their caregivers. Thank goodness it exists! They offer many services and activities to keep my wife engaged – cognitive workshops, which in the early stages are mostly attended by older people (my wife was only 46!), pet therapy with horses, support groups for caregivers where we can talk and share our experiences. We also have the opportunity to speak with a psychologist who helps us understand and, most important, accept this slow but ongoing change.

Last but not least, it’s vital to consult a lawyer for future planning regarding the relationship with the person and their rights. Psychological support plays a crucial role in facing all this. You can’t do it alone; the sooner you understand, the sooner you can build a new relationship with your life partner. I’ve learned that it’s important to carve out moments of freedom for yourself, even just a couple of hours or a weekend with friends, to recharge and come back stronger.

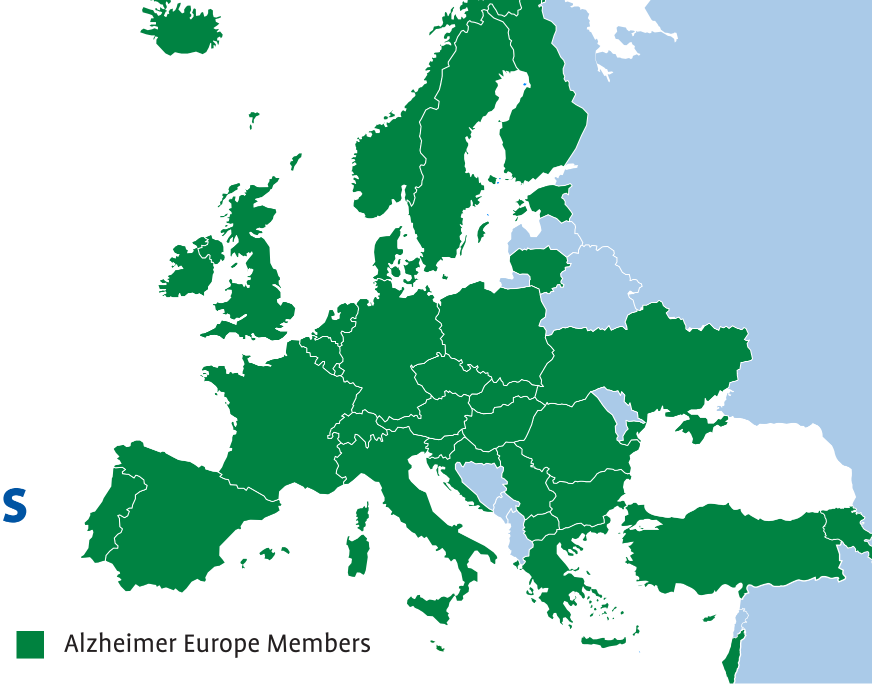
Finally, I want to say a few words about my wife. I’ve been very lucky to have a travel companion like her. She has always been full of life and positivity, with a strong and independent character. It took me a long time to find someone like her, but it was worth it.

This journey has been extremely difficult for her. Thinking about what it means to no longer be able to work, to drive, be autonomous, and everything that this “damned” disease entails. She has the heart of a lion and an incredible strength of spirit. Despite everything, luckily for me, she remains positive even in the darkest moments. Regarding our life together, we’ve always shared travels – that’s why in the photos you see us together in a beautiful place. That’s part of our journey and will forever remain in our hearts; the smell of the air we breathed together, in every place we’ve been fortunate enough to visit.

Life is beautiful and should be lived in every moment day by day.

Enea and Elena

Our members are helping people with dementia and their carers in 36 countries



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