

## HIGHLIGHTS

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## WELCOME

June was an extremely busy month for all of us at Alzheimer Europe, ending with a series of meetings in Luxembourg earlier this week. The Board of Directors held a meeting on Monday, followed by our 2026 Annual General Meeting (AGM) on Tuesday morning and a Public Affairs meeting with members on Tuesday and Wednesday, running concurrently with a meeting of the European Dementia Carers Working Group (EDCWG). Whilst we include reports on the Board meeting and AGM in this edition, our EDCWG and Public Affairs meeting reports will appear in our next newsletter covering July and August.

At our AGM, we were delighted to have 35 out of 41 members represented. Voting delegates approved three new member associations, bringing our new tally up to 44! A warm welcome to Latvijas Alcheimera asociācija (Latvia) and NVO Futura (Montenegro), both of which join us as provisional members, and to Alzheimerfelagið (Faroe Islands), which joins us as a full member.

The AGM also elected our new Board of Directors for 2026-2028 and approved our 2025 Annual and Financial Report. Congratulations to the new Board, and a big thank you to Marco Blom (Netherlands), who is stepping down as Honorary Treasurer after eight years on the Board, as well as to Stefanie Becker (Switzerland) and René Friederici (Luxembourg), for their years of service and vital contributions. They will all be missed!

Speaking of changes and new joiners, I am pleased to welcome Liv Krier to the Alzheimer Europe team. She has had a bit of a baptism of fire in the communications team this month, with plenty of activities to support, including the launch of our latest Dementia in Europe magazine and aforementioned Annual Report, as well as a new position paper on access to anti-amyloid therapies for Alzheimer's disease. There have been a variety of meetings and conference-related announcements, too, plus a number of social media activities for PRIDE month. I am pleased to note that we include, for the very first time, a special section dedicated to PRIDE month in our newsletter., which brings together updates linking dementia and the LGBTQIA+ community.

Applications for our Anti-Stigma Award closed on 26 June, with the announcement of the winners and runners-up scheduled to take place in Dublin during the Networking Dinner of the 36<sup>th</sup> Alzheimer Europe Conference (36AEC). The Early Bird registration period for both the conference and the Networking Dinner have come to an end, with over 1,000 delegates registered for 36AEC so far, but fear not! – you can still register with our standard fees until 26 October. I hope you will join us in Dublin, for what promises to be a fantastic conference and I also hope you will join us for the Networking Dinner, where this year's Anti-Stigma Award Ceremony will recognise a European initiative or artist combining music and dementia.

I wish you all a fantastic summer ahead and look forward to our next newsletter, scheduled for 7 September!

**Jean Georges, Executive Director**

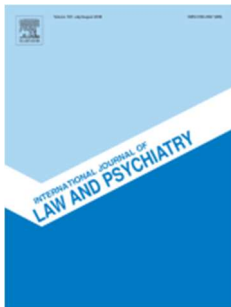
**Alzheimer Europe Board 2024-2026**  
 Chairperson: Maria do Rosário Zincke Dos Reis (Portugal); Vice-Chairperson: Mario Possenti (Italy); Honorary Secretary: Lorène Gilly (France); Honorary Treasurer: Marco Blom (Netherlands); Members: Stefanie Becker (Switzerland), René Friederici (Luxembourg), Andy Heffernan (Ireland), Martina Máttová (Czechia), Mary-Frances Morris (United Kingdom - Scotland), Kevin Quaid, Chairperson of the European Working Group of People with Dementia (Ireland), Trevor Salomon, Chairperson of the European Dementia Carers Working Group (United Kingdom - England), Katarina Sumu (Finland), Jochen René Thyrian (Germany).

**Alzheimer Europe Staff**  
 Executive Director: Jean Georges; Communications Officers: Kate Boor Ellis and Liv Krier; Conference Coordinator: Isabelle Collot; Events Coordinator: Cristina Pencea; Policy Officer: Owen Miller; Administrative and Conference Assistant: Eva Hueso; Project Administrator: Daniela Janeva; Director for Public Involvement and Ethics: Dianne Gove; Public Involvement Lead: Ana Diaz; Public Involvement Officers: Sarah Campill, Faye Forsyth and Soraya Moradi-Bachiller; Director for Research: Angela Bradshaw; Project Officers: Cindy Birk, Lukas Duffner and Margarita Reyes.

## ALZHEIMER EUROPE

28 MAY:

Article looking at whether capacity to consent to healthcare is a uniformly defined concept published in *Law and Psychiatry* journal, co-authored by Alzheimer Europe



On 28 May, an article discussing “Is capacity to consent to healthcare a uniformly defined concept? Insights from a document analysis of laws and national guidelines across six European countries” was published in the journal *Law and Psychiatry*, co-authored by Dianne Gove, Director for Public Involvement and Ethics at Alzheimer Europe.

Capacity to consent or decision-making capacity to healthcare is a key prerequisite for a valid informed consent. A clear understanding of this concept is important to protect patients’ autonomy. Without it, clinical assessments may vary, jeopardising patients’ participation in decisions about their care and increasing the risk of delayed, denied or harmful treatment. Despite substantial international debate and reforms concerning norms on capacity assessment, there remains a paucity of scholarly literature comparing national approaches, which could enable countries to learn from one another. This study aimed to explore how the concept of capacity to consent to healthcare and the assessment is described in documents, guiding healthcare professionals, issued by health authorities in Belgium, France, Ireland, Norway, Sweden and United Kingdom (specifically in England and Wales).

Read the article, here: <https://www.sciencedirect.com/science/article/pii/S016025272600049X>

1 JUNE:

Alzheimer Europe welcomes a new colleague to its Communications team



Alzheimer Europe is pleased to welcome a new colleague, Liv Krier, who joined the team on 1 June 2026. Liv (she/her/hers) joins us as a Communications Officer. She holds a Master’s degree in Cultural and Creative Communica-

tions from the University of Aberdeen (Scotland) and before joining Alzheimer Europe, she worked in international relations and science communication.

Liv joins Kate Boor Ellis in the Communications team, replacing Margarita Reyes who has moved to our Research team as a Project Officer. All the best to both of them in their new roles! See our staff profiles to find out more about our team:

<https://www.alzheimer-europe.org/about-us/who-we-are/staff>

2 JUNE:

Alzheimer Europe co-authors article “National and international models of involving people with lived experience in dementia policy, advocacy and research” in *Frontiers in Dementia*

On 2 June, an article discussing “National and international models of involving people with lived experience in dementia policy, advocacy and research” was published in *Frontiers in Dementia*.



Globally, there is growing recognition of the need to advance approaches to involve people with lived experience of dementia as collaborators in policy, advocacy and research activities. Involvement is viewed as a right by dementia advocates and others, and some organisations have developed mechanisms to support this collaboration, such as through dedicated resources for infrastructure or as a condition of research funding. However, there is limited literature on how national and international organisations support the involvement of people with lived experience of dementia. In this perspective article, the authors describe different approaches to involving people with lived experience in policy, advocacy and research activities across national and international network contexts. They outline and compare the approaches taken by the Engagement of People with Lived Experience of Dementia program and advisory group (Canadian Consortium on Neurodegeneration in Aging), Alzheimer Society Research Network (Alzheimer’s Society UK), European Working Group of People With Dementia (EWGPWD) and European Dementia Carers Working Group (Alzheimer Europe), and the Lived Experience Advisory Group (Global Brain Health Institute, Trinity College Dublin).

Among the authors are Sarah Campill, Public Involvement Officer at Alzheimer Europe, and Jan Runar Eliassen, member of the EWGPWD.

Read the article, here: <https://www.frontiersin.org/journals/dementia/articles/10.3389/frdem.2026.1816031/full>

4 JUNE:

## Alzheimer Europe is delighted to become a full member of the European Federation of Neurological Associations (EFNA)



On 4 June 2026, Alzheimer Europe officially became a full member of the European Federation of Neurological Associations (EFNA), a non-governmental organisation (NGO) that brings together pan-European neurology patient groups. During an online meeting of EFNA's Board, Jean Georges, Executive Director of Alzheimer Europe, gave an overview of our organisation and its strategic objectives and activities, after

which the EFNA Board unanimously accepted Alzheimer Europe as a full member. EFNA's slogan "Empowering Patient Neurology Groups" encapsulates the association's main goal, to add capacity to their members and allow them to be the most effective advocates possible in their own disease-specific areas. EFNA embraces the concept of 'Partnership for Progress' and works with relevant stakeholders in the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

Alzheimer Europe is delighted to join EFNA as a full member and looks forward to working with them. You can find out more about EFNA, here:

<https://www.efna.net/>

countries, these treatments remain inaccessible through public health systems. HTA bodies in Denmark, Finland, France, the Netherlands, Spain, Sweden and the United Kingdom have issued negative coverage recommendations. Anti-amyloid therapies are available in Austria, Germany and Luxembourg, with early coverage through hospital budgets, mainly. The recent negative benefit determination from Germany's HTA agency may have consequences for access in that country, however. Generally, where treatment is available at all, access is typically confined to those who can pay privately, at significant cost to the patient and their family.

The position paper identifies five key concerns:

Meaningful benefit is shaped by individual circumstances and lived experience, and the significant societal cost of dementia, including the often invisible burden on informal carers, is insufficiently captured in many assessment models. The perspectives of people living with Alzheimer's disease, their carers and the patient organisations that represent them must be genuinely and substantively incorporated in assessments from the outset.

Every person with Alzheimer's disease deserves access to a timely and accurate diagnosis, independently of whether treatment is available or reimbursed. Diagnostic infrastructure gaps should not be used as a justification for withholding access to authorised therapies, and investment in diagnostic capacity is essential to prepare for future treatments. People living with Alzheimer's disease deserve the opportunity to make an informed, supported decision on treatment with their doctors and families, based on clear and balanced information about expected benefits, risks and uncertainties. The current absence of reimbursement across most of Europe is deepening inequity. Access is primarily determined by wealth and geography rather than clinical need, compounding disparities that extend beyond treatment to diagnosis, support and care. Managed access frameworks and pilot programmes, of the kind already established for cancer and other serious conditions, offer a practical and proportionate pathway to treatment while real-world evidence continues to develop.



8 JUNE:

## Alzheimer Europe calls for equitable access to new Alzheimer's disease treatments across Europe

On 8 June 2026, Alzheimer Europe published a position paper calling for equitable and timely access to lecanemab and donanemab, the first disease-modifying therapies for Alzheimer's disease authorised in the European Union. Developed following consultation with national member associations, the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG), the paper sets out five areas of concern and calls for concrete action from governments, health technology assessment (HTA) bodies, manufacturers and the research community.

The European Commission's authorisation of lecanemab and donanemab in 2025 marked a significant turning point, as the first therapies able to slow the progression of Alzheimer's disease to be approved in the EU. However, in most European

Alzheimer Europe's position paper sets out a series of specific calls to action. HTA bodies are called on to ensure their assessments reflect the full value of these treatments, with the European Medicines Agency's benefit-risk determination as an important reference point. People with lived experience of Alzheimer's disease, their carers and the patient organisations that represent them must be meaningfully involved in all assessments from the outset, with their contribution clearly documented in the outcome.

National governments are asked to invest in the diagnostic infrastructure and specialist capacity needed to deliver these treatments safely, and to establish pathways for managed access, such as dementia drugs funds, compassionate use schemes and small-scale pilot programmes. Manufacturers are called on to engage constructively with European health systems on pricing. The organisation also calls for a pan-European approach to piloting access, enabling countries to share costs, learning and evidence.

The position paper emphasises that investment in new treatments must be additional to, and not at the expense of, investment across the full spectrum of dementia care. 12 million people in Europe are living with dementia, and many face significant difficulties in accessing post-diagnostic support, psychosocial interventions, symptomatic treatments and social care. These are longstanding, urgent needs, and Alzheimer Europe calls on governments to make dedicated and protected funding commitments across all areas of dementia care.

Commenting on the publication of the position paper, Alzheimer Europe's Executive Director, Jean Georges, stated:

"After decades without any new treatments being approved, the approvals of lecanemab and donanemab represent real progress for the Alzheimer's disease community. However, in most European countries today, these medicines remain out of reach for the people who need them. We are calling on governments, HTA bodies and manufacturers to act, and to ensure that people with Alzheimer's disease receive the same serious consideration for access to new treatments as patients with other life-altering conditions."

Alzheimer Europe welcomed lecanemab and donanemab as the first in a new generation of disease-modifying therapies for Alzheimer's disease. The organisation recognises, however, that the therapies are indicated for a narrowly defined group of patients in the early stages of Alzheimer's disease, that disease progression is slowed but not halted, and that treatment carries significant side effects requiring careful monitoring. Alzheimer Europe hopes that anti-amyloid therapies will act as a catalyst, opening the door to a more diverse and accessible therapeutic landscape while driving systemic improvements in diagnosis, care and patient pathways which are long overdue. Alzheimer Europe remains committed to a holistic approach to dementia, where innovative treatments go hand in hand with counselling, support and adequate care of people with dementia and their carers throughout the disease process.

You can download the position paper, here: <https://www.alzheimer-europe.org/policy/positions/alzheimer-europe-position-access-anti-amyloid-treatments-europe-0>

8 JUNE:

### Luxembourg Centre for Systems Biomedicine visits Alzheimer Europe for exchange meeting



On 8 June, Alzheimer Europe welcomed colleagues from the Luxembourg Centre for Systems Biomedicine (LCSB) to its offices as part of a reciprocal exchange visit, following our visit to the LCSB on 12 May.

The team was pleased to welcome the centre's director Prof. Michael Heneka, as well as Beatriz Monteiro, Françoise Meisch, Jón P. Gales, Sophie Wagner and Dr Tom Scheidt, whose visit fostered meaningful exchange and dialogue across disciplines.

During the visit, Alzheimer Europe delivered a series of presentations outlining our work and expertise across key areas. Angela Bradshaw, Director for Research, opened the session with an introduction to our research project portfolio. This was followed by Dianne Gove, Director for Public Involvement and Ethics, who provided an overview on our approach to ethics in EU projects. Ana Diaz, Public Involvement Lead, then presented Alzheimer Europe's approach to Public Involvement and the integration of lived experience into research. The presentations were followed by an interactive question and answer session, allowing both teams to exchange ideas.

Learn more about the LCSB at: <https://www.uni.lu/lcsb-en/>

11 JUNE:

Research Insights webinar recording now available



Following the launch of Alzheimer Europe’s new Research Insights webinar series, we are pleased to share that the recording of our inaugural session on “Data Sharing in Dementia Research” is now available online.

Held on 22 April and moderated by Angela Bradshaw, Director for Research at Alzheimer Europe, the webinar brought together experts from across academia, industry and the dementia community to explore opportunities and challenges related to data sharing. Speakers shared perspectives on practical approaches, collaboration and the importance of responsible data use in advancing dementia research.

We would also like to extend our sincere thanks to all the speakers who generously contributed their time and expertise to this session: Patrick (Paddy) Crosbie, Member of the European Dementia Carers Working Group (EDCWG); Lukas Duffner, Project Officer at Alzheimer Europe; Matthew Clement, Director, Partnerships & Scientific Strategy from Gates Ventures; Linus Jönsson, Professor of Health Economics at Karolinska Institutet; Petra Ritter, Professor at Brain Simulation at Charité - Universitätsmedizin Berlin; and Alina Solomon, Professor of Neuroepidemiology at the University of Eastern Finland.

If you were unable to attend, you can now watch the full recording on our YouTube channel and read a summary report of the discussion on our website.

To stay informed about upcoming Research Insights webinars, we encourage you to sign up to the dedicated mailing list.

16 JUNE:

Alzheimer Europe co-authors article “Population attributable fractions of modifiable dementia risk factors in the Netherlands: a cross-sectional, time series analysis” in Lancet eClinicalMedicine

On 16 June, an article called “Population attributable fractions of modifiable dementia risk factors in the Netherlands: a cross-

sectional, time series analysis” appeared in the Lancet eClinical Medicine

Approximately 310,000 individuals in the Netherlands are currently living with dementia, and this number is projected to double by 2050. Examining the distribution of modifiable risk and protective factors is essential for developing effective dementia risk reduction strategies. This study aimed to estimate the population attributable fractions (PAFs) of seven common modifiable risk factors for dementia in the Netherlands.

Among the authors is Lukas Duffner, Project Officer at Alzheimer Europe.

Read the article, here:

<https://doi.org/10.1016/j.eclinm.2026.104018>

29 JUNE:

We are pleased to present our latest Dementia in Europe policy magazine



Alzheimer Europe is pleased to introduce issue 51 of the Dementia in Europe magazine! There has been much valuable work taking place across Europe in the domains of policy, research, culture and care, and we are delighted to showcase these in our magazine.

Beginning with the Alzheimer Europe section, we open by providing highlights from our lunch debate in the European

Parliament on dementia policies at an EU level, hosted by European Alzheimer's Alliance Co-Chair, Hilde Vautmans MEP (Belgium). Our sincere thanks to her and all speakers and attendees for an interesting session! Staying with our events, we look at our most recent Alzheimer's Association Academies, which covered health technologies and reimbursement, supporting and involving carers in policy, advocacy and research, and other types of dementia. In the following article, we are pleased to share our new report from Alzheimer Europe, led by Project Officer, Lukas Duffner, examining the barriers to research participation and data sharing. Rounding off this section, we share details of an exchange trip by members of the Alzheimer Europe team to the Luxembourg Centre for Systems Biomedicine (LCSB) at the University of Luxembourg, to learn more about their work.

Opening the Policy Watch section, we hear from Capucine Ulian of the French Government about the country's new neurodegenerative diseases strategy, whilst France Alzheimer provides their hopes and expectations from this development. In the following article, we look at the European Parliament's SANT Committee hearing on neurological conditions, with Elly Hol sharing her view of the key points which emerged during her briefing and presentation at the committee. We then hear from Lucie Davoine and Rosita Scanferla from the European Commission, who outline the key features of the new Commission Communication "Enhancing the strategy for the rights of persons with disabilities up to 2030". Staying with European activities, the team behind the "Joint Action addressing Dementia and Health" (JADE Health) provide an update as the project nears its halfway point. Next up, Claudia Louati from the European Patients' Forum (EPF) tells us about the Critical Medicines Act and EPF's work in this area. In our final article for this section, we include an overview of the most recent meeting of the European Group of Governmental Experts on dementia and the focus of their discussions and exchanges.

The first article of the Research and Public Involvement section marks the conclusion of the project AI-Mind – Artificial intelligence for dementia prevention, with reflections from project coordinator Ira Haraldsen. As one project draws to a close, two more begin! In the articles which follow, we hear about the new DEM-CAPS project, which aims to provide health-economic evidence for psychosocial support interventions, whilst a new JPND Project, ENSURED (Empowering Needs-based Social Health and inclusive care for RarEr Dementias), aims to address the unmet social needs of people living with rarer dementias in moderate to advanced stages. Our closing article marks a new development in Alzheimer Europe's work, the inaugural "Research Insights" webinar which focused on new developments and topics in research. The first session focused on "Data Sharing in Dementia Research" and we look forward to bringing you more in the future!

Moving to our Dementia in Society section, we are pleased to showcase the excellent work of NGO Futura in Montenegro to strengthen dementia care and advocacy at national and local

levels. We then have a trio of articles from members of the European Dementia Carers Working Group (EDCWG), opening with Chairperson, Trevor Salomon, who talks about his involvement in the 2026 Longitude Prize on Dementia and serving as chair of the Lived Experience Advisory Panel (LEAP). This is followed by Annick Germeys who outlines her involvement, together with husband Geert Mathys, in a project to create a "clear language box". Next, Sertaç Hatice reflects on the Turkish translation of the 2023 book "Travelers to Unimaginable Lands: Stories of Dementia, the Caregiver, and the Human Brain" and the profound impact it had on her. Staying with people with lived experience, Lieselotte "Lilo" Klotz, member of the European Working Group of People with Dementia, shares a deeply personal account of living with a diagnosis of dementia and at the same time being a family carer. Closing out our magazine, Clarissa Giebel tells us about the Dementia Explorer Game, which she co-created with primary-school pupils, people affected by dementia and The Lewy Body Society.

We wish you an excellent summer and hope you enjoy this edition of our magazine!

Dementia in Europe magazine issue 51 can be downloaded, here: <https://bit.ly/DementiaInEurope51>

29 JUNE:

## Alzheimer Europe Board meets in Luxembourg

The Alzheimer Europe Board held a meeting on 29 June 2026, at the Alzheimer Europe (AE) offices in Luxembourg. Jean Georges, Executive Director, Angela Bradshaw, Director for Research, Dianne Gove, Director for Public Involvement and Ethics, and Ana Diaz, Public Involvement Lead, were also in attendance.

Ana presented the recent meetings at which AE has been represented, whilst Dianne shared updates on EU project applications. Jean highlighted the current situation of AE's finances and accounts to the Board and shared some forecasts to end of year. He also shared details around preparations for this year's conference and Anti-Stigma Award, as well as updates on other activities including the upcoming exhibition which AE is planning in the European Parliament in Brussels, from 31 August to 4 September. The new mandates for the European Dementia Carers Working Group and the European Working Group of People with Dementia were also discussed, as were the Board elections and new member applications, which were subsequently put to the vote on 30 June, at the organisation's AGM in Luxembourg.

Other areas of discussion at the meeting included the Operating Grant, proposed activities for 2027 and future collaborations with various European organisations.

The next Board meeting will take place on 31 August in Brussels (Belgium).

30 JUNE:

Our 2026 AGM in Luxembourg welcomes three new member associations, a new Board of Directors for Alzheimer Europe, and approves our 2025 Annual and Financial Report



Alzheimer Europe is pleased to welcome three new member associations, a new Board of Directors for the 2026-2028 term, and to present its 2025 Annual and Financial Report. These are just three of the important outcomes from the organisation's Annual General Meeting (AGM), which took place on 30 June 2026, in Luxembourg. At the AGM, 36 full members out of 41 were present or represented, ensuring the meeting had quorum. Alzheimer Europe staff and Board members were also present, together with various other guest observers.

Rosário Zincke dos Reis (Portugal), Chairperson of Alzheimer Europe, moderated the meeting, with the agenda including an in-depth review of the 2025-2026 activities and projects of Alzheimer Europe (presented by Honorary Secretary Lorène Gilly from France), as well as the finances of the organisation (presented by outgoing Honorary Treasurer Marco Blom from the Netherlands). As has been the case since the beginning of 2022, our core activities in 2025 were funded by an operating grant awarded by the European Commission's Citizens, Equality, Rights and Values (CERV) programme, ensuring we can continue providing a voice to people affected by dementia, making dementia a European priority, changing perceptions and combatting stigma, raising awareness of brain health and prevention, strengthening the European dementia movement, and supporting dementia research.

AGM delegates reviewed and unanimously adopted Alzheimer Europe's 2025 Annual and Financial Report and the report is now available on our website, as a PDF publication. Printed copies will be available at our Annual Conference in Dublin in October.

Read our 2025 Annual and Financial Report, here: <https://bit.ly/AE2025AnnualReport>



Three organisations which had previously applied for membership of Alzheimer Europe were then put to a vote, and the AGM voted unanimously to welcome all three of them - two with provisional member status and one as a full member. Alzheimer Europe warmly welcomes them, bringing our membership to 44 members from 39 countries. The three new members are:

- Latvijas Alcheimera asociācija (Latvia) - provisional member
- NVO Futura (Montenegro) - provisional member
- Alzheimerfelagið (Faroe Islands) - full member.

On the agenda too were the elections for the Board of Directors. The AGM took a moment to say farewell and thank you to Marco Blom (Netherlands), who has served on the Board for eight years and is stepping down from his position as Honorary Treasurer, after taking his retirement from Alzheimer Nederland earlier this year. Jean Georges, Executive Director, thanked Marco on behalf of Alzheimer Europe, for his vital contributions to the organisation over the years and for his friendship. He will be sorely missed!

Following Marco Blom's departure, Andy Heffernan (Ireland) who has been a member of the Board since 2022, has been voted in as the new Treasurer. The other office bearers remain unchanged.

The new Board of Alzheimer Europe for 2026-2028 is comprised of the following people:

**Office bearers**

- Chairperson: Rosário Zincke dos Reis (Portugal)
- Vice-Chairperson: Mario Possenti (Italy)
- Honorary Secretary: Lorène Gilly (France)
- Honorary Treasurer: Andy Heffernan (Ireland) - newly appointed (Board member since 2022)

**Members**

- Thanos Chatzikostopoulos (Greece) - new member

- Edyta Ekwinska (Poland) - new member
- Wiesje van der Flier (Netherlands)
- Friederike de Maeyer (Austria) - new member
- Martina Mátlová (Czech Republic)
- Mary-Frances Morris (Scotland, United Kingdom)
- Katariina Suomu (Finland)
- René Thyrian (Germany)



Congratulations to all of them! A big thank you, also to outgoing board members Stefanie Becker (Switzerland), and René Friederici (Luxembourg) for their vital contributions. They will be missed by everyone.

The new terms of office of the European Working Group of People with Dementia (EWGPWD) and of the European Dementia Carers Working Group) have begun following the 2026 AGM, and the members, chairpersons and vice-chairpersons of both groups will be announced soon. Both the chairperson of the EWGPWD and chairperson of the EDCWG will be *ex-officio* members of the Alzheimer Europe Board, with full voting rights.

Kevin Quaid (Ireland), current Chairperson of the EWGPWD and Trevor Salomon (United Kingdom, England), current Chairperson of the EDCWG each gave a speech at the AGM, sharing the excellent work of their respective working groups over the past year and thanking Alzheimer Europe for its support and its commitment to ensuring the voices of people with dementia and carers are heard at the European level.

A big thank you to all members who attended our 2026 AGM in Luxembourg, for the great discussions and for using their

voices and their votes, thus helping to shape the future of our organisation and ensure our important collaborative work continues!

30 JUNE:

**Early bird registration is now closed! But you can still register for #36AEC!**



Early bird registration for the 36<sup>th</sup> Alzheimer Europe Conference is now officially closed. A total over 1,000 early bird registrations were received and we would like to thank everyone who has already secured their place. We are delighted by the strong number of registrations received so far!

Early bird registration has ended for both the conference and the networking dinner, which includes the **Anti-Stigma Award Ceremony**. In addition, the submission deadline for Anti-Stigma Award initiatives has also passed.

For those who have not yet registered, it is still possible to join us at our annual conference in Dublin from 27–29 October 2026. Standard registration remains open for both the conference and the networking dinner/Anti-Stigma Award Ceremony. However, **special rates** continue to be available for people with dementia, carers and students.

The **detailed conference programme** is now available on our website, offering a comprehensive overview of the sessions, speakers and topics that will be featured at this year's event. Visit the **conference website** to learn more about the organisers, travel information, accommodation options and the venue. Explore the programme and secure your place. We look forward to welcoming you to Dublin for #36AEC!

## SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to five new sponsors for its 2026 Annual Conference:



All corporate sponsors have provided sponsorship to support educational and healthcare related activities and have no input in the content or activities produced by Alzheimer Europe.

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2025-sponsorship-opportunities>

## AE NETWORKING

3 JUNE	Sarah and Cindy met online with the Multi-MeMo Advisory Board members
3 JUNE	Cindy, Faye and Margarita attended the FluiDx-AD General Assembly Meeting
4 JUNE	Owen attended the European Non-Governmental Organisations (ENGOS) meeting hosted by the European Disability Forum (EPF)
8 JUNE	Representatives of the Luxembourg Centre for Systems Biomedicine (LCSB) visited the Alzheimer Europe offices as part of an exchange (Senningerberg, Luxembourg)
8 JUNE	Cindy participated in the webinar “From heart to mind: how public and patient involvement supports research to prevent cognitive impairment in cardiovascular disease”, organised by the Association of Cardiovascular Nursing & Allied Professions (ACNAP) in collaboration with the DORIAN GRAY project
11 JUNE	Owen attended a COFACE webinar on the EU’s Anti-Poverty Strategy
16 JUNE	Margarita and Ana attended the online PROMINENT meeting
18 JUNE	Sarah facilitated an online event for the PREDICTOM Advisory Boards
24-26 JUNE	The Conference Coordinator travelled to Dublin to meet with ASI, the Convention Centre Dublin, the Gibson Hotel and the Round Room at the Mansion House (location for the Anti-Stigma award dinner) (Dublin, Ireland)
25 JUNE	Owen attended the Patient Think Tank (PTT) hosted by the European Federation of Pharmaceutical and Industry Associations (EFPIA)
25 JUNE	Ana and Faye facilitated an online consultation with partners from Kings College and InRad exploring data sharing via the InRad platform
29 JUNE	The Alzheimer Europe Board held a meeting (Senningerberg, Luxembourg)

- 30 JUNE Alzheimer Europe's Board, members and staff attended the organisation's Annual General Meeting (Senningerberg, Luxembourg)
- 30 JUNE-1 JULY The European Dementia Carers Working Group held a meeting, facilitated by Alzheimer Europe's Public Involvement team (Senningerberg, Luxembourg)
- 30 JUNE-1 JULY Alzheimer Europe's members and staff attended a Public Affairs meeting (Senningerberg, Luxembourg)
- 3 JUNE Sarah and Cindy met online with the Multi-MeMo Advisory Board members
- 3 JUNE Cindy, Faye and Margarita attended the FluiDx-AD General Assembly Meeting
- 4 JUNE Owen attended the European Non-Governmental Organisations (ENGOS) meeting hosted by the European Disability Forum (EPF)
- 8 JUNE Representatives of the Luxembourg Centre for Systems Biomedicine (LCSB) visited the Alzheimer Europe offices as part of an exchange (Senningerberg, Luxembourg)

# Understanding the scale of dementia in Europe

## Help us give a voice to people with dementia



Donate

**@AlzheimerEurope**  
Non-profit NGO, making dementia a European priority.

Learn about the Prevalence of Dementia in Europe 2025 Report

Check out the Dementia in Europe Yearbook 2025

Join our Public Involvement Pool

Help us give a voice to people living with dementia

Submit an abstract to the #38AEC Conference in Dublin

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## EU PROJECTS

3 JUNE:

### Members of the Multi-MeMo Advisory Board meet online



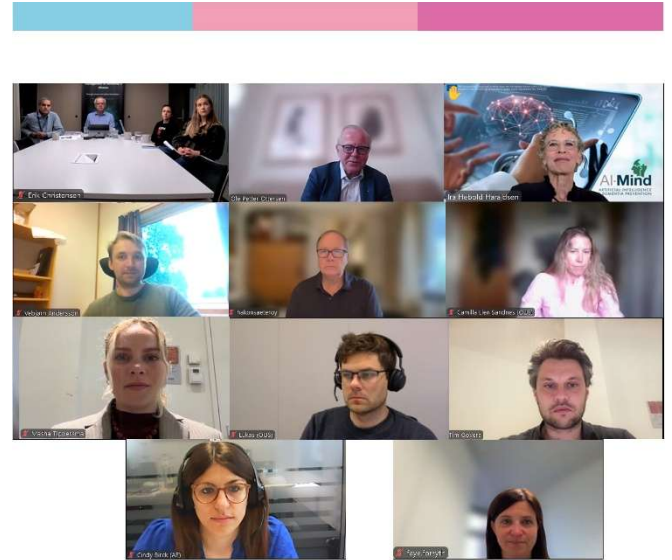
Multi-MeMo (“Shorter- and longer-term mechanisms of multi-modal interventions to prevent dementia”) is a European funded project that focuses on brain health in older people, overall, and tailored, multidomain interventions (i.e., targeting multiple risk factors simultaneously) for the risk-reduction of cognitive impairment and dementia, in particular. In addition to written contributions from two members, three other members of the Multi-MeMo Advisory Board (AB) gathered, on 3 June, for an online meeting. The Advisory Board comprises members of the public, both with and without cognitive impairment, who contribute valuable perspectives to the project’s research activities.

The meeting was facilitated by Sarah Campill (Alzheimer Europe), who was joined by Cindy Birck (Alzheimer Europe), Marissa Zwan (Amsterdam UMC), Mariagnese Barbera (University of Eastern Finland), Laura Forcano, Natalia Soldevila Domenech and Rafael de la Torre (Hospital del Mar Research Institute). The main topic of discussion was the communication of clinical trial results, particularly trials involving multi-modal lifestyle interventions. Advisory Board members provided insightful feedback to help researchers better understand how to communicate research findings in ways that are relevant, engaging and easy to remember for different audiences. Their contributions highlighted the importance of clear, accessible and meaningful communication when sharing scientific results with the public.

The Multi-MeMo consortium would like to thank all Advisory Board members for their time, expertise and commitment.

3 JUNE:

### FluiDx-AD consortium reviews progress at General Assembly meeting



On 3 June, partners of the FluiDx-AD project met online for their General Assembly meeting to review progress across the project’s work packages (WP) and discuss the next steps towards improving the early diagnosis and management of Alzheimer’s disease (AD). FluiDx-AD is funded by the European Union’s Horizon Europe programme and is developing an innovative trio of biomarker-based tests that work complementarily and sequentially along the AD diagnostic journey.

The meeting opened with welcoming remarks from Chairman of Pre Diagnostics and FluiDx-AD Scientific Coordinator, Ole Petter Ottersen. This was followed by a project overview and update on scientific progress from Project Coordinator Ira Haraldsen (Oslo University Hospital) and Erik Christensen (Pre Diagnostics). Ira Haraldsen also delivered a keynote lecture on the future of biomarkers in Alzheimer’s disease research, providing partners with an overview of recent developments and emerging trends in the field.

Scientific updates from across the project followed throughout the day. Ira Haraldsen presented progress on WP1-2, which focus on building a unified, anonymised clinical and biomarker database through a secure Services for Sensitive Data (SSD) cloud platform. Praveen Sharma (HemoDx) outlined developments in WP3-5, dedicated to the SalivaDx-AD test, an at-

home saliva-based screening tool designed to identify individuals at risk of developing AD in its prodromal stages. Erik Christensen (Pre Diagnostics) reported on WP6–8 and the development of PlasmaDx-AD, a minimally invasive and cost-effective blood test for high-precision confirmatory diagnosis of AD. Maria Donate (Pre Diagnostics) presented updates on WP9–10 and BloodCellDx-AD, a whole-blood test being developed to assess the risk of amyloid-related imaging abnormalities (ARIA) before (patient stratification) and during (patient monitoring) Alzheimer’s disease immunotherapy. Partners also received updates on the project’s communication, dissemination and Public Involvement activities. Cindy Birck (Alzheimer Europe) highlighted recent communication and dissemination achievements, while Faye Forsyth (Alzheimer Europe) provided an overview of Public Involvement activities, including the work of the Public Advisory Board and a systematic review examining ethical and social aspects related to the project. Masha Tippersma (Medip Analytics) presented progress on WP14–16, focusing on the development of the project’s health economic analysis dashboard, before Ira Haraldsen concluded the meeting with project management updates. The General Assembly also featured an exploitation workshop led by Marte Sødal (Pre Diagnostics) and Håkon Sæterøy (Pre Diagnostics/HemoDx).

The meeting demonstrated the progress made across all work packages. Having successfully completed our first periodic report, we have now entered Reporting Period 2. A big thank you to all partners for their continued commitment. We look forward to the exciting milestones ahead as we continue to advance the FluiDx-AD project and work towards improving the early diagnosis and management of Alzheimer’s disease.

5 JUNE:

**AD-RIDDLE launches Digital Engagement Platforms in Sweden**



The AD-RIDDLE project is pleased to announce the soft launch of three Digital Engagement Platform (DEP) sites in Sweden for the FINGERS Brain Health Institute (FBHI), the Swedish BioFINDER study

(BioFINDER) and the REAL-AD study (REAL AD).

The DEP platforms have been developed by Gates Ventures in collaboration with leading Alzheimer’s and brain health research institutions. They are designed to help organisations better engage and support their communities by connecting individuals to trusted educational materials, events, brain health resources and research participation opportunities.

This soft launch represents an important milestone for the AD-RIDDLE project. All three platforms are now live with the “Content & Resources” module, which enables each organi-

sation to share trusted educational materials with their communities while also benefiting from a shared library of resources across participating organisations. Content partnerships are underway, including a collaboration with Alzheimer-guiden’s Nadio, providing high-quality Sweden-specific brain health content across all three sites.

The project invites members of the research and clinical communities, as well as participants and collaborators, to explore the platforms:

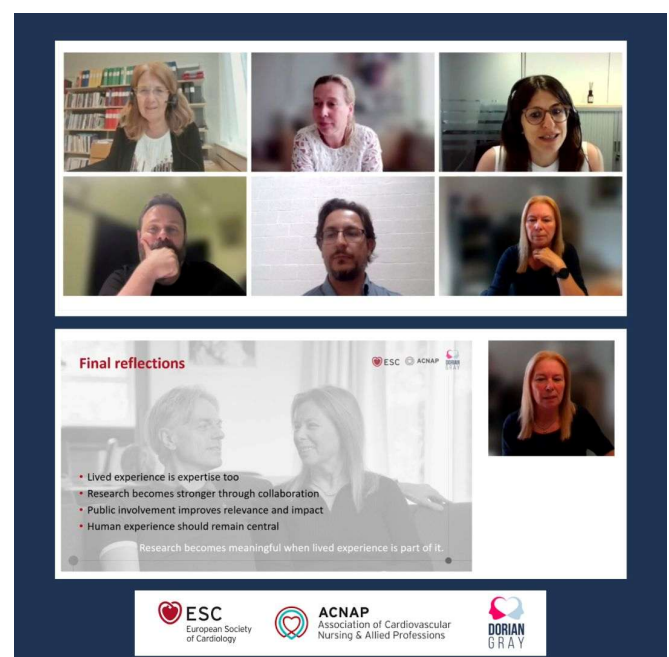
- **BrainPortal for FBHI** – FINGERS Brain Health Institute-Karolinska: [brainportal.fbhi.se](http://brainportal.fbhi.se)
- **BrainWise for BioFINDER** – BioFINDER-Lund: [brainwise.biofinder.se](http://brainwise.biofinder.se)
- **BrainSchool for REAL AD** – REAL AD-Gothenburg: [brainschool.realad.se](http://brainschool.realad.se)

More information can be found on the AD-RIDDLE website:

<https://ad-riddle.org/ad-riddle-launches-digital-engagement-platforms-in-sweden/>

8 JUNE:

**DORIAN GRAY webinar highlights the role of Public and Patient Involvement in research**



On 8 June, the Association of Cardiovascular Nursing & Allied Professions (ACNAP), in collaboration with the DORIAN GRAY project, organised a webinar entitled “From Heart to Mind: How Public and Patient Involvement Supports Research to Prevent Cognitive Impairment in Cardiovascular Disease.” The webinar brought together cardiologists, neurologists, nurses, general practitioners and researchers to discuss how actively involving patients and members of the public can enhance the research process and lead to better outcomes and

more personalised and effective solutions. Speakers highlighted how meaningful Public and Patient Involvement (PPI) improves the relevance, accessibility and real-world impact of research, particularly in projects addressing the complex relationship between cardiovascular disease and cognitive impairment. They underlined that PPI means working alongside individuals as advisors, collaborators and partners, bringing their lived experience to shape how research is designed, implemented and communicated.

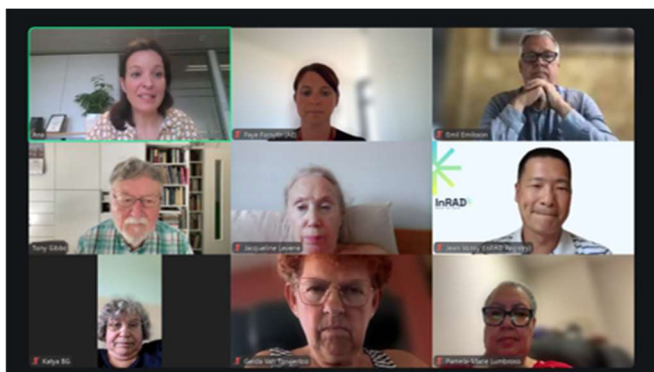
The session was chaired by Tiny Jaarsma (Linköping University). The programme opened with a joint presentation by Tiny Jaarsma and Leonie Klompstra (Linköping University) entitled “Involving Patients in Meaningful Ways: Co-creating Self-care and Interventions to Improve Heart Failure Outcomes.” The second presentation, “Involving Members of the Public in Research: What Does This Mean, Why and How?”, was delivered by Cindy Birck (Alzheimer Europe) on behalf of Soraya Moradi-Bachiller (Alzheimer Europe). This was followed by a presentation from Nicola Lopomo (Politecnico di Milano) and Leonardo Angelini (Haute École spécialisée de Suisse occidentale) entitled “From Insight to Innovation: How Does Public Involvement Benefit Research?”

The final speaker was Annick Germeys, a member of the DORIAN GRAY Advisory Board and the European Dementia Carers Working Group. Speaking from the perspective of a caregiver and expert by experience, she highlighted how Public Involvement brings valuable real-life knowledge into research, helping researchers better understand everyday challenges and develop more human-centered solutions.

<https://www.doriangray-horizon.eu/news/from-heart-to-mind-dorian-gray-webinar-highlights-the-role-of-public-and-patient-involvement-in-research/>

26 JUNE:

### ACCESS-AD holds a second meeting with people with lived experience to explore data management and sharing across the project



On 26 June, the Public Involvement team held a consultation to explore data management and data sharing within the context of the ACCESS-AD (Advancing Clinical Care and Equity through Scalable Solutions in Alzheimer’s Disease diagnosis

and treatment) project. ACCESS-AD is a pan-European, public–private partnership working to ensure that scientific advances in Alzheimer’s disease diagnosis and treatment can be delivered across diverse healthcare settings. By integrating brain imaging, biomarkers, digital tools, new treatments and real-world evidence, ACCESS-AD will enable earlier diagnosis, safer use of disease-modifying therapies and more equitable access to care.

InRAD (International Registry for Alzheimer’s Disease and Other Dementias) a registry that helps with the collection, combination, and comparison of real-world data, a partner in ACCESS-AD, will be used across ACCESS-AD study sites for data collection, ultimately integrating data, people, and local initiatives. Investigators at InRAD are developing the ACCESS-AD governance infrastructure, including developing informed consent forms and patient information sheets. As part of their work, they were interested to hear from people with lived experience to understand their preferences in relation to informational needs and consent preferences for data management and sharing.

Six people with lived experience (three from Alzheimer Europe’s Working Groups and three from Kings College London’s Care Network) attended an online meeting and provided rich and insightful information about potential consent and data sharing process, data stewardship and the use of Artificial Intelligence. Collaborators at InRAD welcomed the feedback and will use the information collected to inform the development of information and consent materials.

The session was facilitated/hosted by Ana Diaz (AE) with the support of Faye Forsyth (AE). The team was joined by Zunera Kahn (Kings Collage London) and Alex Giehl and Jean Vonsy from InRAD, who are ACCESS-AD consortium partners. More information about the ACCESS-AD project can be found here: <https://www.access-ad.org/>. More information about InRAD can be found here: <https://www.inradnetwork.org/>

ACCESS-AD is funded by the European Union, the private members, and those contributing partners of the IHI JU, under grant agreement number 101253010. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the aforementioned parties. None of the aforementioned parties can be held responsible for them.

## EU project acknowledgements



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon 2020, Horizon Europe, the Innovative Medicines Initiative 2 (IMI2) Joint Undertaking (JU), or the Innovative Health Initiative (IHI) JU. Projects funded through the IMI2 or IHI JU receive support from EU Research & Innovation programmes, as well as industry federations and other contributing partners. Please visit the project website(s) listed below for specific details on the organisations, federations and funders providing support for individual projects.

Several projects have also received funding through:



Please see our website, to find out more about each project, its funding, and to explore the project websites: <https://www.alzheimer-europe.org/our-work/current-work>

## MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE



Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **89**, representing **22** Member States of the European Union and seven out of eight political groups in the European Parliament. Alzheimer Europe is grateful to the Co-Chairs of the EAA: Nina Carberry (EPP, Ireland); Tilly Metz (Greens/EFA, Luxembourg); Romana Jerković (S&D, Croatia); Sirpa Pietikäinen (EPP, Finland);

Vladimir Prebilič (Greens/EFA, Slovenia); Hilde Vautmans (Renew Europe, Belgium) and Dainius Žalimas (Renew Europe, Lithuania) for their leadership and for hosting the organisation's European Parliament lunch debates on dementia. Alzheimer Europe would also like to thank the following MEPs for their support of the EAA:

**Belgium:** Kathleen van Brempt (S&D); Johan Van Overtveldt (ECR); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Kristian Vigenin (S&D). **Croatia:** Biljana Borzan (S&D); Romana Jerković (S&D); Tonino Picula (S&D); Tomislav Sokol (EPP). **Cyprus:** Costas Mavrides (S&D). **Czechia:** Ondřej Dostál (NI); Tomáš Zdechovský (EPP). **Denmark:** Kira Marie Peter-Hansen (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe). **Finland:** Maria Guzenina (S&D, Finland); Merja Kyllönen (The Left); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Mélissa Camara (Greens/EFA); Laurent Castillo (EPP); David Cormand (Greens/EFA); Marie Dauchy (PFE); Christophe Gomart (EPP); Catherine Griset (PFE); Céline Imart (EPP); Isabelle Le Callennec (EPP); Nadine Morano (EPP); Philippe Olivier (PFE); Mounir Satouri (Greens/EFA); Majdouline Sbai (Greens/EFA); Marie Toussaint (Greens/EFA). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Manuela Ripa (Greens/EFA); Terry Reintke (Greens/EFA). **Greece:** Tsiodras Dimitrios (EPP); Emmanouil (Manolis) Kefalogiannis (EPP); Nikos Papandreou (S&D); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (PFE); Enikő

Györi (PFE); Kinga Gál (PFE); György Hölvényi (EPP); András Kulja (EPP). **Ireland:** Barry Andrews (Renew Europe); Lynn Boylan (The Left); Nina Carberry (EPP); Luke 'Ming' Flanagan (NI); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Aodhán Ó Ríordáin (S&D); Maria Walsh (EPP). **Italy:** Brando Benifei (S&D); Caterina Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania:** Vytenis Povilas Andriukaitis (S&D); Petras Auštrevičius (Renew Europe); Vilija Blinkevičiūtė (S&D); Liudas Mažylis (EPP); Dainius Žalimas (Renew Europe). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Poland:** Elżbieta Katarzyna Łukacijewska (EPP); Michał Szczęcha (EPP); Anna Zalewska (ECR). **Portugal:** Marta Temido (S&D); Catarina Martins (The Left). **Romania:** Vlad Vasile-Voiculescu (Renew Europe). **Slovenia:** Matjaž Nemeč (S&D); Irena Joveva (Renew Europe); Vladimir Prebilič (Greens/EFA); Marjan Šarec (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Rosa Estaràs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Idoia Mendia (S&D); Diana Riba i Giner (Greens/EFA); Ana Miranda Paz (Greens/EFA). **Sweden:** Pär Holmgren (Greens/EFA); Jonas Sjöstedt (S&D).

## EU DEVELOPMENTS

15 JUNE:

### Council and Parliament reach agreement on air passenger rights



On 15 June, the European Parliament and Council reached political agreement on revisions to the regulation on air passenger rights, which was first introduced in 2004. The Commission's proposals for revisions were first proposed in 2013, with negotiations deadlocked up until this agreement.

The regulation covers all air passengers, strengthening and simplifying their rights in the event of delays or cancellations to flights. Additionally, the revised regulation introduces a number of specific measures for persons with reduced mobility, including people with disabilities. These include:

The regulation covers all air passengers, strengthening and simplifying their rights in the event of delays or cancellations to flights. Additionally, the revised regulation introduces a number of specific measures for persons with reduced mobility, including people with disabilities. These include:

- Airlines must pay for the full cost of replacement for lost/damaged mobility equipment and compensation for injured assistance dogs.
- Airlines must provide temporary replacement at no cost if the person's equipment gets lost/damaged or compensation for injured assistance dogs.
- The right to compensation and rerouting where passengers with disabilities miss a flight due to the lack or delay in the provision of assistance.
- The possibility for passengers with disabilities to sit with an accompanying person free of charge.

Further details on the new passenger rights legislation are available at: <https://www.consilium.europa.eu/en/press/press-releases/2026/06/15/council-and-parliament-reach-landmark-agreement-on-stronger-eu-air-passenger-rights/>

17 JUNE:

### Council of Europe adopts recommendation on autonomy in mental health care

On 17 June the Committee of Ministers of the Council of Europe adopted the "Recommendation on respect of autonomy in mental health care".

The Recommendation aims to ensure respect for the autonomy of persons receiving mental healthcare and to prevent

the use of coercive measures. It reaffirms the principle of free and informed consent, as well as respect for the will and preferences of the person in relation to mental healthcare, whilst also underlining that any exception must be subject to strict legal safeguards. Additionally, the text stresses the need for ensuring equitable access to mental healthcare, including community-based care.

The Recommendation lays down a number of specific provisions in relation to:

- Designing policies and practices, that reflect the principle of autonomy, involving persons with lived experience.
- The provision of mental healthcare in environments that promote autonomy, ensuring that persons are informed of their rights. This includes the right to complain, assistance in the exercise of rights and ability to express and document preferences for future care.
- Addressing stigma and preventing discrimination, including through education and training of health professionals.
- Conducting regular reviews of practices with a view of ensuring respect for autonomy.

The full text of the recommendation is available at: <https://rm.coe.int/09125948802c3067>



18 JUNE:

## European Public Health Alliance holds 2026 General Assembly meeting



On 18 June, the European Public Health Alliance (EPHA) held its 2026 General Assembly (GA).

Around 60% of EPHA's membership was represented at the meeting, which was held online, making it one of the highest participation rates in EPHA history. The positive and

constructive atmosphere left the organisers feeling optimistic about the years ahead.

The EPHA GA adopted the following resolutions:

- Approval of the 2025 annual accounts;
- Approval of a one-off six-month extension of the mandate of the Board elected for the 2026–2028 term, in order to return EPHA to its traditional December Board election cycle.

The GA elected the EPHA Management Board for the 2026–2028 mandate and, during its first meeting later that afternoon, the newly-elected Board appointed its officers.

The EPHA Board for 2026–2028 consists of:

- Elisabeth Dupont (International Diabetes Federation Europe) – President
- Dr Wolfgang Fecke (Association of European Cancer Leagues) – Vice-President
- George Sultana (Malta Health Network) – Treasurer
- Dr Paolo Lauriola (International Society of Doctors for the Environment – Italy) – Board Member
- Prof. Marija Jevtić (The Society of Vojvodina Physicians, Serbian Medical Society) – Board Member.

With a new Board in place, the implementation of EPHA's 2026–2030 Strategy can begin and EPHA looks forward to working with its membership in the years ahead as it continues to advance health equity, strengthen public health, and amplify the voice of civil society across Europe.

Alzheimer Europe is a member of EPHA. Our Executive Director, Jean Georges, represented the organisation at the online EPHA GA of 18 June.

You can find out more about EPHA, here:

<https://epha.org/>

## POLICY WATCH

25 JUNE:

### Reform of long-term care insurance in Germany: Caregivers should not pay the price says German Alzheimer Society



**Deutsche Alzheimer Gesellschaft e.V.**  
**Selbsthilfe Demenz**

There is currently intense debate in Germany regarding a reform of long-term care insurance, with a primary focus on narrowing the funding gap. Financial challenges are already significant, and deficits are projected to rise sharply in the coming years. However, the draft legislation presented by the Federal Ministry of Health entails serious cutbacks that will particularly affect family caregivers. For instance, the pension insurance contributions that the long-term care insurance system pays on behalf of family caregivers are set to be reduced. This increases the risk of old-age poverty, especially for women, as

the majority of care work in Germany is performed by women who often curtail their own professional careers to do so.

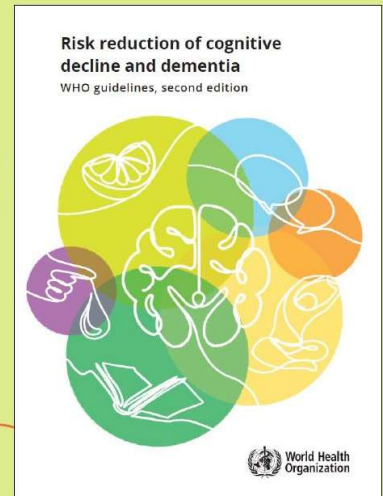
Other cuts to benefits will mean that respite care can only be accessed at a later stage and that certain support services, which have been established in recent years, will disappear.

The German Alzheimer Society - the Deutsche Alzheimer Gesellschaft (DAIzG), together with many other associations, is advocating for amendments to the draft legislation and the withdrawal of many of the planned measures. While it is true that changes are necessary to ensure the long-term financial stability of long-term care insurance in Germany, there are various other options available; in the view of the DAIzG. Shifting the burden solely onto those in need of care and their relatives is unfair, they stress, particularly as around 86% of care in Germany is provided by informal carers. There is strong opposition to the draft bill. The DAIzG hopes the government will back down.

# Official Launch

## WHO guidelines on risk reduction of cognitive decline and dementia, second edition

Join the webinar to learn about the **new and updated recommendations** and explore practical actions individuals, professionals, and decision-makers can take to support brain health.



16 July 2026  
15:30-17:00 CEST

The webinar will be in English with French, Portuguese and Spanish interpretation

## SCIENCE WATCH

1 JUNE:

touchNEUROLOGY shares key neurology trial data and clinical insights from AAN 2026



The late-breaking science sessions at the **AAN Annual Meeting 2026**, which took place in Chicago, Illinois (USA) from 18 to 22 April, brought together a wide range of pivotal and practice-shaping data spanning rare disease, neuroimmunology, headache, epilepsy, neurodegeneration and neuromuscular medicine.

Several presentations reported positive phase III findings, while others offered important lessons from negative studies, biomarker research and emerging therapeutic platforms.

This article covers presentations highlighted in the **LS1: Late-breaking Science 1** and **LS2: Late-breaking Science 2** sessions at the AAN Annual Meeting 2026:

<https://touchneurology.com/insight/aan-2026-late-breaking-science-key-neurology-trial-data-clinical-insights/>

1 JUNE:

touchNEUROLOGY shares insights on diagnosis, emerging therapies and innovations, from the recent 37<sup>th</sup> Global Conference of Alzheimer's Disease International in Lyon



Held from 14–16 April, the 37th Global Conference of Alzheimer's Disease International (ADI), Lyon, France, brought together global expertise and lived experience at the longest-running international forum on dementia.

Structured around the seven areas of the World Health Organization's Global action plan on dementia, the programme covered public health, awareness, carer support, diagnosis, treatment and care, risk reduction, information systems, and research and innovation.

Among the broad range of topics presented, this article highlights some of the key oral presentations from the meeting, with a particular focus on developments in dementia diagnosis and emerging treatments, alongside innovations in dementia care.

touchNEUROLOGY's ADI conference highlights can be viewed here:

<https://touchneurology.com/insight/37th-global-conference-of-alzheimers-disease-international-diagnosis-emerging-therapies-and-innovations/>

2 JUNE:

In Bill Gates' latest "Gates Notes" blog post, he shares his optimism for the Alzheimer's field



On 2 June 2026, Bill Gates shared a new "Gates Notes" blog post called "We're entering a golden age of Alzheimer's research". He opens with the words "I'll never forget the moment I learned that my dad had Alzheimer's disease" and goes on to describe feeling "powerless and scared", but nonetheless hopeful about a potential breakthrough. Despite this hope having proven to be unfounded for quite some time, and despite having since lost his father to the disease (in 2020), Mr Gates shares that he is excited that, finally, things are progressing in the field.

"We are entering a golden age of Alzheimer's research. Our knowledge of how the human brain works is growing at a tremendous rate, and it's revolutionizing how scientists approach saving lives", he writes.

His blog post mentions his visit to the Karolinska Institutet (Sweden) and to the Alzheimer's Therapeutic Research Institute at the University of Southern California (US) and he shares his perspective on the important progress being made

at these (and other) important research centres around the world. He also discusses the roles of data, Artificial Intelligence and technological advances in accelerating progress. Read the full blog post, here: <https://gatesnot.es/42VAcuR>

2 JUNE:

Study finds brain injury and Alzheimer's disease biomarkers are elevated in patients with suspected infection

An observational study of 26 patients with suspected sepsis, conducted in the United Kingdom, has found that the Alzheimer's disease biomarker, phosphorylated-tau-217 (p-tau-217), was elevated in people presenting with suspected infection compared to non-infected age and sex matched control subjects. In this study, blood samples from people with suspected sepsis (the body's extreme, life-threatening response to an infection) and no history of dementia, were collected within 12 hours of their presentation to emergency departments in England and Scotland, and analysed for a range of markers of inflammation and biomarkers of disease pathology. Samples were also collected from 20 non-infected volunteer participants who were enrolled in the National Institute of Health and Care Research BioResource, and nine Alzheimer's disease 'positive' controls.



The authors then used correlation analysis, a statistical method used to determine if a relationship exists between two or more variables (in this case suspected sepsis and p-tau-217 levels), and how strong that relationship is. Lastly, they categorized p-tau-217 levels across all of the samples, according to established thresholds or cut-points used to rule in/out an Alzheimer's disease diagnosis in clinical practice (low <0.4 pg/ml, intermediate 0.4–0.63 pg/ml, and high >0.63 pg/ml). The authors reported that there was a significant difference in p-tau-217 levels between patients with suspected sepsis and healthy controls, but not between patients with suspected sepsis and Alzheimer disease positive controls. This relationship remained even when the authors controlled for certain confounding factors (characteristics that might play a role in the results) and when they removed participants from the analysis who might have another reason for elevated p-tau-217 (past history of stroke). Across all non-infected controls with p-tau-217 results, 90% had levels of p-tau-217 classified as low levels, 67% of Alzheimer's disease controls had levels classed as high (>0.63 pg/ml) and 46% of suspected infection patients with no prior history of dementia had a p-tau-217 level classified as high (29%) or intermediate (17%).

The authors caution that these findings are exploratory and must be confirmed in larger samples, however they conclude they are nevertheless important given the current context of p-tau-217 research and its future clinical application as a diagnostic biomarker. They highlight that the findings might: 1) add weight to the infection hypothesis of neurodegenerative diseases; 2) contribute to our understanding of variability in p-tau-217 levels and the implications this has for the timing of testing, frequency of testing and interpretation of results.

More information on this study is available here: <https://pubmed.ncbi.nlm.nih.gov/41822110/>

3 JUNE:

### Review highlights how stress and stress systems can impact upon Alzheimer's disease



A review published in the journal *Alzheimer and Dementia* has shone a spotlight on stress, stress physiology and Alzheimer disease outcomes. This review, which adopted a narrative, state-of-the-art synthesis approach, collated epidemiological, neuroendocrine and neuropathological evidence linking stress to Alzheimer's disease. In doing so, it demonstrates

why stress is important as both a risk factor and disease modifier and highlights the implications for future research, clinical trial design, and interventions.

In terms of being a risk factors, chronic stress, defined as repeated acute stress, or intense traumatic events that exceed an individual's threshold to change and adapt, can lead to long-term adverse health effects. Research shows that people who experience long-term stress, loneliness, social isolation, childhood adversity, trauma, or conditions such as Post-traumatic stress disorder (PTSD) tend to have a higher risk of developing dementia, including Alzheimer's disease. Stress, when measured by biological markers like cortisol (a stress hormone), heart-rate, blood pressure, and brain imaging has been linked to an increased likelihood of developing Alzheimer's later in life.

Chronic stress may contribute to the biological processes involved in Alzheimer's disease by activating hormonal and nervous-system pathways that, when overused, can damage brain regions important for memory and thinking. Long-term activation of stress chemicals such increase inflammation and have been linked to processes thought to drive Alzheimer's disease (amyloid plaques and tau tangles). Indeed, some of the brain structures involved in the stress response are also

among the first affected by Alzheimer's, suggesting a close connection. In totality, this article suggests a need to monitor stress levels and implement strategies to mitigate stress if possible.

More information on this study is available here:

[https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.71542?utm\\_medium=article&utm\\_source=researchgate.net](https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.71542?utm_medium=article&utm_source=researchgate.net)

5 JUNE:

### CTG issues negative opinion on lecanemab in Belgium

Belgium will not reimburse lecanemab, a treatment for people with early Alzheimer's disease, after the Commission for the Reimbursement of Medicines (CTG) issued a negative recommendation. Health and Social Affairs Minister Frank Vandenbroucke announced that he would follow the committee's advice.

According to a statement released by the minister's office on 5 June, the CTG concluded that the treatment "did not live up to its promises". The committee found that lecanemab's effect on slowing cognitive and functional decline was not sufficiently convincing. The CTG also highlighted the lack of data on long-term outcomes and mortality.

<https://vandenbroucke.belgium.be/fr/actualites/la-crm-rend-un-avis-defavorable-sur-leqembi-le-ministre-vandenbroucke-suit-cet-avis>

17 JUNE:

### Dementia in schizophrenia: Evidence for a distinct cognitive syndrome

In a recent paper by Ujval S. Pathak, Aydan Mehralizade, Terry E. Goldberg and Anthony W. Zoghbi examine the relationship between schizophrenia and dementia. People with schizophrenia are four- to 20-fold more likely to develop dementia than the general population. Up to 70% people



with the disorder may develop dementia by age 80. Schizophrenia is a chronic psychiatric disorder that affects how a person thinks, feels and behaves. It is often characterised by symptoms such as hallucinations (e.g. seeing or hearing

things that are not there), delusions (i.e. false beliefs), disorganised thinking and long-term difficulties with memory, attention and decision-making.

With their study, the authors explored the topic using retrospective cohort study of 155 people with severe, extremely treatment-resistant schizophrenia. The researchers compared cognitive, clinical and genetic data with large datasets of people with Alzheimer disease, frontotemporal dementia, Lewy body dementia, vascular dementia, as well as healthy controls.

The results showed, nearly all participants (98.7%) had cognitive impairment consistent with at least mild dementia and almost half (47.1%) met criteria for severe dementia, with an average MoCA score of 9.8. Importantly, the pattern of cognitive impairment differed from that seen in Alzheimer disease and other common dementias but closely resembled, and appeared to intensify, the cognitive profile previously observed in schizophrenia. Genetic analyses also did not support common dementia causes, as participants lacked typical dementia-related mutations and had a lower frequency of known Alzheimer risk genes such as APOE4. Furthermore, the evidence

suggests that the observed cognitive decline could not be explained by factors such as medications, cardiovascular risk or institutionalisation.

In conclusion, the findings support the longstanding idea that dementia seen in severe schizophrenia represents a distinct clinical syndrome related to the disorder itself rather than being caused by coexisting neurodegenerative diseases or external factors. The authors are hopeful that their findings contribute to reducing misdiagnoses and inappropriate treatment. Further research exploring cognitive decline and dementia in schizophrenia to identify reliable biological signals, is needed, and identifying people with the highest risk for this decline and intervening before the onset of psychosis should be a research priority.

Find the full article here:

[https://jamanetwork.com/journals/jamapsychiatry/article-abstract/2847069?utm\\_source=researchgate.net&utm\\_medium=article](https://jamanetwork.com/journals/jamapsychiatry/article-abstract/2847069?utm_source=researchgate.net&utm_medium=article)

## PRIDE MONTH



This section brings together some updates from Alzheimer Europe, its members and other sources, linking dementia and the LGBTQIA+ community, to celebrate PRIDE month (June).

8 JUNE:

**LEND (Lived Experience Narratives in Dementia) study is recruiting trans and gender-diverse people living with dementia, as well as carers and care partners, to share their experiences**

A new study called LEND (Lived Experience Narratives in Dementia), based at the University of Nottingham (UK), is currently recruiting trans and gender-diverse people living with dementia, as well as carers and care partners, to share their experiences.

If you identify as trans and have dementia or care for someone with dementia, the study coordinators would like to hear from you. LEND aims to share lived experience stories to help support people who may feel isolated and alone.

Contact the LEND programme via email: [LEND@nottingham.ac.uk](mailto:LEND@nottingham.ac.uk)

You can also telephone: (+44) 07791 598 280

**LEND Study**  
Lived Experience Narratives in Dementia

**TRANS & Living with DEMENTIA**

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Dementia, Identity & Trans Voices

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**"TRANS WOMEN ARE WOMEN. TRANS MEN ARE MEN. THIS SHOULDN'T CHANGE JUST BECAUSE YOU HAVE DEMENTIA"**

If you identify as TRANS and have DEMENTIA or care for someone with dementia, then we want to hear from you. We want to share lived experience stories to help support people that may feel isolated and alone.

"I have fought so long and so hard just to be me. I'm not going to stop now."

Contact The LEND (Lived Experience Narratives in Dementia) Programme by emailing [LEND@nottingham.ac.uk](mailto:LEND@nottingham.ac.uk) Or phoning: 07791598280



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LEND 18/June/2025 v1.1 22.09.2025

25 JUNE:

## The German Alzheimer's Association (Deutsche Alzheimer Gesellschaft e.V.) published a brochure on dementia and queer issues



When queer people with dementia forget parts of their own history, this can give rise to entirely new situations and feelings of uncertainty. Given the long history of persecution of gay and queer people also in Germany - which many of today's older adults have experienced firsthand - this is a complex issue that requires knowledge and sensitivity. With the new publication "Dementia and Queer" from the German Alzheimer's Association (DAIzG), a brochure in German language is now available for the first time that addresses the realities of life for queer people with dementia on a nationwide scale. This provides helpful support not only to LGBTIQ\* individuals and their loved ones and their allies, but also to professionals working in counselling and care when dementia occurs.

Swen Staack, President of DAIzG, emphasises: "Queer people with dementia must not be pushed back into invisibility. They have the same right to dignity, understanding, and care that respects their life stories - and that is exactly what we are sending a clear message about with this brochure."

The brochure originated from a project by the Dementia Competence Center in Schleswig-Holstein. Due to high demand from the field, it was revised in collaboration with the Competence Center and is now being published nationwide by the DAIzG in an updated version.

The brochure is available free of charge in print and as a PDF. Additionally, an audio version of the brochure in German is also available at [www.deutsche-alzheimer.de/demenz-wissen/demenz-und-queer](http://www.deutsche-alzheimer.de/demenz-wissen/demenz-und-queer).

The revision, and production of the brochure, as well as the audio version, were made possible by a grant from the Postcode Lottery Germany.

30 JUNE:

## Register for Dementia Researcher's upcoming Research Showcase "Queer Minds Matter: Dementia, Identity, and the Politics of Being Seen"

How well does dementia research reflect the experiences of LGBTQ+ communities? And what happens when people living with dementia are excluded from the conversations that shape research, policy, and care?

A livestream on this topic will take place on 15 July, as part of the Dementia Researcher weekly Showcase series. Each week Dementia Researcher hosts a 45-minute online session bringing researchers together to share their work, methods, and ideas.

In this session, Dáithí Clayton will chat with Dr Claudio Di Lorito, Senior Research Fellow, Primary Care and Population Health, University College London & NIHR Research Support Service (RSS) Advisor and EDI Lead, King's College Hub. Together they will explore the current state of queer dementia research, with a particular focus on the experiences of trans and nonbinary people living with dementia. Drawing on both research and lived experience, they will reflect on how identity, visibility, and inclusion shape the realities of dementia care and support.

The session will examine progress made within the field, highlight ongoing gaps in knowledge and practice, and consider how researchers, practitioners, and policy makers can better address the needs of LGBTQ+ communities affected by dementia.

Dáithí Clayton is a dementia researcher, advocate, and educator based in Belgium. Their work focuses on queer dementia research, challenging inequities in care and representation while amplifying the voices and experiences of people who have often been overlooked within dementia research and practice.

Attendees can expect a thought provoking and discussion led session with time for questions and conversation.

Find out more and register, via: <https://www.dementiaresearcher.nihr.ac.uk/event/research-showcase-queer-minds-matter-dementia-identity-and-the-politics-of-being-seen/>



30 JUNE:

## Our guide aimed at raising awareness of issues around sex, gender and sexuality in dementia is available in five different languages



This PRIDE month, we are pleased to share that Alzheimer Europe's publication "Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers" is available in five languages - Czech, English, French, German and Italian.

Sex, gender and sexuality are fundamental aspects of our lives, which influence how we see ourselves, how others see us and our position in society. In recent years, there has been increasing awareness about sex, gender and sexuality and the many different gender identities and sexual orientations that people have. Unfortunately, there is still a lack of information on this topic in dementia care where this central part of our identity is far too often invisible.

We therefore hope to raise awareness and provide health and social care workers with recommendations on how to provide sensitive, appropriate and good quality care and support to people with dementia and their carers or supporters of different sexes, gender identities and sexual orientations. We also hope to challenge assumptions and inequalities and help ensure that everyone is free from violence, discrimination and harassment. Our goal is to ensure good dementia care and support for everyone, irrespective of their sex, gender identity and sexual orientation.

The guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. It is not limited to the experience of LGBTQ+ people, but their experience is often qualitatively different to that of non-LGBTQ+ people, and they encounter several issues that others do not, hence the frequent reference to this group.

The guide is based on the ethics report Sex, gender and sexuality in the context of dementia: a discussion paper, published by Alzheimer Europe in December 2021. This report was produced by a working group of experts in the fields of dementia, gender studies, ethics, ageing, service provision, training of healthcare professionals, nursing and psychology. The group was made up of men and women with and without dementia, and with different gender identities and sexual orientations.

We realise that some readers are familiar with the concepts of sex, gender and sexuality and others less so, but terminology is constantly evolving. Some terms have become obsolete or offensive, and others have gone a complete circle from being considered offensive to becoming a preferred term. Some require a bit of explanation as they are not used in everyday conversations, but they are closely linked to assumptions, practices and prejudice which affect the wellbeing of and respect for many people with dementia. We have therefore included a footnote when they are used for the first time and at the end of the report you will find a more detailed explanation of some of these terms and a concise glossary.

Originally published in English in 2023, this guide is also available in Czech language, thanks to our member Česká alzheimerovská společnost (Czech Alzheimer Society) and their colleagues at Freya, z. s. - Institut sexuality a vztahů (Freya - Institute of Sexuality and Relationships); in French - as well as French in the context of Luxembourg, thanks to our members France Alzheimer & Maladies Apparentées and Association Luxembourg Alzheimer, and their colleagues at CESAS (Centre national de référence pour la promotion de la santé affective et sexuelle); in German, thanks to our members Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (German Alzheimer's Association), Alzheimer Schweiz Suisse Svizzera, Alzheimer Austria and Association Luxembourg Alzheimer, and their colleagues at CESAS (Centre national de référence pour la promotion de la santé affective et sexuelle); and in Italian, thanks to our national member Federazione Alzheimer Italia.

You can download the guide here, in its various versions: [English](#) / [Czech](#) / [French](#) / [French in the context of Luxembourg](#) / [German](#) / [Italian](#).

## MEMBERS' NEWS

15 MAY:

### Spominčica - Alzheimer Slovenia organises 13th International Dementia Conference ASK 2026 "Dementia Today: Challenges and Solutions!"



On Friday, 15 May 2026, Spominčica – Alzheimer Slovenia successfully organised its 13th International Dementia Conference ASK 2026 entitled “DEMENTIA TODAY: CHALLENGES AND SOLUTIONS!” at Cankarjev dom conference centre in Ljubljana.

More than 200 participants attended the conference and, through expert lectures, discussions, a round table, and parallel workshops, they jointly explored answers to current challenges in the field of dementia while presenting good practices and innovative approaches to supporting people with dementia and their carers.

The conference was held under the honorary patronage of the President of the Republic of Slovenia, Dr Nataša Pirc Musar. Opening addresses were delivered by Boštjan Koritnik, Deputy Mayor of the Municipality of Ljubljana, Denis Kordež, State Secretary at the Ministry of Health of the Republic of Slovenia, Paola Barbarino - the former Executive Director of Alzheimer's Disease International (ADI), Angela Bradshaw – Director for Research at Alzheimer Europe, and Štefanija L. Zlobec, President of Spominčica.

Renowned Slovenian and international experts presented the latest findings in the fields of diagnostics, treatment, prevention, palliative support, brain neuroplasticity, long-term care, and innovative approaches to working with people with dementia. Special emphasis was also placed on the role of local communities, the destigmatisation of dementia, and the inclusion of people with dementia in society.

The parallel programme at the conference also attracted considerable interest, featuring creative workshops, presentations

of therapeutic approaches, an interactive workshop on the importance of nature for people with dementia, and a round table discussion on living with dementia in the community, support systems, volunteering, and cooperation.

The ASK Dementia Conferences continue the tradition of the Psychogeriatric Meetings, which have been taking place since 1998, and carry forward the mission of the founder of Spominčica, Dr Aleš Kogoj — to spread professional knowledge, understanding, compassion, and support for people with dementia and their families.

Spominčica's sincere thanks go to all lecturers, moderators, participants, volunteers, partners, sponsors, and attendees who, through their support, cooperation, and presence, helped create such an important and heartfelt event.

1 JUNE:

### National Dementia Carers Action Network, assisted by Alzheimer Scotland's Active Voice Team, has published a leaflet on caring for a person in the advanced stages of dementia

For Carers, By Carers

#### Caring for a person in the advanced stages of dementia

Caring for someone in the advanced stages of dementia can be incredibly challenging, but it's also a compassionate and meaningful role – and one that requires patience, empathy, and unwavering dedication. This leaflet, written for carers, by carers, offers practical tips, encouragement, and shared experiences from those who've walked this path.

There is no single agreed definition of advanced dementia, but it's widely recognised as a stage where symptoms become more complex and severe. This leads to increased dependency and greater care needs. Familiar tasks may become difficult or impossible, and the person may increasingly rely on you, their carer, for comfort, safety, and support with their overall wellbeing. Advanced dementia affects each person in their own way. There's no set pattern or timeline for how this stage unfolds, and every person living with dementia is unique. What works well for one person may not work for another – but we share these reflections in the hope that they help you look beyond the challenges and discover approaches that work for you. It's also important to remember that every carer has their own threshold. Much of this guide focuses on supporting someone at home, but if you're considering residential care, please don't feel guilty. It's not a failure – it's a decision made with love in a way that's sustainable for you both.

*"For me, I knew the situation was getting more advanced when I realised, I could no longer leave mum on her own."*

The members of the National Dementia Carers Action Network (NDCAN), assisted by Alzheimer Scotland's Active Voice Team, recently produced a leaflet which has focused on appropriate strategies and skills for carers who are supporting persons living in the advanced stages of dementia. This is the ninth leaflet of a series to have been published under the general heading of “For Carers, By Carers”. In common with the previous ones, it is aimed at giving advice and encouragement to those undertaking their devoted and well-targeted duties. Essential tasks undertaken prior to the publication were based on a thorough analysis of the challenges and chores which



carers had experienced and in identifying feasible resolutions and successful routines.

The leaflet presents a synopsis of how alertness and care regarding vulnerable persons can be operationally apposite and planned to maintain a high standard of provision. At all stages, arrangements will require to be well-focussed on each individual's particular needs in order to take full account of the tasks which have to be faced. While noting there is no single agreed definition, set pattern, or timeline for advanced dementia, it highlights general principles and practical tips which, on many occasions, have been shown to be both relevant and advantageous. Throughout the leaflet there is a series of quotations from experienced carers expressing their personal views on practices which they have found to be applicable.

From the outset, it is stressed that an essential aspect of effective caring is for carers to look after themselves as their own good health and wellbeing will strengthen and reinforce the quality of the first-rate daily care and comfort which they want to deliver. It emphasises that, if a carer is feeling stressed or overwhelmed, they should not hesitate to seek help and guidance from other carers, family and friends, professionals and local services. Advice, counselling, and moments of relaxation can make a colossal difference.

A wide range of helpful suggestions is included regarding important topics such as: providing daily care and comfort; responding to changes in behaviour; support with eating and drinking; being well prepared for the effectual management of difficulties relating to incontinence; emotional and sensory connection; and practical aids and adaptations. As elsewhere in the leaflet, methods concerning advantageous procedures and interventions are outlined briefly in each of these areas. All are worthy of thoughtful consideration when caring for persons in the advanced stages of dementia.

In the closing remarks carers are reminded that there is no single "right way". They are encouraged to assess their own practices and to discover which approaches work best for both themselves and those receiving their care. Situations will change and plans for both carers and those living with dementia will require to be reviewed. If help is needed, carers should not shrink from requesting assistance. Even in their most challenging and darkest moments, it is essential that they should remain assured that they are not alone. Giving them a true voice will safeguard a sense of authentic togetherness. Advice, compassionate inspiration, and genuine empathy should always be within reach.

The new leaflet "For Carers By Carers - Caring for a person in the advanced stages of dementia" can be downloaded, here: <https://www.alzscot.org/wp-content/uploads/2026/04/For-Carers-By-Carers-Advanced-stages-of-dementia-002.pdf> National Dementia Carers Network (NDCAN) is a national member-led campaigning and awareness-raising group of current and former dementia carers in Scotland.

More about NDCAN: <https://www.alzscot.org/campaign-for-change/active-voice/national-dementia-carers-action-network/>

*With thanks to Frank O Hagan, NDCAN member for writing this article.*

2 JUNE:

## Ten years of advocacy for people living with dementia: More than one third of Estonians have been affected by dementia

On 2 June 2026, the Estonian non-profit organisation Life with Dementia (MTÜ Elu Dementsusega) celebrated its tenth anniversary, marking a decade of advocacy, awareness-raising, and support for people living with dementia and their families.

Founded in 2016 by people with lived experience of dementia, the organisation has become Estonia's leading voice in promoting dignity, inclusion, and right for better quality of life for those affected by the condition. Over the years, it has helped bring personal stories into public discussion, organised community events, contributed to policy development, and built cooperation between healthcare professionals, social care providers, decision-makers, and families.



The anniversary comes at a time when dementia is affecting an increasing number of people across Estonia. A nationwide survey conducted in April 2026 found that 35% of Estonian adults have had direct or indirect experience with dementia. Of these, 20%—representing more than 200,000 people—have encountered dementia within their own family or through a close loved one. A further 15% reported experience through friends or more distant relatives.

The findings underline that dementia is no longer a marginal issue but a growing societal challenge affecting individuals, families, communities, and public services.

The survey also highlighted generational differences in attitudes toward dementia. Younger respondents were significantly more willing to speak openly about a diagnosis than older age groups. Among people aged 18–24, 44% said they would openly discuss a dementia diagnosis, compared with only 11% among those aged 75 and older. Older respondents were also more likely to say they were uncertain about how they would react if faced with such a diagnosis.

These findings demonstrate both progress and continuing challenges. While public awareness has improved in recent years, stigma and fear surrounding dementia remain

significant barriers to seeking support and speaking openly about the condition.

During the anniversary event, speakers emphasised that dementia affects far more than memory. It influences relationships, identity, independence, and quality of life. Families often face emotional, practical, and financial challenges long before formal support services become available.



Guests at the event included healthcare professionals, representatives of disability and patient organisations, policymakers, and community partners. Discussions focused on human dignity, support for family caregivers, and the importance of ensuring that people living with dementia remain visible and included in society.

“Over the past ten years, we have learned that dementia is not only about memory loss,” said representatives of NGO Life with Dementia. “It touches relationships, identity, dignity, and love. A diagnosis may change a person's abilities, but it never diminishes their value as a human being or their need for understanding, connection, and care.”

Looking ahead, the organisation hopes to continue strengthening awareness, improving access to support services, and ensuring that people living with dementia and their families are heard in public discussions and policy decisions.

As populations age across Europe and globally, the organisation believes that creating dementia-friendly communities and reducing stigma will become increasingly important. Their message remains simple: no person or family should have to face dementia alone.

14 JUNE:

## Alzheimer Hellas achieves Guinness World Record title for the largest Zeibekiko dance to raise awareness for Alzheimer's disease



Alzheimer Hellas is proud to announce that it has officially achieved a Guinness World Records™ title for the Largest Zeibekiko Dance ever performed. During the landmark event, “Dancing Zeibekiko for an Important Cause,” held on 14 June 2026 at Aristotelous Square in Thessaloniki, Greece, 830 participants from 13 countries came together in a unique choreographed performance, earning the Guinness World Records title for the Largest Zeibekiko Dance. At the same time, the event delivered a strong message of awareness, solidarity, and support for people living with dementia and Alzheimer's disease.

The record attempt was officially assessed on-site by Guinness World Records™ Adjudicator Lena Kuhlmann, who, following all required verification procedures and participant counts, confirmed that the previous world record had been successfully surpassed.

Professor Emerita of Neurology Magda Tsolaki, President of the Panhellenic Federation of Alzheimer's Disease and Related Disorders, highlighted the importance of dance as a form of physical activity in promoting brain health and reducing the risk of dementia. She also emphasised the event's role in showcasing the spirit, culture, and traditions of Greece to an international audience.

Stelios Angeloudis, Mayor of Thessaloniki, underlined the significance of raising awareness about Alzheimer's disease and stated that such an important message could not have found a more fitting setting than the city's iconic Aristotelous Square. This remarkable achievement represents international recognition not only for Alzheimer Hellas and its work, but also for the strength of collective action, and the unique ability of culture to bring people together, across borders, languages, and traditions, for a good cause.

Beyond the world record itself, the initiative aimed to raise public awareness about the importance of prevention, early diagnosis, and support for individuals living with dementia and their

families. Thousands of citizens attended the event, while its message reached audiences across Greece and internationally through extensive media coverage.

“This record belongs to everyone. To every dancer, volunteer, partner, and supporter who believed that a collective dance could become a global message of solidarity, remembrance, and hope for people affected by Alzheimer’s disease. Today, we celebrate more than a world record. We celebrate the power of communities coming together for a common purpose.”

**Record details**

Record Title: Largest Zeibekiko Dance

Official Guinness World Records™ Statement:

The largest zeibekiko dance consists of 830 participants and was achieved by Alzheimer Hellas – Greek Association of Alzheimer’s Disease and Related Disorders (Greece), in Thessaloniki, Greece, on 14 June 2026.

Date of Official Attempt: 14 June 2026

Location: Thessaloniki, Greece

**24 JUNE:**

**Türkiye Alzheimer Association shares updates from a busy May and June**



May and June were exceptionally active and encouraging months for the Türkiye Alzheimer Association, with a wide range of educational, awareness-raising, and community engagement activities taking place across the country.

As part of a collaboration with Koç University School of Nursing, nursing students prepared educational materials on healthy ageing, including an informational brochure and awareness article. On 7–8 May, the Association participated in a volunteer festival at Istanbul Technical University’s Ayazağa Campus, where it hosted workshops and an information stand. The enthusiasm, creativity, and social awareness demonstrated by young people gave the Association great hope for the future.

Throughout May, branches across Türkiye organised events to mark Psychologists’ Day and Nurses’ Week, celebrating the valuable contributions of healthcare professionals. On 13 May, experts from different regions of the country travelled to the Association’s easternmost branch, in Van, to deliver presentations and share expertise. The Association also held a training meeting at Darülaceze, Istanbul’s historic care institution, on 15 May.

Several branches organised local events, including Adana’s Spring Festival featuring music, dancing, and social activities, as well as educational seminars in Denizli and Samsun. The

Marmara Branch hosted a brain health and dementia prevention event in Edirne, while the İzmir Branch organised a public programme titled “Dementia from A to Z”.

Intergenerational engagement remained a strong focus, with young volunteers in Tunceli organising a community tea gathering under the theme “Youth Connects, Solidarity Grows,” and the branch later hosting an event for World Elder Abuse Awareness Day. In June, students from Fenerbahçe University and volunteers from Polisan participated in a painting activity with people living with dementia and helped refresh parts of the Association’s Active Living facility.

Türkiye Alzheimer Association also participated in a national Patient Associations Development Academy workshop, bringing together representatives from academia, industry, health technology assessment bodies, policymakers, and clinical research organisations.

Perhaps the most encouraging news came from Kayseri, where preparations are underway for the opening of the first Alzheimer Day Care Centre operated under the Ministry of Family and Social Services.

Overall, May and June were marked by vibrant activities, growing community engagement, and promising developments for dementia care and awareness throughout Türkiye.

**24 JUNE:**

**Greek psychogeriatric association “Nestor” organises animation workshop in collaboration with ANIMASYROS International Animation Festival**

The special centre for people living with Alzheimer’s disease of the psychogeriatric association “Nestor” in Kozani (Greece) is pleased to announce the completion of an innovative two-day animation workshop within its cognitive training groups, in collaboration with the ANIMASYROS International Animation Festival.



This initiative is a natural continuation of the creative writing programme implemented within the centre’s cognitive training groups by psychologist Agapi Terzopoulou. Through a collaborative, creative process, participants developed an original story, which will be brought to life through the art of animation by creating a storyboard, drawing the characters, building visual compositions and the animated frames, and transforming it into a short film.

Animation is a highly creative and innovative tool for older adults, as it combines entertainment with cognitive and mental stimulation. Through participation in the workshops, beneficiaries have the opportunity to strengthen cognitive functions such as memory, attention, and concentration, improve fine motor skills, and activate their imagination and creativity.

The workshop was hosted at the Kozani Folklore and Natural History Museum of the Association of Letters and Arts of Kozani Prefecture, providing an ideal environment for inspiration and creative expression for all participants. The session was led by Agesilaos Rompolas.

The film created through this project will be presented as part of ANIMASYROS 2026, which will take place in Syros in September.

The initiative was made possible through the generous support of West Group; a leading provider of Security and Facility Services headquartered in the city of Kozani.

26 JUNE:

### Greek Association of Alzheimer’s Disease and Related Disorders of Chalkida (REMIND) implements project mapping knowledge and needs regarding memory problems in central Greece



The project successfully completed a regional initiative exploring the knowledge, attitudes and needs of older adults regarding memory problems and dementia across Central Greece. The initiative was implemented by the Greek Association of Alzheimer’s Disease and Related Disorders of Chalkida (REMIND) and funded by the Region of Central Greece through the Regional Social Inclusion Observatory.

The initiative delivered 38 community actions across 29 urban, rural and remote areas, reaching more than 1,800 older adults and family caregivers. Additionally, 340 memory assessments

were conducted, supporting early identification and access to services.

To assess dementia literacy, participants completed the Dementia Knowledge Assessment Tool (DKAT-2), complemented by caregiver focus groups exploring challenges, misconceptions and educational needs.

The project identified important gaps in awareness, particularly in early recognition of cognitive decline, caregiver support and access to services in geographically remote areas. These findings highlight the need for stronger integration of dementia awareness, early detection and psychosocial support within community-based health and social care systems, and an improved coordination between primary and specialist care to reduce diagnostic delays and caregiver burden.

Beyond the regional context, the project demonstrates the value of structured needs assessments as a policy instrument for informing healthy and active ageing strategies and addressing inequalities in dementia care. Its methodology is transferable to other European regions facing similar demographic and service challenges.

The mapping initiative was designed and implemented by the Greek Association of Alzheimer’s Disease and Related Disorders of Chalkida (REMIND), with funding from the Region of Central Greece. It has since been recognized as a Good Practice within the European FABCOM project, in which the Region of Central Greece participates alongside European partners and REMIND contributes as a regional stakeholder, supporting exchange and dissemination of community-based dementia care approaches across Europe.

#### Mapping initiative

<https://www.youtube.com/watch?v=rxBjftMDt-A>  
<https://www.alzheimer-chalkida.org/chartografisi-anagkon-nimimis-stin-triti-ilikia/>

#### FABCOM project

<https://www.interregeurope.eu/fabcom>  
<https://www.interregeurope.eu/openregioculture/news-and-events/news/co-creation-workshop-on-accessibility-in-chalkida>

#### REMIND

<https://www.alzheimer-chalkida.org/>



## LIVING WITH DEMENTIA

24 JUNE:

### Sertaç Hatice, member of the European Dementia Carers Working Group, celebrates her mother's 80<sup>th</sup> birthday

My mother turned 80 this June. In many ways, she is a pioneer. She is the first woman in her family to live this long. Her mother died at 72 or 73, six months after a hip fracture. At that time, hip replacement surgery was not widely accessible. My mother's grandmother passed away peacefully in her sleep at 71. Yet my mother, despite her many health challenges, reached her 80<sup>th</sup> birthday surrounded by her family.

Her journey has not been easy. She was diagnosed with mixed dementia, including both Alzheimer's disease and vascular dementia, at the age of 72. Brain imaging showed extensive small-vessel disease, the result of vascular risk factors accumulated over many years. She has also lived with hypertension, prediabetes, hearing impairment, osteoporosis-related fractures, and other age-related conditions.

During the past three years, my mother's three closest friends have all passed away. Yet she is still here.

This is an important reminder that a dementia diagnosis is not the end of life. With appropriate medical care, family support, rehabilitation, social engagement, and attention to overall health, many people with dementia can continue living for years. Their lives still matter. Their birthdays still matter.

My mother's story is also a story of progress. She was better educated than the women who came before her. She benefited from advances in medicine, surgery, diagnostics, rehabilitation, and public health that were unavailable to previous generations. Because of that progress, more people today will live into their eighties and beyond.

For generations, the challenge was surviving long enough to reach old age. Today, many of us will do just that. We are succeeding in helping people live longer, but we have not yet fully adapted our thinking to what those extra years require.

Blood pressure, diabetes, hearing loss, physical activity, social engagement, sleep, and cardiovascular health all influence how we age. We should not wait until old age to start taking care of our brains. The choices we make in midlife may shape our cognitive health decades later.

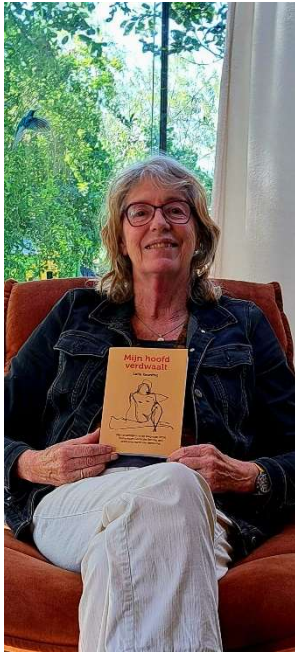
As we celebrated my mother's 80<sup>th</sup> birthday, I found myself reflecting on a simple truth: thanks to education, science, and social progress, many of us will live longer than our parents and grandparents. Our challenge now is to ensure that we spend those extra years as healthily, actively, and meaningfully as possible.



## NEW RESOURCES AND PUBLICATIONS

2 JUNE:

**Dutch book “Mijn hoofd verdwaalt” - written by Laila Keuning about her experience of living with a rare form of dementia - now available in English under the title “My Mind Wanders”**



Laila Keuning, the author of “My Mind Wanders” (“Mijn hoofd verdwaalt” in the original Dutch), lives in the Netherlands and has a diagnosis of Posterior Cortical Atrophy (PCA), a rare form of dementia. After receiving her diagnosis, she felt that there was very little information available from the perspective of someone actually living with this condition and so she decided to write a book about her journey, her thoughts, her challenges, and the way she experiences the world around her.

“Sometimes there is a moment in life when everything shifts. For me, that moment was when I received the diagnosis of

Posterior Cortical Atrophy (PCA). A rare, bewildering brain disease that stealthily works its way into your thinking, your seeing, and your doing. From that moment on, nothing felt certain anymore, nothing was the same. Instead of losing myself in fear, I began to write. At first just brief notes and fragments, which later grew into this book. Not because I see myself as a writer, but because I wanted to capture something—for myself, for my loved ones, and for others who live with uncertainty or confusion. This book is my voice, my search, and my way of finding some grasp on an illness that remains invisible to me and even to much of the medical world. The “pecas”—the invisible little creatures that live in my head—are a metaphor. Invented by me, but brought to life and made visible through the drawings of my granddaughter, which you will see throughout this book. They form a red thread, making visible what is so often unseen: the damage, the frustration, but also the humor and the hope.”

Laila Keuning believes that sharing personal stories and experiences can help others feel less isolated and can provide insight into the daily realities of this rare condition. As someone living with PCA, raising awareness of PCA is very important to her, and she is on a mission to share her story as

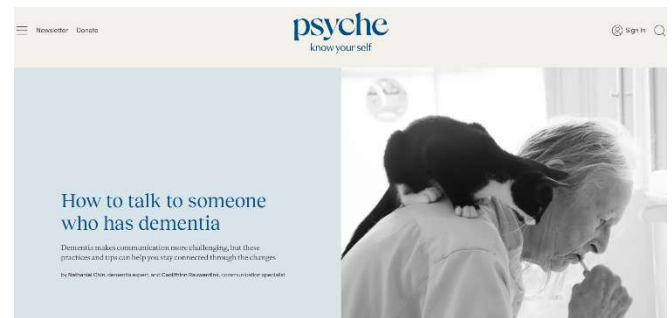
widely as possible in the dementia community and beyond. Her story has recently been shared within the ALZConnected community of the Alzheimer’s Association in the US and she is delighted to also share her story with Alzheimer Europe’s network, in the hope that this book can help increase awareness and understanding of PCA among patients, families, caregivers, healthcare professionals, and the wider public.

Amazon link to “My Mind Wanders”:

<https://www.amazon.com/dp/B0FRMWZZTQ>

11 JUNE:

**“How to talk to someone who has dementia” is a new online guide from Psyche magazine**



A new online guide titled “How to talk to someone who has dementia”, is available via digital magazine Psyche. The guide is written by dementia expert Nathaniel Chin and communications specialist Caoilfhinn Rauwerdink. It offers practical, compassionate advice on communicating with someone who has dementia, with a focus on maintaining connection through the changes.

View the guide, here: <https://psyche.co/guides/how-to-talk-to-someone-who-has-dementia>

Psyche magazine is dedicated to helping readers to understand themselves better and to live better.

## AE CALENDAR 2026

DATE		
6 JULY	Welcome meeting with European Working Group of People With Dementia	PI team
9 JULY	Welcome meeting with European Dementia Carers Working Group	PI team
9-10 JULY	AD-RIDDLE General Assembly Meeting (Barcelona, Spain)	Cindy, Ana, Sarah and

## CONFERENCES 2026-2027

DATE	MEETING	PLACE
1-3 JULY	IPA 2026 International Congress, "Across borders, beyond boundaries: Connecting research, education and practice for better mental health in older people" <a href="https://bit.ly/4pbWkuA">https://bit.ly/4pbWkuA</a>	Leiden, Netherlands
27-29 October	36 <sup>th</sup> Alzheimer Europe Conference (#36AEC), "Sláinte: Building momentum in dementia through policy, research and partnership"	Dublin, Ireland
16-20 March 2027	AD/PD 2027 <a href="https://adpd.kenes.com/">https://adpd.kenes.com/</a>	Barcelona, Spain

# 36<sup>th</sup> Alzheimer Europe Conference

Sláinte: Building momentum in dementia through policy, research and partnership

**27 - 29 OCTOBER 2026**  
DUBLIN, IRELAND



Join healthcare professionals, researchers, policy makers and advocates to explore advances in dementia care, research and policy.  
Connect, contribute and drive progress! **#36AEC**



[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)