DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE

Alzheimer Europe

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Jean Georges

reflects on 30 years leading Alzheimer Europe, as he prepares to step down at the end of the year



Nina Carberry MEP
European Alzheimer's Alliance Co-Chair hosts Alzheimer Europe exhibition and reception in the European Parliament



Katarzyna Kęcka
Deputy Minister for Health shares insights into Poland's National Dementia Programme for 2025-2030



Kieran O'Donnell
Irish Minister for Older People and Housing talks about the latest developments in dementia policy in Ireland

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Welcome



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

I am delighted to introduce issue 52 of the Dementia in Europe magazine, which is being launched in Dublin, at the 36th Alzheimer Europe Conference. This edition of the magazine and this conference mark the final ones during the tenure of our Executive Director, Jean Georges, who will take retirement at the end of this year. After 30 years leading our organisation, he will leave behind an impressive legacy. Together with my colleagues on the Board of Directors, as well as everyone at Alzheimer Europe and across our membership, we wish Jean a wonderful retirement, but we will all miss him very much.

With Jean's retirement in sight, our first article in this edition is an interview with him looking back at some highlights and milestones, together with many photos from throughout the years.

Up next in the Alzheimer Europe section, we have an article about our recent position paper calling for equitable and timely access to lecanemab and donanemab, the first disease-modifying therapies for Alzheimer's disease authorised in the EU. After this, we share the outcomes of our Annual General Meeting, including announcing our Board of Directors for 2026-2028. I am honoured to have been re-elected as Chairperson and to continue working with our Vice-Chairperson Mario Possenti and Honorary Secretary Lorène Gilly. We say goodbye and a huge thank you to outgoing Honorary Treasurer Marco Blom, who has done a fantastic job in his years with us. A warm welcome to his successor Andy Heffernan who I am sure will do a great job in his new role! Our final article in this section focuses on the July edition of our "Alzheimer's Association Academy".

Our Policy Watch section opens with a feature on our European Parliament exhibition and reception, which took place at the beginning of World Alzheimer's Month. The exhibition was held under the title "Alzheimer Europe: Shaping Europe's response to dementia" and we are incredibly grateful to Nina Carberry MEP (EPP, Ireland) for hosting this event. We were delighted with the number of MEPs who showed their support at the reception and at the level of interest garnered during the exhibition. I would like to congratulate the Alzheimer Europe team for all the hard work that went into making this such a success.

Our next article in the policy section delves into the newly-launched dementia strategy in Poland, with insights from Katarzyna Kęcka, Deputy Minister for Health, and from Edyta Ekwińska, President of Alzheimer Poland. Our focus then shifts to the broader European and international context, with articles from the European Commission, exploring new EU legislation on the protection of adults in cross-border situations, and from the World Health Organization, which has published guidelines to reduce dementia risk across the life course.

The Research and Public Involvement section of our magazine begins with an article describing our involvement in this year's Alzheimer's Association International Conference. We then introduce the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) as they begin their new mandates. Congratulations to Kevin Quaid, Chairperson of the EWGPWD, Gerda Van Tongerloo, Vice-Chairperson of the EWGPWD, Trevor Salomon, Chairperson of the EDCWG, and Roslynn Vella, Vice-Chairperson of the EDCWG, who have all retained their positions. Welcome to new members and a big thank you departing members for all your contributions to our work.

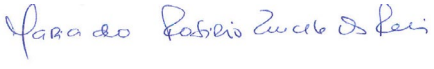
Next, we cover three EU-funded projects in which we are a partner: eBRAINHealth and EPND, which have both come to completion; and DORIAN GRAY, which began last year. Closing out the section, we have a piece about the INTERDEM Academy.

Our Dementia in Society section begins with an interview with Marco Blom, who is not only leaving his position on our Board but has also taken retirement after 29 years as Scientific Director at Alzheimer Nederland. Julie Meerveld also contributed to this article, following her departure after 21 years. We then hear from Wiesje van der Flier, the new CEO of Alzheimer Nederland. A lot of change for our Dutch colleagues – I wish them all the best.

We then explore a variety of work at the national level, starting with Belgium, where a roundtable discussion on dementia took place under the chairmanship of His Majesty the King of the Belgians at the Royal Palace, involving several organisations including La Ligue Alzheimer (Belgium), Alzheimer Liga Vlaanderen (Flanders) and Alzheimer Europe. This meeting preceded the opening of the exhibition "The Royal Palace as a Memory Palace". Other articles in this section focus on initiatives, projects and events taking place in Bulgaria, Estonia and Italy. Congratulations to all our members for their hard work in raising the profile of dementia, contributing to research and supporting people living with the condition and their families! Finally, we present a recently-published book on human rights in dementia care.

Our final section shines a spotlight on Ireland, where we are hosting the 36th Alzheimer Europe Conference (36AEC) in Dublin between 27 and 29 October. We are very grateful to our co-hosts The Alzheimer Society of Ireland, for coordinating and contributing articles, including one from the Irish Minister for Older People and Housing, Kieran O'Donnell.

If you are reading this at our conference – welcome to Dublin and enjoy 36AEC!



Executive Director Jean Georges steps down after 30 years at Alzheimer Europe

After 30 years leading Alzheimer Europe, Jean Georges is stepping down and taking retirement at the start of 2027. In this interview, he reflects on three decades of work, achievements and milestones, changes and challenges, and shares the importance of collaboration and partnership with organisations and individuals across Europe. He discusses what it has meant to him to be the first Executive Director of Alzheimer Europe, what he is most proud of and his hopes for the future.



Jean Georges

On 1 November 1996, you joined Alzheimer Europe as its first Executive Director. After 30 years in this role, why have you decided to step down?

My decision to step down in 2026 is driven by both very personal and professional reasons.

On a personal level, my husband and I are now in our early 60s, and we feel incredibly fortunate to be in a position where we can slow down professionally, retire and enjoy this next chapter of our lives. We are looking forward to travelling, having more time for each other, as well as spending more time with our families.

Our decision has also been shaped by our own family experiences. We both lost our fathers when they were in their 60s – my father to heart problems, and my father-in-law, who was diagnosed with early Alzheimer's disease in his early 60s. These experiences have made us very conscious of how precious and unpredictable time can be. They have encouraged us to make the most of the time we have together and to retire while we are still in a position to enjoy it fully.

Professionally, after 30 years at the helm of Alzheimer Europe, I also feel that the time is right to hand over the reins to a younger colleague. Leading this organisation for three decades has been an enormous privilege, and I am very proud of what we have achieved together.

Knowing that Angela Bradshaw will be my successor, supported by Dianne Gove, Ana Diaz, Cindy Birck and the whole fantastic Alzheimer Europe team, has made this decision much easier. I have enormous confidence in the people who will take the organisation forward, and I know that Alzheimer Europe will be in incredibly safe hands. That has given me the reassurance and peace of mind to feel that now is the right time to step aside and begin this new chapter of my own life.

Alzheimer Europe's role has evolved and now looks very different to its beginnings. What was it like in the early days?

When I joined Alzheimer Europe in 1996, the organisation was already six years old, but it was still a relatively small and very informal network. At that time, the main activity was to bring together representatives of national Alzheimer's associations once a year so that they could share their experiences, exchange ideas and learn from one another. Much of this work was coordinated by volunteers from the Alzheimer Europe Board.

I joined at an exciting moment because the European Commission was beginning to support projects relating to Alzheimer's disease, and Alzheimer Europe was fortunate enough to receive funding for four important initial projects. These included developing



Alzheimer Europe team, June 2026, Senningerberg (Luxembourg)



Alzheimer Europe team in the year 2000



Angela Bradshaw (left), Jean Georges (right) and the Alzheimer Europe Board, June 2026, Senningerberg (Luxembourg)



Members voting at the Alzheimer Europe AGM, October 2011, Warsaw (Poland)

Alzheimer Europe as a European network of national Alzheimer's associations, organising a European conference on Alzheimer's disease in Warsaw, producing a practical manual for family carers of people with dementia, and developing recommendations and tools for associations wishing to establish telephone helplines, including training for their staff and volunteers.

As the organisation's first employed and paid Director, one of my first tasks was to build a team to deliver these projects. One of the first people I recruited was Dianne Gove, who, incredibly, is still with Alzheimer Europe today and is now our Director for Public Involvement and Ethics. Looking back, I feel very fortunate that some of the people who joined me at that early stage have remained such an important part of the organisation's journey.

In those early years, our small team was very much focused on supporting national Alzheimer's associations. We wanted to create opportunities for them to learn from each other, share good practices and realise that, although each association faced its own challenges, they were not alone.

At the same time, we quickly discovered that there was a real appetite for Alzheimer Europe to bring people together on a much larger scale. Our Annual Conferences became an important part of this work, and I still remember with pride how quickly they grew. The conferences in Helsinki in 1997 and Lucerne in 1998 already attracted close to 1,000 delegates. For such a young and relatively small organisation, this was quite remarkable – and it gave us a sense that Alzheimer Europe could become something much bigger and more influential than we had initially imagined.

The membership and activities of Alzheimer Europe have grown significantly during your time in charge. What have been some of the major milestones in your view and what are some of the most important projects, initiatives and other areas of work in which Alzheimer Europe has been involved over the past 30 years?

When Alzheimer Europe was founded in 1990, it brought together representatives from national associations in Belgium, Finland, Ireland, the Netherlands, Poland and Spain. By the time I joined in 1996, the Alzheimer Europe family had already grown considerably, with associations from Austria, Denmark, France, Germany, Italy, Luxembourg, Portugal, Romania, Sweden, Switzerland and the UK having joined.

Since then, it has been incredible to see how far we have come. What started with 17 organisations when I joined Alzheimer Europe in 1996 has grown into a family of 44 national member organisations from 39 European countries. I have always felt that this sense of being part of a wider European Alzheimer's family is one of Alzheimer Europe's greatest strengths. We have different languages, cultures and healthcare systems, but we share the same commitment to improving the lives of people with dementia and their families.

As I mentioned earlier, Alzheimer Europe's initial focus was very much on supporting national Alzheimer's associations in their efforts to raise awareness of Alzheimer's disease and other forms of dementia, and on providing information and support to family carers. This remains an important part of our work today.

But over the years, we realised that we could – and needed to – do much more.



Inaugural meeting of Alzheimer Europe in 1991



Eurocode project meeting in 2008



Public Affairs meeting with members in 2011



Jean Georges (right) speaking with Wiesje van der Flier (left) at Alzheimer Europe's exhibition in the European Parliament, 1 September 2026, Brussels (Belgium)



First Alzheimer Europe meeting at the European Parliament in 1999

Alzheimer Europe gradually broadened its role, particularly in the areas of political advocacy and lobbying. By the time we developed our first business plan in 2002, making dementia a political and research priority at both European and national level had become one of our key objectives.

We also began to focus more strongly on legal and ethical questions, developing positions on issues such as legal capacity, advance directives and genetic testing. This was an important development for the organisation, as we increasingly recognised the need not only to support people with dementia and their families, but also to influence the policies and decisions that directly affect their lives.

One of the milestones I remember with particular pride was the adoption of the Paris Declaration in 2006. In it, we called on policymakers to develop national dementia strategies and to strengthen cooperation on dementia at European level. This gave a real focus and momentum to our campaigning work.

And we soon saw some very tangible results. In 2007, we succeeded in establishing the European Alzheimer's Alliance, which attracted more than 80 Members of the European Parliament who wanted to support our cause. The following year, during the French Presidency of the EU, a major conference was dedicated to "The fight against Alzheimer's disease". These were important moments in putting dementia firmly on the European political agenda.

Our campaigning ultimately contributed to the European Commission's first Communication on Alzheimer's disease and to the launch of the Joint Programme for Neurodegenerative Disease Research (JPND). At the same time, a number of European countries began developing their own national dementia strategies.

Looking back, I think we can be genuinely proud of what we achieved. None of this would have been possible without the commitment and determination of our national member organisations. Their support, their advocacy and their willingness to work together were absolutely crucial. So, for me, these early successes are not just milestones in Alzheimer Europe's history – they are a wonderful example of what can be achieved when our Alzheimer's family comes together with a common purpose.

Looking forward, this is a truly exciting period for the European dementia community, as we have seen some amazing advances in how we diagnose, treat and prevent Alzheimer's disease and other types of dementia. Again, this is testimony to the concerted efforts and dedication of the researchers involved in the Alzheimer's field and gives me hope for true innovation and progress in the years to come.

The organisation has achieved so much and has grown exponentially in terms of reach and reputation. This must give you a real sense of pride, not just for yourself, but for everyone involved in this success. Which achievements make you proudest?

Looking back over 30 years, it is not easy to choose just one development that stands out above all others. Alzheimer Europe has achieved so much, and there are many milestones of which we can be proud. However, when I think about my favourite achievement, there is one that immediately comes to mind: the journey towards the full and meaningful involvement of people with dementia in everything we do.

When I joined Alzheimer Europe in 1996, Alzheimer's associations were largely run by and for family carers of people with dementia. Our discussions focused on how best to support families, develop services and improve the lives of those caring for a loved one with dementia. However, the



Jean Georges (centre) at the 2008 French Presidency Conference with Joel Menard and Antoni Montserrat



Alzheimer Europe joining ALCOVE - the European Joint Action on Dementia, 2011



Jean Georges speaking about the Paris Declaration at a European Parliament lunch debate, 9 December 2008 , Brussels (Belgium)



European Alzheimer's Alliance MEPs and Alzheimer Europe (AE) team members at the AE exhibition in the European Parliament in 2007



Founding members of the EWGPWD in 2012

voices of people living with dementia themselves were largely absent from these conversations.

This was also the case when we discussed legal and ethical issues. We were debating how best to promote the autonomy, rights and self-determination of people with dementia, but these discussions were taking place without the direct involvement of the very people whose lives were most affected. Recommendations were developed together with lawyers, ethicists, philosophers and representatives of national Alzheimer's associations, but not with people living with dementia themselves.

A real turning point came at our Annual Conference in Maastricht in 2002, when Peter Ashley became the first person with dementia to address our delegates and share his personal experience of receiving a diagnosis and the impact it had on both himself and his family. His powerful message that he was "living with dementia, not dying from dementia" challenged many assumptions and left a lasting impression on everyone who heard him.

Ten years later, in 2012, Alzheimer Europe took another major step forward by officially establishing its European Working Group of People with Dementia (EWGPWD). The aim was clear: to ensure that people with dementia would be actively involved in all aspects of our work, including meetings, projects and initiatives. The Chair of the EWGPWD also became an ex-officio member of the Alzheimer Europe Board, ensuring that the perspectives of people with dementia are represented at the highest level of the organisation.

The transformation since then has been truly remarkable. Today, it would be unthinkable for Alzheimer Europe to organise activities without the full, active and meaningful involvement of people living with dementia. Between 30 and 50 people with dementia now attend our Annual Conference each year, where they play an active role by organising plenary sessions, presenting at parallel sessions, moderating discussions, sharing posters and even contributing to the evaluation of conference abstracts.

Their contribution has also been fundamental to the development of our public involvement work in dementia research. People with dementia are now involved in European research projects, advising researchers on methodologies and study protocols, contributing to discussions on ethical questions and reviewing informed consent documents. It is incredibly rewarding to hear leading researchers and experts recognise the value of these contributions and acknowledge the important role played by Alzheimer Europe and our dedicated Public Involvement Team in making this possible.

Perhaps the greatest achievement is that this involvement is no longer seen as exceptional – it has become an essential part of how we work. The expertise, experience and perspectives of people living with dementia have changed Alzheimer Europe for the better and have also helped change the wider dementia landscape.

Building on this success, Alzheimer Europe has continued to recognise the importance of



Jean Georges (2nd from right) with members of the EDCWG and EWGPWD at the first plenary session of the 34th Alzheimer Europe Conference, 8 October 2024, Geneva (Switzerland)

listening to all those affected by dementia. In 2020, we established the European Dementia Carers Working Group (EDCWG) to ensure that the voices of family carers are also heard and included alongside those of people living with dementia.

For me, this journey represents the very best of Alzheimer Europe: recognising the importance of lived experience, challenging assumptions and ensuring that the people most affected by dementia are not just included in our discussions, but are helping to shape the future.

There must also have been some difficulties along the way. What have been some of the main challenges for the organisation these past 30 years and how have these been overcome?

When looking back at the many achievements of Alzheimer Europe over the past 30 years, it might sound as though the journey has always been straightforward. However, like any organisation, we have faced our share of challenges along the way. One issue that has been a constant concern throughout the years has been securing the financial resources needed to support our ambitious goals, objectives and work programmes.

During my first five years with Alzheimer Europe, we were fortunate to receive support from the European Commission for specific projects on Alzheimer's disease. This funding was essential in helping us build the organisation and develop our activities. However, when this dedicated budget line was discontinued, we faced a very uncertain period. In 2004 and 2005, and again in 2009, Alzheimer Europe had to continue its work without any EU funding.

Fortunately, we had already started to diversify our income sources and had developed activities and programmes that could be supported by corporate partners and other funders. This early decision to broaden our funding base proved to be extremely important for the sustainability of the organisation.



Jean Georges giving his final speech in the European Parliament, as Executive Director of Alzheimer Europe, 1 September 2026 , Brussels (Belgium)



Alzheimer Europe Board meeting, July 2014, Luxembourg

A major milestone came in 2010 with the introduction of operating grants through the EU Health Programme, which provided Alzheimer Europe with a more stable foundation for over a decade, until 2021. From 2022 onwards, we have been able to benefit from operating grants under the Citizens, Equality, Rights and Values (CERV) programme, recognising our role as a European organisation representing the interests of people with disabilities.

At the same time, we continued to strengthen other areas of our work. We expanded our portfolio of EU research projects, increased income generated through our Annual Conference and our corporate partnerships, and developed stronger relationships with foundations and other supporters.

Looking back, I am very proud that what initially appeared to be a major vulnerability became another strength of Alzheimer Europe. We have built a more resilient organisation with a diverse range of funding sources, allowing us to continue our work with greater security and independence.

One of the things that gives me the greatest confidence as I prepare to hand over the leadership of Alzheimer Europe is knowing that I am leaving the organisation in a strong financial position. This provides Angela and the whole team with a solid foundation from which to continue developing Alzheimer Europe and achieving even more for people with dementia and their families in the years to come.

Could you share some of your hopes for the future of the organisation and a few words of wisdom for your successor, as she steps into the role in 2027?

Collaboration and partnership are words that are often used, but at Alzheimer Europe they truly reflect the way we work and the values that have guided us over the years.

As Angela takes over the leadership of the organisation, she will have the great advantage of being surrounded by an incredible network of people and organisations who are deeply committed to Alzheimer Europe's mission. The support and commitment of our Board has always been a tremendous source of strength. Board members fully understand their role in providing good governance and strategic direction, while trusting the Director and



Alzheimer Europe Foundation Board meeting, 7 August 2025, Senningerberg (Luxembourg)



INTERDEM partnership agreement is signed, 2 October 2017, Berlin (Germany)

staff with the day-to-day management of the organisation. This balance has been essential to Alzheimer Europe's success.

I have also been incredibly fortunate to work alongside such a dedicated and professional staff team. Each member of the team brings their own expertise and commitment, working effectively within their respective areas while also showing the ability to take initiative and work independently when needed. Their passion for Alzheimer Europe and the people we represent has been a constant source of inspiration.

Over the years, I have had the opportunity to work with a number of European umbrella organisations, and I can honestly say that the commitment and engagement of Alzheimer Europe's member organisations are truly exceptional. They do much more than simply belong to a network. They actively participate in meetings, contribute to consultations, share their experiences and ensure that our newsletters, publications and advocacy work are connected to the realities of people living with dementia and their families at national level.

Another unique strength of Alzheimer Europe is the involvement of our two working groups – the European Working Group of People with Dementia and the European Dementia Carers Working Group. They constantly remind us of the reason behind everything we do. Their experiences, perspectives and contributions keep us focused on the people who are at the heart of our work, whether we are advocating for better policies or contributing to European research projects.

I am confident that Angela will be able to build further on these strong foundations. She will have the opportunity to strengthen existing relationships, develop new collaborations and make the most of the remarkable network of partnerships that Alzheimer Europe has built over the past 30 years. This collective strength is one of our greatest assets and will continue to drive the organisation forward in the years ahead.

How does the future look for you and what are you looking forward to? What will you miss?

I have to admit that it feels rather strange to think about life after Alzheimer Europe. For 30 years, this organisation has been such an important part of my life, and it is difficult to imagine not being involved in its day-to-day activities. But when I look back, one thing is certain: these years have never been boring. Alzheimer Europe has constantly evolved, with its objectives, activities and challenges growing and changing over time.

What has made this journey so special has been the people I have had the privilege of working with. I have loved working alongside my colleagues on the Board and the amazing Alzheimer Europe staff team. Their dedication, commitment and friendship have made these 30 years incredibly rewarding.

I have also been deeply touched by the welcome and support I have received from the members of our two working groups, the representatives of our national member organisations and the wider dementia community. They have always opened their doors to me, invited me into their activities and meetings, and shared their experiences and perspectives. Their contributions have enriched not only Alzheimer Europe's work, but also my own life. I will certainly miss the regular meetings, the many inspiring conversations, the debates and discussions, and the excitement of following new developments in dementia policy and research.

At the same time, I am looking forward to following Alzheimer Europe's journey from a little further away. This is such an exciting time for the dementia field, with important progress and innovation taking place in diagnosis, treatment, prevention and care. I have every confidence that Alzheimer Europe will continue to play a vital role in



EWGPWD with supporters and Alzheimer Europe staff, in September 2017 , Münsbach (Luxembourg)



Alzheimer Europe Board in 2002



Alzheimer Europe meets Luxembourg Health Minister together with a delegation from the European Patients' Forum, in 2004



LtR: Heike von Lützau-Hohlbein, Birgitte Vølund, Jean Georges, Sabine Jansen, Iva Holmerová at the Alzheimer Europe AGM, 31 October 2016, Copenhagen (Denmark)

ensuring that these advances translate into real improvements for people affected by dementia and their families.

As for me, I am looking forward to a different pace of life – one with fewer deadlines, work plans and budgets demanding my attention. Travel will certainly still be part of my future, although hopefully with fewer hours spent sitting in conference centres! I may even take up some of the kind invitations I have received over the years from representatives of our national associations to visit their countries and let them show me around. So, don't be too surprised if I appear in your country one day, ready to discover the sights and perhaps expecting a very personal guided tour!

To all of you, I wish continued success in the incredible work that you do. Every day, you are making a real difference to the lives of people affected by dementia, and you should be immensely proud of everything you have achieved.

For me, it has been an honour and a privilege to be part of this extraordinary adventure over the past 30 years. I will always be grateful for the experiences, the friendships and the memories that this journey has given me.

A few words from Angela Bradshaw



Angela Bradshaw

Taking on the role of Executive Director at Alzheimer Europe is a huge honour. Over the past three decades, Jean's leadership has helped unite the wider dementia community in Europe, building an organisation that lives and breathes its motto of changing policy, perceptions and practice, to improve the lives of people affected by dementia. I am immensely grateful to Jean for everything I have learned from working alongside him, and for leaving Alzheimer Europe in such a strong position.

I joined Alzheimer Europe in 2019, after completing a PhD at the University of Cambridge and later working for many years at the University of Glasgow. I joke that I am a "recovering academic", but in many ways I feel like I have found a professional home at Alzheimer Europe: one that has given me opportunities to work across research, policy and stakeholder engagement, most recently as Director for Research. Luxembourg is also my home in the personal sense. I was born and raised here, attending the European School and growing up in an environment where different languages, cultures and perspectives were just a part of everyday life. It taught me early on that bringing different experiences and perspectives together can make us stronger.

This is something I recognise in Alzheimer Europe. As a European umbrella organisation, we bring together national associations with different histories, priorities and realities, but with a shared commitment to improving the lives of people affected by dementia. The strength of Alzheimer Europe lies in the diversity of the European dementia movement: in our ability to learn from each other, find common ground and speak with a strong collective voice at European level. Over the last 7 years, it has been a privilege to work with representatives of our 44 member associations, hand in hand with our Board, and with the European Working Group of People with Dementia and European Dementia Carers Working Group. Their expertise and commitment are a constant reminder that people affected by dementia must remain at the heart of everything we do.

As I prepare to follow in Jean's very sizeable footsteps, I am enormously reassured to know that I will be doing so with the support, expertise and experience of our fantastic team, Board and membership. It is an extraordinary time to take the helm: new possibilities are emerging for the prevention, diagnosis, treatment and care of dementia, and growing momentum for a European neurological health strategy offers a real opportunity to put dementia higher on the European political agenda. At the same time, the challenges facing people with dementia, their families and carers remain immense and urgent. I am excited, humbled - slightly nervous - but immensely proud to lead Alzheimer Europe into this next chapter, building on Jean's remarkable legacy and working together to ensure that our collective voice continues to change policy, perceptions and practice across Europe.

A few snapshots from the past 30 years
























ALZHEIMER EUROPE





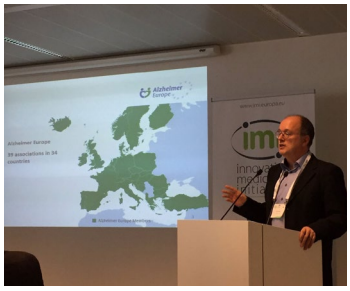




















Alzheimer Europe calls for equitable access to new Alzheimer's disease treatments across Europe

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.

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 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:

1. 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.
2. 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.
3. 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.
4. 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.
5. 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.

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.

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://bit.ly/AE_AntiAmyloidTreatmentAccess

Alzheimer Europe welcomes new Board of Directors and three new members at its Annual General Meeting

Alzheimer Europe's Annual General Meeting took place on 30 June 2026 in Luxembourg, welcoming three new member associations, electing a new Board of Directors, and approving the organisation's 2025 Annual and Financial Report.



Annual General Meeting, 30 June 2026, Senningerberg (Luxembourg)

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.

Annual and Financial Report 2025

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

New member associations

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.



Kevin Quaid



Jean Georges and Marco Blom



Trevor Salomon

Address from the European Working Group of People with Dementia and the European Dementia Carers Working Group

The new terms of office of the European Working Group of People with Dementia (EWGPWD) and of the European Dementia Carers Working Group (EDCWG) began following the 2026 AGM, and you can find out who the members, chairpersons and vice-chairpersons of both groups are in our article on pages 32-35.

The Chairs of both groups at the time of the AGM, Kevin Quaid (Ireland) for the EWGPWD and Trevor Salomon (United Kingdom, England) for the EDCWG, each gave a speech at the AGM, sharing the excellent work of these 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.

New Board of Directors for 2026-2028

Also on the agenda 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! You will find an interview with Marco on pages 45-47.

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 consists of the following office bearers and members:

Office bearers

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

Members

5. Thanos Chatzikostopoulos (Greece) - new member
6. Edyta Ekwińska (Poland) - new member
7. Wiesje van der Flier (Netherlands) - new member
8. Friederike de Maeyer (Austria) - new member
9. Martina Mátlová (Czech Republic)
10. Mary-Frances Morris (Scotland, United Kingdom)
11. Katariina Suomu (Finland)
12. René Thyrian (Germany)

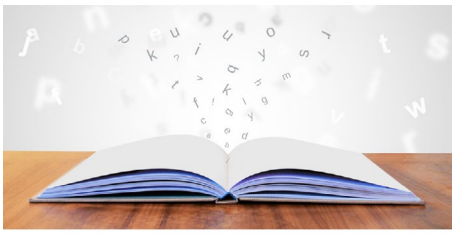
Congratulations to all of them! A big thank you, also to outgoing board members Stefanie Becker (Switzerland), and René Friederici (Luxembourg) for their vital contributions. They will be missed by everyone.



The new Alzheimer Europe Board

Alzheimer's Association Academy focuses on dementia as a disability

On 7 July 2026, Alzheimer Europe held a session of its online workshop series, the Alzheimer's Association Academy, entitled "Dementia as a disability". The Academy is a series of online capacity-building workshops bringing together representatives of national Alzheimer's associations with members of the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG), as well as representatives from pharmaceutical companies, to learn about dementia advocacy, care, policy, research and treatment.



On 7 July 2026, Alzheimer Europe held a session of its online workshop series the Alzheimer's Association Academy, entitled "Dementia as a disability".

Our Academies are a popular series of online capacity-building workshops bringing together representatives of national Alzheimer's associations with members of the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG), as well as representatives from pharmaceutical companies, to learn about dementia advocacy, care, policy, research and treatment.

Dianne Gove, Director for Public Involvement and Ethics at Alzheimer Europe chaired the session, welcoming close to 50 participants from 13 countries and three companies (Bristol Myers Squibb, Lilly and Roche), as well as several members of staff from Alzheimer Europe.

Speakers at the Academy of 7 July included:

- Kevin Quaid, Chairperson of the EWGPWD, who delivered a personal account of his experiences of having dementia as a disability and shared a very moving poem which he wrote about the impact that Lewy Body Dementia has had on his life.
- Dr Paula Jacobs Research Fellow in Social Work at the University of Stirling and the University of Edinburgh (Scotland, UK), who was unable to attend the session live, but shared a video presentation focusing on the work she has done together with Professor Karen Watchman and Professor Heather Wilkinson, on the topic of people with intellectual disabilities and dementia.
- Haydn Hammersley, Social Policy Coordinator at the European Disability Forum (EDF), who discussed EDF's reaction to the report "Enhancing the Strategy for the rights of persons with disabilities up to 2030" which was published by the European Commission in May of this year. The EDF notes that the report's focus on new legislation is too weak and makes no real commitment, but that the revision of existing legislation is promising despite too much focus on non-binding measures.
- Owen Miller, Policy Officer at Alzheimer Europe, who shared our perspective on proxy decision making and institutionalisation in the context of disability policy and dementia. He highlighted the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) perspective, noting some of the strengths of, and caveats to, the UNCRPD. He also shared Alzheimer Europe's position on de-institutionalisation and on substitute/supported decision-making.

Following each of these engaging and insightful presentations, there was an opportunity for the audience to ask questions.

We hope that our Academy delegates enjoyed this online event and we would like to say a huge thank you to all our speakers and to our Gold and Silver sponsors, Bristol Myers Squibb, Eisai, Eli Lilly and Company, Johnson & Johnson, and Roche as well as to the European Union's Citizen's, Equalities, Rights and Values (CERV) programme, without whom our Academy sessions would not be possible.

Acknowledgement

A huge thank you to our Gold and Silver sponsors, Bristol Myers Squibb, Eisai, Johnson & Johnson, Lilly and Roche as well as to the European Union's Citizen's, Equalities, Rights and Values (CERV) programme, without whom our Academy sessions would not be possible.

Co-funded by the European Union

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.

Alzheimer Europe hosts exhibition and reception in the European Parliament

Between 31 August and 4 September, Alzheimer Europe held an exhibition and reception in the European Parliament under the title "Alzheimer Europe: Shaping Europe's response to dementia", aiming to raise awareness and support to prioritise dementia as a policy issue at an EU level, with the support of MEP Nina Carberry (EPP, Ireland).

Between 31 August and 4 September, Alzheimer Europe held an exhibition and reception in the European Parliament under the title "Alzheimer Europe: Shaping Europe's response to dementia". We are incredibly grateful to Nina Carberry MEP (EPP, Ireland) and her staff for their support, without which the exhibition would not have been possible.

Key objectives of the exhibition

During the exhibition, Alzheimer Europe presented posters on the current state of dementia across Europe, highlighting issues including the prevalence of the condition, emerging treatments and developments in policy. In addition, panels featured information on Alzheimer Europe, the European Working Group of People with Dementia (EWGPWD), the European Dementia Carers Working Group (EDCWG), as well as an overview of the Anti-Stigma Award. The key objectives for the event were to:

- Raise awareness of dementia prevalence.
- Showcase developments over the past decade, as well as ongoing actions and developments in the dementia field, including at the European and national level.
- Highlight continuing gaps, challenges and inequalities.
- Present clear recommendations for EU policymakers.
- Encourage political commitment and action.

The target audience was primarily MEPs, European Parliament staff and visitors, with whom we shared information and knowledge, whilst exploring opportunities for collaboration to prioritise dementia at an EU level.

In addition to the posters on display during the exhibition, a screen displayed interactive maps and displays of the prevalence of dementia in Europe, as well as videos of the EWGPWD and EDCWG explaining why dementia should be prioritised as a policy matter. Alzheimer Europe distributed copies of "The Prevalence of Dementia in Europe 2025" report, brochures of the posters and edition 51 of the Dementia in Europe Magazine.

Additionally, Alzheimer Europe created "commitment cards" for MEPs to sign, which indicated their support for prioritising dementia at an EU level, as well as capturing specific policy actions.

Key messages from the exhibition

Throughout the exhibition, the intention was to convey a set of core messages, central to Alzheimer Europe's public policy work. The intention was to build on the work of Alzheimer Europe's #DementiaNeedsEU campaign, which was launched during the European Parliament Elections in 2024. In doing so, Alzheimer Europe's messages and calls to action remained consistent, whilst incorporating the latest context and information e.g. updated prevalence figures, developments in anti-amyloid treatments. Taken together, the key messages of the event were:

- Dementia is one of Europe's most significant health and societal challenges, with the number of people affected expected to rise significantly in the coming decades.



Nina Carberry



Kevin Quaid



Trevor Solomon



Jordan Adams



Jean Georges

- Policy decisions have a direct impact on people living with dementia and their carers.
- Early diagnosis, equitable access to support and dementia-inclusive communities improve quality of life.
- Initiatives to combat stigma and negative perceptions associated with dementia improve understanding of the condition and the lives of people living with dementia.
- Collaboration between European-level institutions, national governments and communities is essential to address current and future challenges.
- Continued political commitment is needed to ensure dementia remains a priority within European policy.

Online support to mark World Alzheimer's Month

The exhibition and reception marked the beginning of World Alzheimer's Month, which takes place during the month of September. As part of this, Alzheimer Europe invited MEPs to record and share video messages about the need for dementia to be prioritised as a policy issue at an EU level, which were then shared on social media.

The MEPs who contributed were:

- Vytenis Andriukaitis (S&D, Lithuania)
- Nina Carberry (EPP, Ireland)
- Maria Guzenina (S&D, Finland)
- Sirpa Pietikäinen (EPP, Finland)
- Tilly Metz (Greens/EFA, Luxembourg)
- Manuela Ripa (Greens/EFA, Germany)
- Tomislav Sokol (EPP, Croatia)
- Hilde Vautmans (Renew, Belgium)
- Kristian Vigenin (S&D, Bulgaria)
- Maria Walsh (EPP, Ireland).

Across the ten videos shared, MEPs highlighted a number of different aspects of dementia, including those relating to prevention, gender, diagnosis and treatments with a common message: The need for coordinated action at an EU level.

Official launch reception

To mark the launch of the exhibition, on the evening of 1 September, a reception was hosted by Nina Carberry MEP (EPP, Ireland), attended by around 90 people, including national member associations, people with lived experience and industry partners, including 13 MEPs.

MEP Carberry opened the reception by sharing her hopes for the exhibition, as well as highlighting the importance of addressing dementia as a priority issue at an EU level. Additionally, she spoke of the need to raise awareness, bring lived experience to the centre of the conversation and to turn the demonstrable cross-party political commitment on dementia, into concrete actions at an EU level.

Kevin Quaid, Chair of the EWGPWD, called for the exhibition to be seen by all decision-makers, highlighting that dementia is not only a health issue but also a social, economic and a human rights issue. He additionally stressed the importance of listening to the voices of people with lived experience.

Trevor Salomon, Chair of the EDCWG, shared his experience as a carer, highlighting challenges including in obtaining a diagnosis for his wife, in addition to a lack of support for both him and his wife from the care and social protection systems. He called on the forthcoming European Care Deal to be developed in partnership with carers.

Jordan Adams, one of the "FTD brothers", shared the brothers personal experience of losing their mother to frontotemporal dementia (FTD), their confirmed genetic predisposition to FTD, and their endurance challenges to raise awareness of the condition.

Contributions were also heard from MEPs: Ondřej Dostál (NI, Czechia), Tilly Metz (Greens/EFA, Luxembourg), Sirpa Pietikäinen (EPP, Finland), Vladimir Prebilič (Greens/EFA, Slovenia), Tomislav Sokol (EPP, Croatia), Michal Szczerba (EPP, Poland) and Kristian Vigenin (S&D, Bulgaria).

They spoke of the need for a coordinated EU approach to dementia, integrating health, social care, research and support for carers. This included priorities such as earlier diagnosis, reducing inequalities in access to care, protecting dignity and equal opportunities, strengthening research and data collection, as well as securing stronger, funding through future EU programmes and budgets.

Jean Georges, Executive Director, Alzheimer Europe, rounded off the evening by reflecting on progress in prevention, diagnosis, care, and early treatments. He stressed the importance of translating innovation to practice, whilst noting that with the forthcoming SANT Committee report on neurological health, there was cause for optimism.

Following the speeches during the reception, attendees were invited to explore the exhibition and to network.

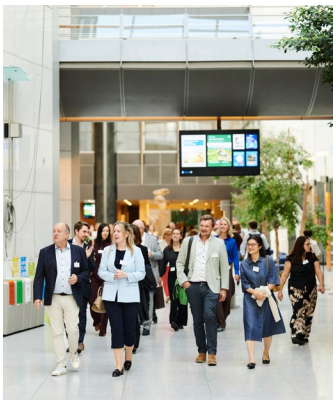
Further information on the exhibition, is available at: https://www.alzheimer-europe.org/european-parliament-exhibition?language_content_entity=en

Highlights from the exhibition and reception




































FINE GAEL
epp
NINA
CARBERRY
MEP




Alzheimer Europe
Exploring prevalence, policy and the need for coordinated European actio










I SUPPORT
PRIORITISING
DEMENTIA
AT AN EU LEVEL




Does your country have a national dementia strategy?





Poland launches first national dementia strategy

On 17 December 2025, the Polish Government adopted the National Dementia Programme for 2025-2030, the country's first national dementia strategy. In this article, Deputy Minister for Health, Katarzyna Kęcka, talks about how the strategy was developed and plans for its implementation. In addition, we hear from Edyta Ekwińska, President of Alzheimer Poland, about their reaction to the strategy.



Katarzyna Kęcka

Could you present the background that led to the development and publication of the strategy?

The development of the strategy stems primarily from the need to ensure patient safety and to respond to the real and growing needs of society. Poland's demographic situation is changing dynamically; the population is ageing rapidly and the proportion of people aged 60+ and 80+ is increasing, among which dementia occurs most frequently. At the same time, increasing life expectancy and the phenomenon of "double ageing" further increases the scale of health and care-related challenges.

International commitments were also an important impetus. Poland, as a Member State of the World Health Organization (WHO), endorsed the objectives of the Global Action Plan on the public health response to dementia 2017–2025 in 2017, during the 70th World Health Assembly in Geneva, which were subsequently extended to 2031.

This document sets out directions for the development of national policies and systemic solutions, emphasising the need to recognise dementia as a public health priority and to develop coordinated actions across prevention, diagnosis and care.

Additional factors included the conclusions of the Supreme Audit Office and national strategic documents, which indicated the need to implement coherent and systemic measures in this area. According to the "PolSenior2" study (Medical University of Gdańsk, 2017), it is estimated that, on average, one in six people aged 60+ in Poland may have cognitive problems suggestive of dementia.

Taking these considerations together, the Minister of Health decided to develop a comprehensive strategic document in this area, aiming to organise and coordinate activities at the national level and to develop new solutions through inter-ministerial cooperation, with the participation of civil society organisations (CSOs).

Could you tell us how people with dementia and their carers were involved in the development of the strategy?

The voices of people with dementia, their carers, as well as CSOs representing their interests, is extremely important in the process of shaping and implementing measures for people with dementia and their loved ones. Taking their experiences, needs and perspectives into account makes it possible to create solutions that are more appropriate, effective and responsive to the challenges faced by people living with the condition and carers.

Therefore, at the initial stage of work on the Programme, a debate was organised with the participation of CSOs, during which the planned directions for its implementation were discussed. At later stages, meetings were also held with CSOs. Information on the Programme was presented, among other occasions, at a meeting of the Council of Patient Organisations operating under the Minister of Health. The draft document was also subject to public consultation as part of the legislative process, during which any interested entity could submit comments, with organisations supporting people living with the condition and their carers informed about the consultations.

What are the overarching objectives of the strategy, and what specific commitments and measures are intended to achieve them?

The Programme is based on several key areas of action.

First, we place strong emphasis on raising public awareness, including measures aimed at reducing the stigmatisation of people living with the condition, educational campaigns addressed to various groups (e.g. children and young people, representatives of non-medical professions), as well as initiatives supporting the creation of dementia-friendly environments.

The second important objective is to reduce the risk of developing the condition. In this

area, information activities concerning modifiable risk factors and the promotion of prevention are planned. An important element will be the preparation of guidelines for local governments to help implement local programmes supporting healthy ageing and the prevention of dementia.

Another area is support for early diagnosis, for which the strategy aims to improve the diagnostic pathway for people with suspected dementia and implement tools that increase the detection of diseases at an early stage. This is vital for the effectiveness of subsequent treatment and care.

For treatment, care and support for people living with the disease, measures envisaged include the development of day care and home care, the preparation of diagnostic and therapeutic recommendations at different levels of the system and measures to strengthen the protection of the rights of people with dementia.

Support for carers is no less important. The Programme provides for the development of psychological and information support, training for informal carers, an analysis of the possibility of expanding respite care and the operation of a helpline offering both information and psychological support.

The strategy also provides for the development of data collection systems, with the aim of improving monitoring through the systematic collection, analysis and publication of data on dementia, to allow for more accurate planning of public policies.

The final, but essential, element is scientific research. Population-based analyses and the development of research on early diagnosis are planned, including the use of modern technologies such as biomarkers and artificial intelligence.

All these measures are complementary and mutually reinforcing – their common objective is to create a system that will not only respond to patients' needs but also effectively prevent disease and provide comprehensive support at every stage of the condition.

In your view, what role do civil society organisations (CSOs) play in implementing the strategy and achieving its objectives?

The role of CSOs in the implementation of the Programme is complementary to, and supportive of, the activities of public institutions. They perform an important function, among other things, in raising public awareness of dementia, counteracting the stigmatisation of people affected and promoting attitudes of solidarity and social sensitivity.

Furthermore, they engage in educational and information activities addressed to people living with the condition, carers and the public, contributing to increased knowledge of prevention, early recognition and available forms of support. An important area of their activity is also the initiation and implementation of projects including psychological and social support.

CSOs often act as a bridge between people living with the condition and their families on the one hand, and the healthcare and social assistance systems on the other, facilitating access to information about available forms of support. They also represent the interests of these groups in dialogue with public administration, including local governments. Because CSOs operate within local communities, they can effectively identify needs and respond to emerging challenges, thereby supporting the Programme's objectives.

At the same time, to conduct evaluation and monitoring of the Programme as effectively as possible, it is planned to establish a Programme Implementation Monitoring Team, whose work will involve representatives of CSOs. The Team will be able to submit recommendations for possible amendments to the Programme, including in relation to the adopted indicators, and will be responsible for its evaluation.

Has the government committed dedicated funding to the oversight and implementation of the strategy?

No dedicated funding has been allocated for the overall implementation of the Programme. Its primary aim is to structure and coordinate activities undertaken at the governmental level. Individual measures will therefore be implemented within the available sources of funding, in particular the state budget, including the National Health Fund, the National Health Programme and European Union funds.

The Programme is the first strategic document on this subject in Poland – when planning the activities, efforts were made to use the available resources and funds as effectively as possible in order to increase awareness of dementia disorders, reduce the stigmatisation experienced by people living with the condition and their carers and increase the number of early diagnoses. Above all, it indicates to partners from various national institutions that it is necessary to undertake a range of interventions addressing dementia, including those beyond the remit of the Minister of Health.

However, the government has committed to providing dedicated funding for the oversight and implementation of the Neurodegenerative Diseases Strategy.

The strategy builds on investments that are already in place, including around EUR 450 million allocated each year to memory clinics and specialised dementia care, to ensure nationwide access to diagnosis, follow-up and expert support. This long-standing funding provides a strong structural foundation for the implementation and monitoring of dementia-related measures.

Additionally, the government has allocated new, targeted funding to support the implementation of the 2025-2030 strategy, with nearly EUR 30 million in additional funding mobilised for 2026 to accelerate priority actions.

These investments are accompanied by governance arrangements, such as national oversight and follow-up mechanisms, to ensure that the funding translates into tangible improvements. Taken together, this approach reflects a dual commitment to sustaining core services over time and providing new resources to drive change and innovation.

Response from Edyta Ekwińska, President of Alzheimer Poland

In December 2025, after many years and numerous efforts, the Polish Government accepted the National Dementia Programme for 2025-2030, to be implemented into Polish law. It is the first ever strategic document concerning support for people with dementia and their families. It is estimated there are currently over 600,000 people who live with dementia in Poland, sometimes still without a diagnosis.

For years, the Polish Alzheimer's associations have been emphasising that without such a strategic document, it is very difficult to build a comprehensive support system for those in need. In 2011, the Polish Alzheimer's Association, an organisation of medical researchers, whose current president is Professor Tomasz Gabryelewicz, as well as the Nationwide Agreement of the Alzheimer's organisations, signed an agreement in favour of creating the Polish Alzheimer's Plan. At the time we spoke about an Alzheimer's Plan, while today we have the Dementia Programme.

A patient who has been diagnosed with dementia has many years of good life ahead of them and we know their lives can be well organised, but only when systemic support is in place. Dementia will be part of life for many people in Poland, as demographic changes have already shown. So far, we have not had systemic solutions which are designed and tailored to the needs of people living with Alzheimer's or other types of dementia. Alzheimer's organisations have been providing support often using instruments and services addressed to other groups: older people, people with disabilities or people with mental disorders.

The board of Alzheimer Poland has been actively participating in the development and consultations related to the document. In our opinion, the Polish Dementia Programme, which consists of seven support pillars, presents in a holistic way solutions which are already available or are going to be implemented, and which should improve the quality of life of both the person with dementia as well as their carer. Those pillars are: 1. Raising awareness; 2. Lowering the risk of dementia; 3. Supporting early diagnosis; 4. Treatment, care and support for patients; 5. Supporting carers; 6. Building data gathering systems; 7. Research.



Edyta Ekwińska

The pillar which needs to be implemented as soon as possible is supporting early diagnosis. Often, people who live with dementia (and their families) seek help quite late. The earlier they get a diagnosis, the better the chance they will receive pharmacological and non-pharmacological treatment.

Another important pillar is treatment and care. We hope it will have an impact on the belief that there is a real chance to change the course of the disease, by slowing it, for example, and that people will therefore think about the importance of early diagnosis, tests, biomarkers and will start treatment as soon as possible. What we still see is that adult children do not associate their own difficulties with family history, as in the past the condition was neither treated nor named.

The third pillar which we consider significant is support for carers. Recently, the Patients' Rights Ombudsman, in partnership with Alzheimer Polska, launched the first free nationwide Dementia Helpline (800 201 801), which is operated by psychologists, occupational therapists and lawyers. The helpline is dedicated to people who have not received any diagnosis but want to know about dementia, as well as to people with dementia and their family carers and formal caregivers. It is also a part of a broader awareness-raising campaign. The database which has been created for the purpose of the helpline is being updated all the time. It contains information on locally available forms of support, such as day care, nursing homes, support groups or other services. The data has been collected in cooperation with NGOs and local governments and authorities. People who call the helpline often ask about the diagnosis of dementia, because they have noticed some symptoms but do not know where to go or which doctor to see. They receive comprehensive answers and support.

The Polish Dementia Programme, the first such important legal act in our history, is also the first significant step towards building an inclusive community for persons living with dementia and their families in our country. We are really grateful for the document and I would like to thank the Ministry of Health for their hard work on the Programme.

New EU legislation on the protection of adults in cross-border situations

In May 2023, the European Commission proposed a legislative package, including a Regulation and Council Decision, with the aim of protecting the rights of vulnerable adults in cross-border situations. In May 2026, the European Parliament and Council of the EU reached agreement on the Regulation. In this article, Pia Lindholm, Deputy Head of the Civil Justice Unit, Directorate-General for Justice and Consumers, European Commission, explains the background to the proposals and what this will mean in practice.

Background

Currently, there is no EU legislation specifically addressing the protection of adults in cross-border situations. In this context, adult refers to a person who has reached the age of 18 years old, while protection means representation, support or other measures that enable adults to exercise their legal capacity through supported decision-making, co-decision-making or representation, or that concerns protecting the person or property of adults.

This gap in EU law will soon be closed since new EU legislation is due to be adopted in autumn 2026. In May 2026, the European Parliament and the Council as the EU co-legislators reached an agreement on a new Regulation on cross-border protection of adults in the EU which will apply among EU Member States.

A Council Decision dealing with international aspects of the protection of adults is being finalised in parallel and aims at providing a legal framework on the cross-border protection of adults with non-EU countries.

The Commission proposed this legislative package consisting of a Regulation and a Council Decision in 2023 to ensure that the protection or support needed by adults who are vulnerable is maintained in cross-border situations and that their fundamental rights, including the right to autonomy, access to justice, equality, the right to be heard, right to property and right to free movement, are protected. Their freedom to make their own choices as regards their person, property and living arrangements needs to be respected. The aim was also to improve the effectiveness and speed of proceedings concerning the protection of adults by establishing clear, simple and functional mechanisms for cooperation in cross-border proceedings.

The new legislation will safeguard adults who, by reason of impaired or diminished decision-making capacity, may need additional support and safeguards to protect their interests. These may be permanent or temporary, and may also be connected with a health condition, such as Alzheimer's disease or a coma.

The ageing population in the EU combined with the increasing mobility of people leads to a growing number of cross-border situations involving adults who need support. This legislation can also apply to persons with disabilities, whose rights are guaranteed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which both the EU and its Member States are contracting parties.

"The new legislation will safeguard adults who, by reason of impaired or diminished decision-making capacity, may need additional support and safeguards to protect their interests."

Specific function of the Regulation and the Council Decision

The future Regulation will provide for rules that apply within the EU. In particular, it will establish which court has jurisdiction, which law is applicable, under what conditions a foreign measure or foreign powers of representation should be given effect, as well as strengthening cooperation between Member States, including digital communication.

One aim is to enhance cross-border electronic communication between Member States' authorities to make cooperation speedier and more efficient. The Regulation also introduces a European Certificate of Support and Representation, which will make it easier for representatives to support or represent the adult in another Member State.

"One aim is to enhance cross-border electronic communication between Member States' authorities to make cooperation speedier and more efficient. The Regulation also introduces a European Certificate of Support and Representation, which will make it easier for representatives to support or represent the adult in another Member State."



The future Council Decision provides for a uniform legal framework for the international protection of adults in situations between an EU Member State and a non-EU country and obliges those Member States which are not yet parties to the HCCH 2000 Protection of Adults Convention to join it.

So far 13 EU Member States have joined this Convention, but the situation is not satisfactory as it does not provide legal certainty and a level playing field for citizens in all EU Member States. Indeed, if not all Member States are parties to the Convention, different and often contradictory provisions are applied in cross-border situations involving citizens of EU Member States and third countries.

What will the new legislation mean in practice?

This legislative package will apply only in cross-border situations and will not affect Member States' national substantive rules on the protection of adults such as rules concerning legal capacity, the types of protection measures or the powers a representative may have.

As an example, adults concerned or their representatives may need to manage assets or real estate in another country or adults may undergo planned or emergency medical care abroad or relocate to another EU Member State for various reasons. In such situations they often face complex situations which can involve legal uncertainty and lengthy proceedings – the legislation aims to simplify this process.

How will the European Certificate of Support and Representation work?

It can be requested and used by adults themselves or representatives supporting or representing them. It will make it easier and more efficient to demonstrate who has the right to support and represent the adult in another Member State when dealing, for example, with authorities, notaries, banks or healthcare bodies. The Certificate includes a range of standardised features aimed at streamlining and speeding up cross-border interactions for both citizens and national authorities. These include a harmonised issuance procedure, a uniform format, consistent content, clearly defined legal effect and availability in all official EU languages to avoid translation costs.

To ensure that the Certificate remains up to date and based on a valid measure or confirmed powers of representation, its validity is limited in time to one year (although the issuing authority may, where justified, extend or reduce the period of validity).

It should be underlined that the adult or the adult's representative who is entitled to apply for a Certificate or to whom a Certificate has been issued is under no obligation to apply for or use the Certificate. They are free to use national documents instead.

When will the new rules apply?

Once the Regulation has been formally adopted (which is expected in autumn 2026 together with the Council Decision), it shall apply 30 months after its entry into force. The Council Decision shall enter into force on the twentieth day following its publication in the Official Journal of the EU. Member States will then have 30 months to become parties to the Convention. Regarding the Regulation, the period of 30 months is needed to allow Member States sufficient time to prepare for the application of the Regulation, which is directly applicable.

The Commission's role will be to support Member States in the application of the legislation and to monitor its implementation. The Regulation also specifies that a practice guide will be prepared, within the framework of the European Judicial Network in civil and commercial matters (EJN civil), to provide information and guidance on the application of the Regulation. A practice guide for the application of the Convention already exists and is available on the website of the Hague Conference on Private International Law.

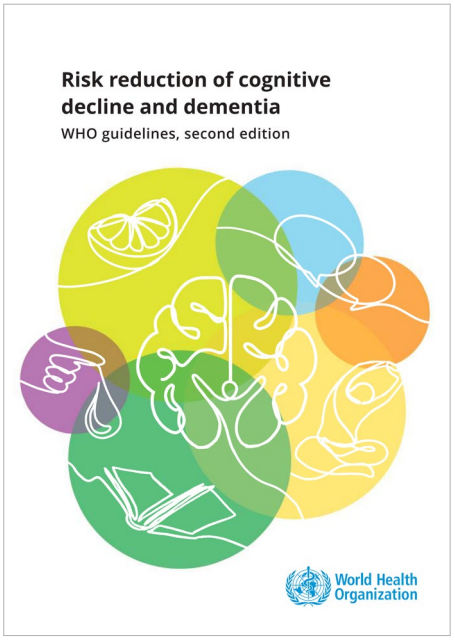
Further information on the new legislation is available on the European Commission website at: https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/civil-justice/civil-and-commercial-law/protection-adults_en

Further information and resources on the HCCH 2000 Protection of Adults Convention are available at: https://www.hcch.net/en/instruments/conventions/specialised-sections/adults

Disclaimer: The opinions expressed in this article are those of the author and do not bind the European Commission.

New WHO guidelines highlight opportunities to reduce dementia risk across the life course

On 15 July 2026, the World Health Organization (WHO) published the second edition of its guidelines on "Risk reduction of cognitive decline and dementia", responding to developments in the field since the guidelines were last published in 2019. In this article, the WHO outlines the background to the updating of the guidelines, the takeaway messages for key stakeholders and some considerations for implementation.



Background

Dementia affects millions of people worldwide with nearly 10 million new cases occurring each year, and has profound impacts on individuals, families, communities and health systems. Dementia onset may be delayed or prevented through interventions that address modifiable risk factors across the life course. In line with this, the World Health Organization (WHO) recently updated its guidelines on evidence-based interventions to reduce the risk of cognitive decline and dementia.

Through efforts such as the Lancet Commission on Dementia Prevention, Intervention and Care, modifiable factors that can increase dementia risk have been well established, while generic WHO guidance provides evidence-based recommendations for interventions to address these risk factors. However, their impact on cognitive function or dementia risk is not well understood. The updated WHO dementia risk reduction guidelines close this gap and highlight effective interventions that reduce dementia risk and may ultimately prevent dementia (see Figure 1).

Why an update was needed

Since the publication of the first WHO dementia risk reduction guidelines in 2019, science has advanced significantly. New evidence has strengthened or refined our understanding of the risk factors and recommendations already included in the first edition and required a full review of the literature for instances where previously no recommendations could be made due to insufficient evidence. Similarly, new evidence emerged for additional risk factors and interventions that were previously not considered in the 2019 guidelines such as population-level and multidomain interventions.

The updated guidelines respond to this growing evidence base and underscore that in the absence of a widely accessible treatment or cure, addressing modifiable dementia risk factors is a public health imperative.

What should individuals, healthcare professionals and policy makers know?

Individuals should remain physically active, maintain a healthy balanced diet, avoid tobacco, reduce harmful alcohol use, stay socially connected, and engage in cognitively stimulating activities to promote brain health and lower their risk of developing dementia. It is also important for dementia risk reduction to manage health conditions that you might have such as hypertension, diabetes, obesity, dyslipidaemia and hearing loss.

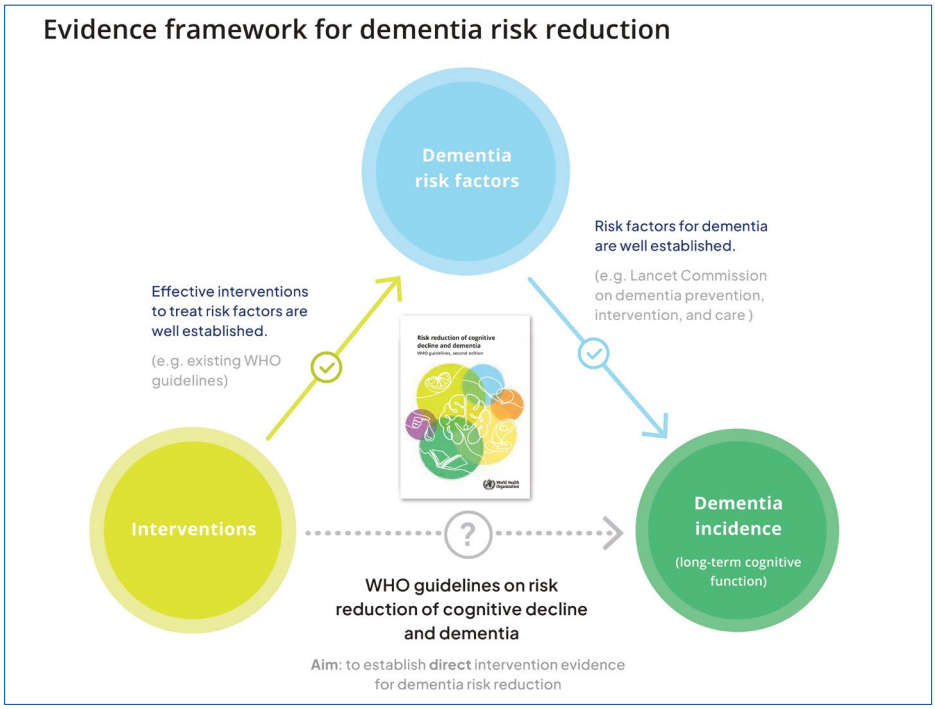


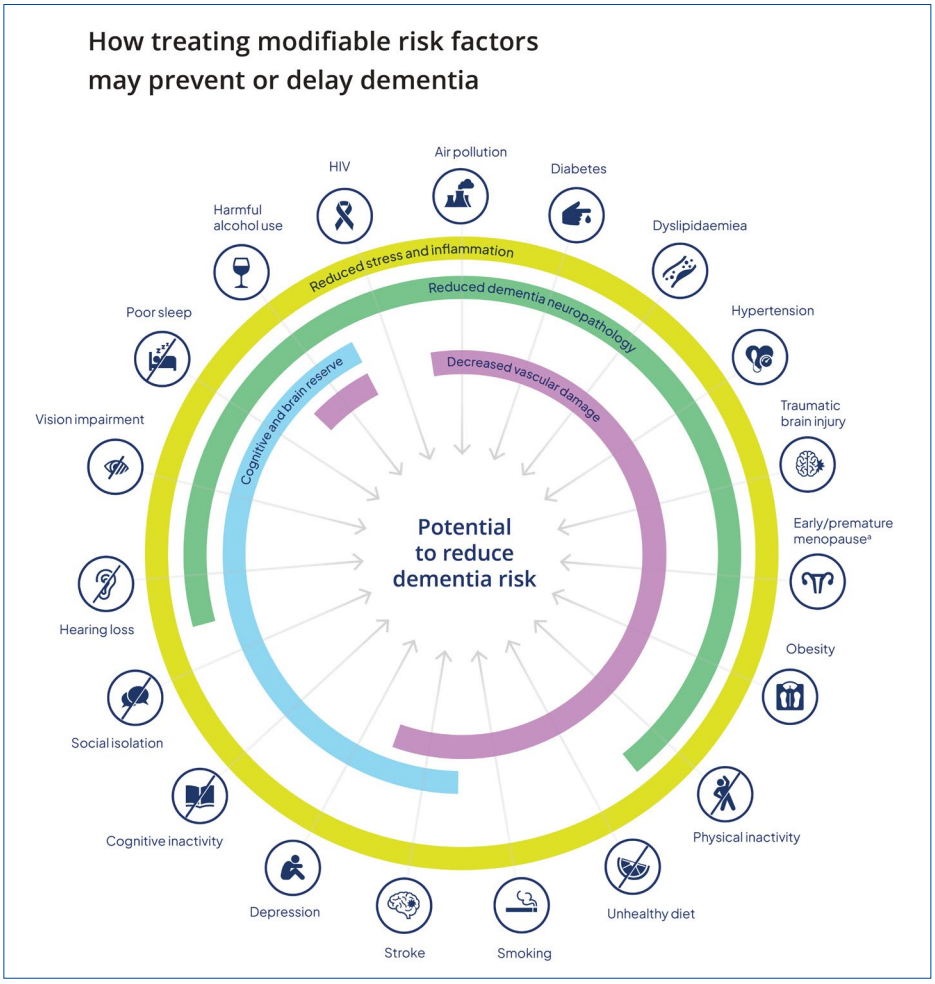
Figure 1

Healthcare professionals can support dementia risk reduction by integrating these evidence-based interventions into routine care and prevention efforts while also tailoring care to the individual by addressing multiple risk factors based on the person's needs risks and context. At the same time, healthcare professionals should not be prescribing dietary supplements in the absence of a deficiency or menopausal hormone therapy in women 65 years old and older for the purpose of dementia prevention. Even if current intervention evidence is insufficient to make dementia-specific recommendations for the treatment and management of depression, HIV, stroke, traumatic brain injury, vision impairment, sleep-wake disorders and poor sleep, in order to reduce dementia incidence, these conditions should be treated in line with existing standards of care. Insufficient evidence in these areas largely reflects limitations in the available research, rather than suggesting that managing these conditions is not important.

Policy-makers can help create environments that reduce dementia risk through actions such as improving air quality and ensuring equitable access to healthcare services. They should review national policies and strategies to assess the alignment of existing dementia, healthy ageing, noncommunicable disease (NCD), mental health and neurological disorder policies with the updated recommendations, while considering local needs and contexts. Effective implementation of the guidelines will also require investment. Sustainable funding should be allocated and long-term resources must be mobilised to support the implementation, monitoring and scale-up of dementia risk reduction interventions.

Implementation of the guidelines

The updated WHO guidelines send a clear message: there are actions that individuals, communities and governments can take today to support brain health and reduce dementia risk. Reducing dementia risk is not solely the responsibility of individuals. It also requires supportive environments, equitable access to healthcare and policies that enable people to live healthier lives. The guidelines also recognise that dementia risk accumulates across the life course. Supporting brain health therefore requires action not only in older age, but throughout life.



Countries do not need to create entirely new systems to act on dementia risk reduction. Many recommended interventions can be incorporated into existing programmes addressing noncommunicable diseases, healthy ageing, primary health care and community-based services. This creates opportunities for more efficient use of resources while strengthening person-centred care.

Implementation will require strengthened workforce capacity, public awareness and equity-oriented planning. It also demands bridging evidence gaps and addressing persistent inequities as most available evidence comes from high-income countries, while data from low-resource settings or disaggregated by sex, age or socioeconomic status, are missing.

Looking ahead

As countries work towards implementing the global action plan on the public health response to dementia, these guidelines provide an important tool to inform policy, strengthen prevention efforts and support healthier ageing across populations. They also support the implementation of the UN Political Declaration on Noncommunicable Diseases and Mental Health by providing evidence to guide multisectoral policies on addressing modifiable risk factors, promoting healthy environments and strengthening integrated people-centred primary health care approaches that support brain health across the life course.

WHO will support countries in implementing the guidelines through training, workshops, and learning initiatives, using both digital and in-person approaches to promote sustainable integration into health systems.

The second edition of the risk reduction guidelines is available to download at: https://www.who.int/publications/i/item/9789240123557

Alzheimer's Association International Conference 2026 takes place in London

From 12-15 July 2026, the US Alzheimer's Association hosted its International Conference (AAIC) in London. In this article, our Deputy Executive Director Angela Bradshaw reports back on some of the research headlines from the conference, and we hear perspectives from our colleagues Lukas Duffner and Sarah Campill, as well as from Richard Oakley, Associate Director for Research and Innovation at the Alzheimer's Society



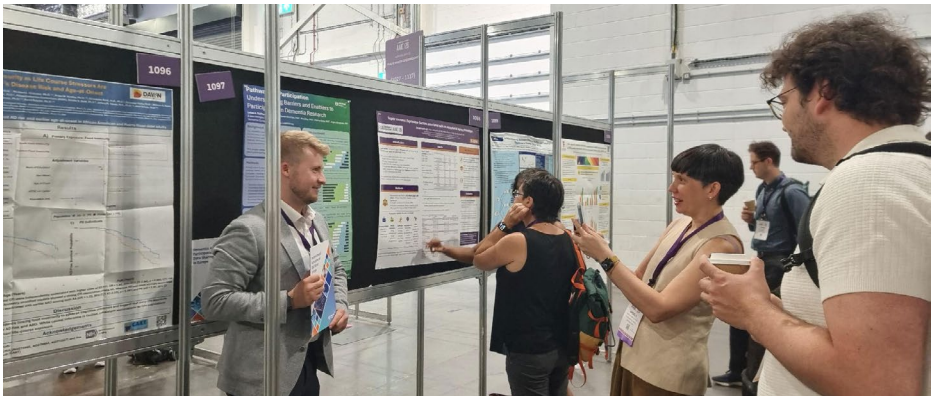
Left to right: Sarah Campill, Angela Bradshaw, Lukas Duffner

The first Alzheimer's Association International Conference (AAIC) took place in 1988, in Las Vegas, Nevada (US). Every summer since then, AAIC has featured some of the latest results from research on the diagnosis, prevention and treatment of Alzheimer's disease and other forms of dementia. AAIC is also where the global dementia research community comes together: researchers, clinicians, clinical trialists, funders, industry, national Alzheimer associations, as well as people living with dementia and their families. This year's edition was held in London (UK) from 12 to 15 July, and we were delighted to have three Alzheimer Europe team members in attendance: our Deputy Executive Director, Angela Bradshaw, as well as Project Officer Lukas Duffner and Public Involvement Officer Sarah Campill.

Research headlines from AAIC26

Diagnosis always features prominently on the AAIC programme and 2026 was no exception. Blood-based biomarkers for Alzheimer's disease, and particularly p-tau217, were covered in several presentations. For example, investigators reported that levels of p-tau217 can help estimate the risk of future cognitive impairment in people who are cognitively healthy today. The analysis pooled data from nearly 2,700 unimpaired older adults, who were followed for close to five years on average. Adults with very high p-tau217 had an estimated 78% likelihood of developing cognitive impairment within ten years. Those with moderately elevated levels had a risk of around 45% over the same period. However, researchers were careful to note that age, genetics and kidney function can all influence biomarker levels. Longer follow-up in more diverse populations is now needed.

On treatment, three sets of results drew particular attention. Roche presented long-term data from the Phase Ib/IIa Brainshuttle AD study of trontinemab, an anti-amyloid antibody engineered to cross the blood-brain barrier more efficiently. At the 3.6 mg/kg dose, 92% of participants fell below the amyloid positivity threshold after 28 weeks, with ARIA-E side-effects in fewer than 5% of participants. Roche also set out the design of PrevenTRON, a Phase III trial in preclinical Alzheimer's disease. With anti-amyloid therapies now approved in over 40 countries and with coverage in the US and Japan, we also learned more about how these innovative therapies are performing in the real-world context. For example, Eisai and Biogen



Lukas Duffner presenting his poster on barriers and enablers to participation in dementia research

presented results of the real-world LEADER study of lecanemab, showing that nearly 83% of the 432 enrolled patients remained stable (75.9%) or improved (6.6%) while receiving treatment over an average of 17 months.

Finally, we heard about next-generation approaches to target the underlying biological causes of Alzheimer's disease. Of note, Biogen presented Phase II CELIA data for diranersen, a tau-targeting antisense oligonucleotide delivered via intrathecal injection. Although the study did not meet its primary endpoint, the lowest dose was associated with slowing of cognitive decline, and substantial reductions in tau in cerebrospinal fluid and on PET were reported across all doses. Based on these results, the company announced its intention to move to Phase III.

Prevention was equally prominent. The headline results for the LatAm-FINGERS study, the first randomised trial of a multidomain lifestyle intervention in Latin America, were presented at AAIC and simultaneously published in The Lancet. LatAm-FINGERS enrolled 1,065 adults aged 60-77 across 11 countries. The structured programme produced around 55% greater improvement in global cognition than periodic health advice, and 82% of participants completed two years of follow-up. Importantly, each component was adapted to local cultures, foods and settings.

Alzheimer Europe was well represented at AAIC. I attended together with Lukas Duffner and Sarah Campill, who presented five posters between them, on barriers to research participation and data sharing, Public Involvement in care pathways, adherence to risk reduction interventions, and modifiable risk factors in national dementia strategies. What struck all of us was the growing volume of work on real-world practice, on inequalities in access, and on strategies and approaches to address them. The prevailing message was that research advances will only be meaningful if they reach everyone who could benefit, and that this requires a concerted effort on implementation.

A few words from Richard Oakley



Richard Oakley

AAIC in London was a unique opportunity as the UK's biggest support and research charity to connect with researchers from across the globe and to celebrate the contribution of the UK to dementia research.

Given the huge progress seen in recent years it's been interesting to witness how researchers, clinicians, funders, innovators, and policymakers are increasingly working together with a shared determination to turn scientific discovery into real-world impact.

We're in a time of great hope thanks to new diagnostics, changes in clinical practice, and a growing understanding of how technologies and treatments are working in the real world.

As you'd expect there were a staggering number of sessions on blood-based biomarkers, particularly on how they are being used in clinical practice around the world, which is useful learning for us in the UK. Researchers are pushing this to the next level, exploring the potential for blood tests to be used not only to support a diagnosis, but also for staging and very early intervention.

Although disappointingly not yet available in our healthcare system, the UK must prepare to deliver disease-modifying treatments. Emerging evidence on the real-world impact of lecanemab and donanemab was incredibly useful to understand the true value and cost of these medications.

As always AAIC was inspiring and energising. I left with an optimism grounded in changes that are very much a reality today, thanks to the incredible progress being made in detection, prevention, and treatments.

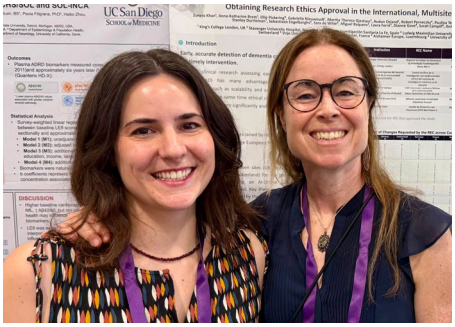
A few words from Lukas Duffner

Attending AAIC in London was a valuable and inspiring experience. It was a unique opportunity to learn about the latest developments in dementia research and to connect with researchers, industry representatives and other stakeholders from across the world. Beyond the scientific programme, I particularly appreciated the atmosphere of collaboration at the conference - AAIC brings together people from many different backgrounds and countries, creating opportunities to exchange experiences, learn from different perspectives and build new connections. It was inspiring to be part of this global community and to see the shared commitment to improving the lives of people affected by dementia.

I was pleased to represent Alzheimer Europe and share our work on research participation and data sharing. Through two posters, we presented findings from our public opinion poll and stakeholder interviews, exploring views on participation in research and the use of health data. I also presented a poster on the analysis of the distribution of modifiable dementia risk factors throughout European countries, carried out as part of the ongoing AD-RIDDLE project.

The conference also provided an opportunity to meet with colleagues from Alzheimer Europe's member organisations and discuss common priorities, including projects related to healthcare system preparedness. I left AAIC with new insights, valuable connections and a greater appreciation of the importance of collaboration in advancing dementia research and care.

A few words from Sarah Campill



Sarah Campill with Anna-Katharine Brem from King's College London

Taking part in AAIC can be overstimulating, exciting, and inspiring in the best possible way. It gives you the feeling of being part of something much bigger than yourself. It is a vast community, as diverse as dementia itself.

A personal focus of interest for me this year was women's health in its broadest sense. I attended a brilliant session on "Menopause as a Window of Alzheimer's Disease Risk: Neurocognitive Pathways in Women", as well as an event organised by the Women's Alzheimer's Movement, founded by Maria Shriver. Both painted an encouraging picture of how women's health is finally receiving the attention that it deserves in research and funding, bringing us closer to understanding both protective factors and the mechanisms underlying the development and progression of Alzheimer's disease.

The plenary sessions by Betty Tijms on "Proteomic Subtypes of AD: What Do They Mean and How Will They Influence or Benefit Drug Development for Alzheimer's Disease?" and by Dag Aarsland on "Prevalence of Alzheimer's Disease Pathology in the Community" were particular highlights. Both are true researchers at heart, whom I have had the pleasure of meeting and working with through the FIGARO and PREDICTOM projects. I can confidently say that they are just as stellar off stage as they were on the plenary stage.

It was also wonderful to present two posters on Alzheimer Europe's Public Involvement work. One focused on work carried out within Multi-MeMo, "Views of the Public on Adherence to Dementia Risk Reduction Interventions: A Public Involvement Approach". The other, "Public Involvement: Creating Ethical and User-Friendly Care Pathways", highlighted experiences drawn from several IHI-funded European research projects, including PREDICTOM, AD-RIDDLE, EPND, and PROMINENT.

I was grateful for the opportunity to talk about the shared work and Public Involvement activities across the many projects in which Alzheimer Europe is involved. Surrounded by researchers, clinicians, and industry partners, it is essential not to lose sight of those who matter most: the people living with dementia today and those at risk of developing it tomorrow. They remain the beneficiaries of our collective efforts and the reason this work matters.



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EMEA-ALNP-26-00068 | August 2026

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

Alzheimer Europe is pleased to announce that the membership of both the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) has been renewed, and both groups officially began their new mandates after the Annual General Meeting (AGM) of Alzheimer Europe on 30 June 2026. Both groups are heavily involved in our Public Involvement activities across many European research projects, as well as in other aspects of our work.

The new European Working Group of People with Dementia

The European Working Group of People with Dementia (EWGPWD) was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights.

As of 13 July 2026, the group has also voted in its Executive members (Chairperson and Vice-Chairperson), both of whom remain unchanged for the new mandate. Congratulations to Kevin Quaid (Ireland) and Gerda Van Tongerloo (Netherlands) for retaining their positions as Chairperson and Vice-Chairperson, respectively.

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

Farewell to Erla Jónsdóttir

Alzheimer Europe would like to express its gratitude to outgoing EWGPWD member, Erla Jónsdóttir (Iceland) for her important contributions. She will be sorely missed!

The members of the new group

The EWGPWD is now composed of the following 14 members, two of whom are new to the group:



Kevin Quaid (Ireland), Chairperson

Kevin Quaid lives in Ireland with his wife, Helena. He has Parkinson's disease and Lewy body dementia. He is a co-founder of Lewy body Ireland and is Chairperson of the Irish Dementia Working Group. Kevin was nominated to join the EWGPWD by The Alzheimer Society of Ireland in 2020. Prior to becoming the group's Chairperson in 2024, he was Vice-Chairperson from 2020-2024. As the group's Chairperson, he is an *ex-officio* member of the Board of Alzheimer Europe. *"Like every year we have to say goodbye to members whose time has come to an end and welcome new members, which is both a happy and a sad occasion. The new members drive the group from strength to strength, and I don't think it's lost on them that they are standing on the shoulders of giants - the people who have gone before them. It is one of the biggest honours of my life to be Chairperson of such a fantastic group of people and together our main aim is to try and make the lives of the people with dementia, as well as people who have yet to be diagnosed with dementia in all its forms, a bit better and a bit easier."*



Gerda Van Tongerloo (Netherlands), Vice-Chairperson

Gerda Van Tongerloo lives in Zeist, the Netherlands, with her three dogs. She was diagnosed with Vascular Cognitive Impairment in 2017 and is an active member of the working group of people with dementia of Alzheimer Nederland and a member of Alzheimer Nederland's Social Advisory Board. She is also a co-researcher in Brain Power, a research group of the University of Applied Sciences Utrecht, a member of the DEEP UK Network of Dementia Voices, and a participant and evaluator of projects from the Expertise Centre for Dementia and Technology of the Eindhoven University of Technology.
Gerda was nominated to the group by Alzheimer Nederland in 2024 and became Vice-Chairperson in 2025.
"As a member of the EWGPWD, I speak up for those who can't. My aim is to explain what everyday life with dementia is like and to advocate for a dementia-friendly society."



Georgios Aidonas (Greece), new member

Georgios was born in Thessaloniki, Greece, in 1948 and studied law at the Aristotle University of Thessaloniki. He practiced law for 42 years as a lawyer (1974 – 2016), has five children and lives in Thessaloniki with his wife, Lina. He was diagnosed with Alzheimer's dementia one year ago but notes that the results of this year's evaluation were very encouraging and

showed that there was no deterioration, demonstrating that personal effort and adherence to expert advice can have a significant impact on the progression of the disease.
Georgios was nominated by Alzheimer Hellas.



Stuart Dougall (United Kingdom – Scotland)

Stuart Dougall lives with his wife in West Lothian, Scotland. He spent 36 years working with the prison and police services before his diagnosis of young onset Alzheimer's dementia in 2022, when he joined the Scottish Dementia Working Group (SDWG). He is involved in a wide variety of work with the SDWG, including research activities, developing dementia-related supports, and communication projects. He has also taken part in many studies and research opportunities in relation to dementia.
Stuart was nominated to join the EWGPWD by Alzheimer Scotland in 2025.



Kjell Ehn (Sweden)

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



Jan Runar Eliassen (Norway)

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



Hafsteinn Ágúst Friðfinnsson (Iceland)

Hafsteinn Ágúst Friðfinnsson is from Reykjavík, Iceland, but lives in Mosfellsbær, a town close to the capital. He and his wife Kolbrún have two daughters and one son. Hafsteinn has Lewy body dementia. Shortly after his diagnosis, he joined Alzheimer Iceland and attends "Seiglan", a daily service provided by Alzheimer Iceland, regularly.
He was nominated to join the group by Alzheimer Iceland, in 2025.



Katya Genadieva (Bulgaria)

Katya Genadieva is 67, lives in Bulgaria and has limited cortical atrophy. She is married and has one daughter. She worked as a general nurse and a then in the field of mental health, before she retired. When she was working in mental health, she fought for the rights of her patients and now, she hopes to help make improvements in the lives of people with dementia.
She was nominated by Alzheimer Bulgaria in 2025.



Jost Hamschmidt (Switzerland)

Jost Hamschmidt is 60 years old and lives with his wife and their two sons in St. Gallen, Switzerland. Their daughter is studying abroad. In 2021, he was diagnosed with young onset Alzheimer's dementia and, through an association called "mosa!k" for people with young onset dementia, he was introduced to Alzheimer Schweiz Suisse Svizzera (Alzheimer Switzerland).
Alzheimer Switzerland subsequently nominated Jost to join the EWGPWD in 2025.



Lieselotte "Lilo" Klotz (Germany)

Lilo Klotz is from a small town near Cologne, Germany, but now lives in Hennef, close to Bonn. She lives with Lewy body dementia and has two daughters and one son. She is a passionate sailor and spent her career mainly in the IT sector. Since her diagnosis, she has volunteered at the German Alzheimer Society - Deutsche Alzheimer Gesellschaft (DAlzG) in Berlin.
She was nominated to the EWGPWD by DAlzG in 2022 and served as Vice-Chairperson from 2024-2025. Lilo stepped down from the group in September 2026. We thank her for her years of service and her important contributions to the group and to our work.



Angela Pototschnigg (Austria)

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



Jari Puranen (Finland), new member

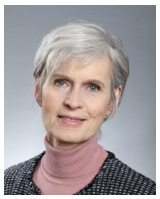
Jari Puranen is 61 years old and lives with his wife in Helsinki, Finland. They have two adult daughters, aged 28 and 30. He was diagnosed with Alzheimer's dementia three years ago. With the support of his wife, he has been participating in community activities through a local memory association, marking the beginning of a new, meaningful phase in his life. Travel is also important to him, as he enjoys discovering new places and cultures together with his loved ones. He feels it is important to give a voice to people with dementia and to promote their rights, inclusion, and quality of life.
Jari was nominated the group by Muistiliitto – The Alzheimer Society of Finland.



Shelagh Robinson (United Kingdom – England)

Shelagh Robinson has Alzheimer's dementia and volunteers for the Alzheimer's Society. She is passionate about good support at the time of diagnosis, and good end-of-life care.

She was nominated to join the group by the Alzheimer's Society, in 2022.



Věra Ryšavá (Czechia)

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

European Dementia Carers Working Group
ALZHEIMER EUROPE

The new European Dementia Carers Working Group

The European Dementia Carers Working Group (EDCWG) was launched by Alzheimer Europe and its member associations in 2022. The group is composed both of current carers, relatives and supporters of people with dementia, and of people with prior experience in a carer's role, within the five years prior to their first nomination to the group.

In tandem with the EWGPWD, the carers group works to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of carers and supporters of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights.

As of 13 July 2026, the group has also voted in its Executive members (Chairperson and Vice-Chairperson), both of whom remain unchanged for the new mandate. Congratulations to Trevor Salomon (United Kingdom - England) and Roslynn Vella (Malta) for retaining their positions as Chairperson and Vice-Chairperson, respectively.

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

Farewell to departing member Chris Ellermaa

Alzheimer Europe would like to express its gratitude to outgoing EDCWG member Chris Ellermaa (Estonia) for her important contributions. She will be sorely missed!

The members of the new group

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



Trevor Salomon (United Kingdom – England), Chairperson

Trevor Salomon lives in London, England. He stepped away from his job in 2011 to devote time to his wife Yvonne who was diagnosed with young onset Alzheimer's dementia when she was 57 years old.
Trevor was nominated to the EDCWG by the Alzheimer's Society in 2022 and held the position of Vice-Chairperson from 2022 to 2024, when he was voted in as Chairperson.
"Our group is held together by the strong bond we share, based on empathy and mutual understanding, a deep emotional connection - rooted in grief, compassion, frustration and humour - shared adversity and a united sense of purpose."



Roslynn Vella (Malta), Vice-Chairperson

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

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



Bill Alexander (United Kingdom – Scotland)

Bill Alexander retired nine years ago and lives near Stirling, Scotland. His late wife, Christine, was diagnosed with mixed dementia in 2019 and sadly passed away just before Christmas 2024. She was a member of Scottish Dementia Working Group and Bill joined the National Dementia Carers Action Network.
He was nominated to the EDCWG by Alzheimer Scotland, in 2025.



Peter Banda (Slovakia)

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



Patrick "Paddy" Crosbie (Ireland)

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



Sylva Dneboská (Czechia)

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



Emil Emilsson (Iceland)

Emil Emilsson lives in Garðabær, Iceland, with his wife Erla who was diagnosed with young onset Alzheimer's dementia in 2020 at the age of 63. She and Emil joined Alzheimer Iceland and the Icelandic working group of people with dementia. Erla was also a member of the EWGPWD from 2020 to 2026.
Emil joined the EDCWG in 2024, following his nomination by Alzheimer Iceland.



Annick Germeys (Belgium)

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



Zornitsa Karagyozova (Bulgaria)

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



Timo Pässilä (Finland), new member

Timo Pässilä lives in Kouvola, Finland. He is retired and got involved with the Kouvola Memory Association and the activities of the Alzheimer Society of Finland - Muistiliitto when his wife Leena was diagnosed with Alzheimer's dementia and Parkinson's in 2022. Their family includes adult children and several grandchildren. Both of his wife's parents and his own father also had dementia, and he knows numerous people close to him and their spouses with dementia. His sister lives in a care home and has a developmental disability. All of these experiences have given him extensive insight into the lives of people with dementia. Half of his career was in the education sector and the other half as a pioneer in digital media, developing multilingual learning platforms, among other things.
He was nominated by the Alzheimer Society of Finland – Muistiliitto.



Hatice Sertaç Süslü (Türkiye)

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



Peter Thörngren (Sweden)

Peter Thörngren lives close to Gothenburg, Sweden. He works full-time for a Swedish private engineering company and has been his wife's primary carer since her first symptoms several years ago. She was diagnosed with Alzheimer's dementia at the age of 59 and has since moved into a care home.
Peter was nominated in 2025, by the Swedish Dementia Association, Demensförbundet.



Liv Thorsen (Norway)

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



Olivera Vasilevska Danev (North Macedonia)

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



Christina Zioga (Greece)

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

Digital twins for the brain: eBRAIN-Health project comes to a close

eBRAIN-Health, a four-year Horizon Europe project in which Alzheimer Europe led Public Involvement and ethics activities, has now come to a close. In this article, we look back at the project's journey and its key results, and hear from project coordinator Petra Ritter, Johanna Quandt Professor for Brain Stimulation at Charité – Universitätsmedizin Berlin.



eBRAIN-Health and TEF-Health joint public event, 9 June 2026, Berlin (Germany)

Four years ago, a European consortium set out to build a research platform capable of modelling the human brain, in health and in disease, while keeping the most sensitive data secure. eBRAIN-Health has now reached the end of its Horizon Europe funding period, and the project leaves behind a working infrastructure, a set of digital tools, and many lessons learned about what it takes to combine neuroscience, data protection and patient voice in a single undertaking.

The foundations of eBRAIN-Health

eBRAIN-Health, coordinated by Petra Ritter, Johanna Quandt Professor for Brain Simulation at Charité Universitätsmedizin Berlin, drew on three existing programmes: the EBRAINS research infrastructure, the VirtualBrainCloud's virtual research environment for sensitive data, and the AI-Mind project's tools for dementia risk estimation. The primary goal of the project was to bring these programmes into a distributed platform with thousands of multilevel virtual brains, drawn from patients and from healthy controls, for research and innovation.

Dementia is a major public health concern for Europe. Alzheimer Europe's most recent prevalence estimates put the number of people living with dementia across Europe at over 12.1 million in 2025, a figure projected to reach almost 20 million by 2050, a rise of 64%. The economic weight is substantial, too: a 2026 study across 30 high-income European countries put the annual societal cost of dementia at over EUR 221 billion, an average of EUR 25,200 per person per year, much of it borne by unpaid family carers. Dementia is also biologically complex. Changes in the brain can begin decades before symptoms appear, and multiple systems and biological factors influence its development and progression, which adds a layer of challenge that no single approach or discipline can tackle alone.

To tackle this challenge, eBRAIN-Health brought together 21 organisations, including universities, hospitals, SMEs and non-profit organisations, spanning neuroscience, computer science, law and policy, and working across 11 scientific and management work packages, from ethics and legal research to biophysical modelling and brain simulations.

Integrating public perspectives in eBRAIN-Health

Alzheimer Europe led the project's Public Involvement activities, ensuring that people living with dementia and their carers had a say in how digital brain twins and other eBRAIN-Health innovations were designed and developed. Among other topics, Alzheimer Europe worked closely with Charité and the University of Vienna to develop an ethical and legal framework for the project, addressing questions that extend beyond code and computing infrastructure. These include the ownership and governance of sensitive brain data, the conditions under which such data may be accessed and reused, and the meaning of informed consent in a context where a participant's cognitive capacity may change over the course of a long-running research project.

This work distinguished eBRAIN-Health from a purely technical infrastructure project. By embedding Public Involvement, legal and ethics work throughout the project's lifetime, rather than treating these as a compliance step at its conclusion, the consortium was able to keep such questions under continuous review. In December 2025, Alzheimer Europe, Charité and the University of Vienna presented their combined work to a panel of external experts in ethics, data protection law and information technology, providing an independent assessment of whether the project's technical ambitions were matched by appropriate safeguards.

Future perspectives

eBRAIN-Health concludes at a time of significant activity on the European policy front. Neurological conditions are now recognised as the leading cause of poor health and disability worldwide, and the World Health Assembly's Intersectoral Global Action Plan on epilepsy and other neurological disorders has raised the profile of prevention, treatment and

research on the international agenda. Within Europe, the European Health Data Space Regulation entered into force in March 2025, establishing common rules for the primary and secondary use of health data across the Union. The EU AI Act introduced a risk-based regulatory framework for trustworthy artificial intelligence, and tools of the kind developed within eBRAIN-Health, for example for diagnosing Alzheimer's disease or analysing neuroimaging data, fall within its high-risk category. EBRAINS is separately working towards European Digital Infrastructure Consortium status, a legal framework that would connect a European Brain Data Space to the wider European Health Data Space.

The European Partnership on Brain Health, launched in January 2026 with a planned budget of approximately EUR 500 million over ten years, reflects the direction of European policy priorities in this field. eBRAIN-Health's federated, GDPR-compliant Health Data Cloud, and its adherence to FAIR data principles, demonstrate that data sharing and data protection can be pursued jointly rather than as competing objectives. This has direct relevance for European policymakers and for the patients and families that the project was designed to serve, as such approaches move from demonstration towards implementation at scale.

Digital tools for clinical care and research

Beyond its infrastructure, eBRAIN-Health advanced the development of several tools now approaching practical application. BrainSymph combines biomarker data with AI-driven analytics to assess brain health and estimate dementia risk. The SmartMe&You-TELEMAIA platform enables home-based telemonitoring of sleep, physical activity and cognitive function in older adults, and is already operational on the CINECA cloud infrastructure in Italy. Eodyne's Rehabilitation Gaming System extends game-based therapy from clinical to home settings.

On the research front, iMapper and KG-Orchestra address the harmonisation of fragmented biomedical datasets, a necessary though less visible component of translational research. Building on these tools, studies using resting-state electroencephalography conducted within the project have demonstrated that Alzheimer's disease can be distinguished from Lewy body disease using inexpensive, non-invasive recordings, an approach with potential to support diagnosis in routine neurology clinics. The Virtual Brain, an open-source platform for constructing personalised computational models of the brain, was further developed and validated throughout the project.

These tools were designed from the outset with a pathway to independent validation through TEF-Health, the EU's Testing and Experimentation Facility for health, which shares synergies with eBRAIN-Health around the certification and market access of trustworthy AI tools in healthcare. The two initiatives came together at a joint public event in Berlin on 9 June 2026, where around 200 participants from research, industry and policy discussed the transition from brain research to va lidated, deployable AI tools in health.

Looking ahead - a few words from Petra Ritter



Petra Ritter

"One personal highlight has been watching virtual brain modelling move from a research concept to tools with a genuine route into clinical practice, in the space of just four years. We now have a working, GDPR-compliant infrastructure capable of generating thousands of virtual brains, alongside a real portfolio of tools, from risk estimation to home-based monitoring, that are progressing towards actual use.

> “One personal highlight has been watching virtual brain modelling move from a research concept to tools with a genuine route into clinical practice, in the space of just four years.”
> *Petra Ritter*

There are clear parallels with AI-Mind, whose risk estimation work fed directly into what we built here. TEF-Health addresses a related but distinct problem: a European network of real-world testing facilities, including one focused specifically on neurotechnology, through which AI and robotics solutions for health can be rigorously tested and brought towards certification and market access.

Taken together, initiatives of this kind illustrate the importance of coordinated European infrastructure, not only for advancing research, but for ensuring that its results can ultimately be implemented for the benefit of patients and health systems."

> “Initiatives of this kind illustrate the importance of coordinated European infrastructure, not only for advancing research, but for ensuring that its results can ultimately be implemented for the benefit of patients and health systems.”
> *Petra Ritter*

eBRAIN-Health

For more information about the project, visit: https://www.ebrain-health.eu/

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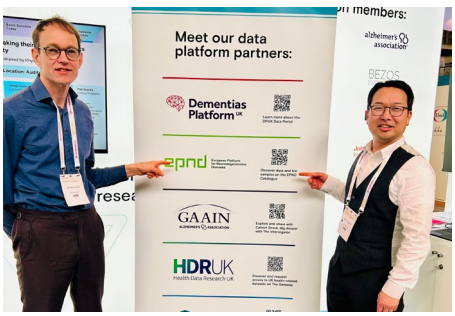
From shared resources to scientific progress: EPND's co-Leads reflect on five years of collaboration

For the past five years, the European Platform for Neurodegenerative Diseases (EPND) has been working to accelerate biomarker research by making datasets and biosamples easier to find, share and reuse. As the project draws to a close, we talk to its co-Leads about EPND's mission, what it has achieved, and how its work will continue.

epnd European Platform for Neurodegenerative Diseases

Launched in 2021 with support from the Innovative Medicines Initiative (IMI), EPND brought together 28 partners from academia, industry, patient organisations and research infrastructures. EPND's ambition was to create a more collaborative environment for neurodegeneration research centred on better sharing and reuse of the wealth of data and biological samples that already exist across Europe. At the heart of this work is EPND's Technical Hub, a platform through which researchers can discover studies, datasets and biosample collections.

To learn more, we spoke to Anthony Brookes (Professor of Genomics and Health Data Science at the University of Leicester), Niranjan Bose (Managing Director for Health and Life Sciences at Gates Ventures), Phil Scordis (Head of Patient Data Analytics at UCB Pharma) and Pieter Jelle Visser (Professor in the Molecular Epidemiology of Alzheimer's Disease at Maastricht University), co-Leads of EPND.



EPND co-Lead, Pieter Jelle Visser (left) presented results from EPND at AAIC 2025, Toronto (Canada)

When EPND started in 2021, what challenge did you want to address?

Anthony Brookes: The starting point for EPND was actually a paradox. Across Europe, researchers had already collected enormous quantities of valuable data and biological samples from people with neurodegenerative diseases. Yet finding and accessing these resources remained difficult. Data and samples were dispersed across institutions, studies and countries, with different standards, technical systems and governance requirements. Sharing biosamples also presents specific challenges, as sharing requires physical transfer as well as appropriate consent, governance and agreements between institutions.

EPND therefore set out to address data and biosample sharing, making existing resources more visible, discoverable and accessible while developing the technical, scientific, ethical and legal frameworks needed to use them responsibly. This challenge is becoming increasingly important as the number of people living with neurodegenerative diseases grows. Biomarkers have the potential to transform how we understand these diseases: supporting more timely and accurate diagnosis, but also earlier detection, prediction of disease risk and progression, and the design, selection and monitoring of treatments.

Looking back, what do you see as EPND's most important achievement?

Niranjan Bose: The EPND Hub is perhaps the clearest expression of that original vision. It provides a unified gateway through which researchers can discover studies, datasets and biosample collections and initiate requests for access.EPND has also developed dedicated functionality for biosample discovery and requests, helping researchers establish whether suitable biological materials exist across different studies before approaching individual cohorts. The AD Data Initiative's AD Workbench acts as the backbone to the EPND Hub, providing researchers with secure cloud-based environments where data can be analysed, using an extensive suite of tools and applications. Through the AD Workbench and its network of data platform partners, the Hub is linked to a wider global ecosystem of research infrastructures, helping to reduce fragmentation and increase the reach and value of the resources made discoverable through EPND.

By 2025, the Hub contained metadata from more than 100 studies, alongside over 100 datasets and more than 30 biosample collections. As a result, previously fragmented research resources are more visible and potentially reusable by the wider research community. Essentially, the Hub creates opportunities for larger and more diverse analyses, validation of findings in independent cohorts and new cross-disease research. We must also remember that behind every data point and biological sample is an individual who has generously contributed their time and personal information to research.

By enabling these valuable resources to be responsibly discovered and reused, the EPND Hub helps maximise the scientific value of the contributions made by research participants, as well as the considerable efforts of the researchers and clinical teams involved.

How did you make sure this worked in practice?

Pieter Jelle Visser: From the outset, EPND's biomarker case studies provided a way to road-test the platform while addressing important scientific questions.

Four initial case studies brought together samples and data across Alzheimer's disease, Parkinson's disease and dementia with Lewy bodies. They examined a range of biomarkers and technical platforms, including complement proteins, gut microbiome biomarkers and large-scale untargeted CSF proteomics. A fifth case study was subsequently selected through an open call to the research community – with results soon to come!



EPND co-leads, LtR: Anthony Brookes, Pieter Jelle Visser, Niranjan Bose, Phil Scordis

The first and second case studies have already generated new learnings and results, bringing together samples and clinical data from 350 participants across ten European cohorts. This allowed researchers to examine shared amyloid, tau and other biomarker characteristics across different neurodegenerative diseases. The resulting harmonised dataset has subsequently been made available through the EPND Hub.

Just as importantly, the case studies tested the practicalities of sharing. Researchers had to identify relevant samples across cohorts, harmonise accompanying clinical data and coordinate sample transfer and analysis across different partners. Lessons from these processes fed back into the development of EPND.

Has EPND's contribution gone beyond the Hub and Case Studies?

Phil Scordis: Very much so. One of the lessons from EPND is that sustainable data and sample sharing cannot be achieved through technology alone. We also need to address the practical, legal and governance barriers that can prevent researchers and institutions from sharing.

Early in the project, EPND mapped these barriers in a White Paper examining the fragmented European landscape for data protection and biobanking and identifying gaps and requirements for cross-cohort sharing. The findings helped shape the governance and access framework for the EPND Hub, with a second White Paper reflecting how this evolved as we put it into practice.

An important part of this work has been to make sharing easier for researchers and resource providers. EPND has developed common approaches, templates and language for access requests, data use conditions and agreements, providing support for permissioning and material transfer. The EPND ELSI Support Desk provides additional help with ethical, legal and contractual questions around data and biosample sharing.

We have also developed scientific guidance and standard operating procedures covering biosample collection, biobanking and biomarker validation, complemented by webinars, videos and instructional materials to help researchers put them into practice.

Together, these activities reflect an important lesson from EPND: removing barriers to sharing requires more than a technical platform.

What has EPND taught you about collaboration?

Anthony Brookes: One of the strongest lessons has been the value of public-private partnership. EPND brought together academic researchers, pharmaceutical and biotechnology companies, research infrastructures, technology partners and patient organisations around a challenge that no single sector could solve alone.

The IHI, model creates a space in which these different forms of expertise and resources can be combined. This is particularly valuable for biomarker research, where moving from discovery towards validated tools requires access to high-quality samples and data, specialist technologies and expertise across multiple disciplines and sectors.

Sharing also multiplies the value of previous research investment. Data and samples collected for one study can support new hypotheses, independent validation and entirely new analyses when they can be responsibly discovered and reused.

What comes next?

Niranjan Bose: Perhaps the strongest indication of EPND's legacy is that its infrastructure is already supporting the next generation of European research programmes.

AD-RIDDLE is making resources discoverable through EPND as it develops approaches for earlier detection, prevention and diagnosis of Alzheimer's disease. ACCESS-AD will leverage EPND infrastructure as it works to improve timely diagnosis, treatment and monitoring in real-world healthcare systems. The end of the funded project is not the end of EPND: EPND+ has been established to provide a sustainable home for EPND's infrastructure, tools and services, and will also provide support to a further IHI project, to be launched later this year.

This is an important part of EPND's legacy: we have not only demonstrated that data and biosamples can be made more discoverable and reusable across diseases, countries and sectors, but have created an infrastructure that can continue to grow and support new research. The project may be ending, but the platform, partnerships and community it has built will continue on.

EPND+ is an independent, non-profit European organisation, providing researchers with data infrastructure, tools and services to advance research into neurodegenerative diseases and other health conditions. With organisational and technical support from the AD Data Initiative, EPND+ continues EPND's mission to enable data discoverability and collaboration between researchers, with infrastructure that can be adapted to support other research initiatives. Learn more at: https://www.epndplus.org/.

Acknowledgement
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DORIAN GRAY: Bridging cognitive decline and cardiovascular disease for healthy ageing

DORIAN GRAY is an EU Horizon Europe initiative combining heart–brain research, AI innovation, multimodal data integration and avatar-based coaching exergames to prevent cognitive decline in cardiovascular disease.

Overview

The DORIAN GRAY project is a five-year Horizon Europe initiative investigating the link between cardiovascular disease (CVD) and mild cognitive impairment (MCI) in the ageing population. Its overarching aim is to better understand the mechanisms underlying this relationship and to design a personalised multidomain intervention to delay the progression of CVD-related cognitive decline.

In parallel, the project is developing innovative digital health solutions to support adherence to these interventions including Artificial Intelligence (AI)-driven tools, digital twin modelling and avatar-based digital coaching approaches. By integrating clinical, lifestyle and real-world data from wearable devices, DORIAN GRAY aims to enable earlier detection of cognitive decline and more tailored prevention strategies.

The project is coordinated by the University of Brescia and brings together a consortium of 25 partners from across Europe including clinicians, researchers, data scientists and patient organisations.

Project progress

Since its launch in January 2025, the DORIAN GRAY project has made strong progress across its scientific, technological and stakeholder engagement activities.

First, a Data Management Plan was developed at the beginning of the project and will be revised to ensure it remains up to date and aligned with evolving project needs. Partners are actively engaged in data acquisition and feature extraction and access to nearly all relevant datasets has now been achieved. Another important milestone has been the establishment of standardised protocols for data management, interoperability and ethical compliance across participating institutions, ensuring that data collection and analysis are consistent, secure and aligned with EU regulatory frameworks.

In parallel, consortium partners have advanced the design of the project's digital health tools, including the development of the PORTRAIT platform and the MIRROR app. The PORTRAIT platform is a digital twin technology based on a big data framework that uses AI-driven simulations to model disease progression, identify trends and monitor progress, allowing for the personalisation of interventions tailored to individual patient profiles. The MIRROR app will offer an avatar-based exergaming system that combines cognitive training and physical activity in a gamified environment. This adaptive system personalises exercises based on user progress, aiming to increase engagement and promote healthy ageing.

Another important component of the project is the socio-economic evaluation and regulatory strategy. A systematic review has been conducted to synthesise trial-based economic evidence on preventive interventions targeting vascular risk–related cognitive decline, including MCI and CVD. The review focuses on reported costs, quality-adjusted life years, effect sizes and the types of comparators and delivery models used across both randomised and implementation-oriented studies.

Clinical partners are currently progressing with study preparation activities, including ethical approvals, sponsor agreements and protocol development. These steps are paving the way for upcoming clinical trials, with patient recruitment expected to start in early 2027.

Visibility within the research and wider community

The project has also strengthened its visibility within the cardiovascular and cognitive health research communities.

In May 2026, DORIAN GRAY was featured at the Heart Failure Association Congress of the European Society of Cardiology in Barcelona, one of the leading international meetings in the field of heart failure. During a dedicated session, consortium members presented the project's innovative approach to integrating



Public Involvement Board members testing the exergames

cardiovascular and cognitive health research, highlighting its ambition to improve prevention strategies for cognitive decline in people living with CDV. These dissemination activities have strengthened collaboration with the wider scientific community and helped ensure the project's findings reach key stakeholders across Europe.

Public Involvement activities were also highlighted through a webinar held on 8 June 2026 in collaboration with the Association of Cardiovascular Nursing and Allied Professions and the European Society of Cardiology. Entitled "From Heart to Mind: How Public and Patient Involvement Supports Research to Prevent Cognitive Impairment in Cardiovascular Disease", the webinar explored how Public Involvement contributes to cardiovascular and cognitive health research. The event showcased practical examples from DORIAN GRAY including the development of mobile applications and exergames, demonstrating how involving people with lived experience can improve research quality and patient outcomes.

Ensuring research is guided by lived experience

A key feature of DORIAN GRAY is its strong commitment to Public Involvement. Alzheimer Europe leads the Public Involvement activities within the project and established the DORIAN GRAY Public Involvement Board (PIB) in early 2025. The PIB consists of 13 members from nine European countries, bringing together a wide range of people with lived experience including people living with MCI, vascular cognitive impairment, Lewy body dementia, heart failure, caregivers and members of the public.

Since its creation, the PIB has met online regularly to contribute to the design of the project's digital coach and avatar-based exergame. PIB members have provided feedback on usability, accessibility, motivation and engagement, ensuring that the tools being developed are suitable for older adults with diverse needs. Researchers have actively incorporated this feedback into iterative design improvements.

An important milestone was reached in May 2026, when the PIB met face-to-face with researchers in Milan, Italy at the Department of Design - Politecnico di Milano. During the meeting, they tested the digital coaching system and exergame directly, providing hands-on feedback on usability, comfort and motivational design. This in-person exchange was greatly appreciated by PIB members and marked an important step in strengthening collaboration between researchers and end users and reinforcing the project's co-creation approach.

Perspectives from the Advisory Board

"I haven't seen anything else like it. I will use it tomorrow morning. I have found out more about my cognitive ability in the last two days that I have in the last five years, so that's definitively going in the right direction. I want to thank you for what you've done and for involving us. It makes us feel brilliant", said Kevin, member from the DORIAN GRAY Public Involvement Board.

"As a caregiver, we often see things that would otherwise remain invisible. We know what daily life really looks like and we understand what causes stress, confusion, motivation or comfort. Sometimes a solution looks excellent on paper but turns out to be complicated, too demanding or simply unrealistic in everyday live. That is why, in my opinion, lived experience is so important in research projects like DORIAN GRAY", said Annick, member from the DORIAN GRAY Public Involvement Board.

"Testing the exergames firsthand made me realise how deeply they engage both body and mind simultaneously. Although demanding, this experience immediately activated a tester's mindset. Sharing in real-time my physical and cognitive impressions face-to-face with the researchers showed how insights could actively and meaningfully shape the design process. Moving forward, I hope to have the opportunity to test these exergames at a slower pace, and I would like to express my deepest appreciation to the researchers, with whom I look forward to continuing to interact and collaborate", said Miriam, member from the DORIAN GRAY Public Involvement Board.

Perspectives from researchers

"When we first defined the exergame platform in the DORIAN GRAY project, we wanted to connect clinical goals with the reality of exercising at home. Involving people with lived experience in co-design, as we did in Milan, was essential to understanding what would fit into a real day, and whether the experience could feel useful, trustworthy, and even desirable. Listening to their voices shaped concrete design choices, from how difficulty adapts to how progress is celebrated. That exchange keeps the technology honest, humane, and grounded in the people it is meant to serve", said Nicola Francesco Lopomo, researcher at Politecnico di Milano.

"Working with people with lived experience has been essential for the design of the MIRROR app and its digital coach. Their feedback reminded us that Human-Computer Interaction is not only about usability, but about understanding expectations, motivations, and the need for personalisation. During the co-design sessions, we realised that seemingly small design decisions can strongly influence users' trust, engagement, and willingness to interact with the system. These insights help us create a digital coach that balances clinical objectives with an experience that is meaningful, accessible, and adaptable to different users' needs and preferences", said Leonardo Angelini, researcher at Haute École Spécialisée de Suisse Occidentale.

DORIAN GRAY

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Investing in the future of psychosocial dementia research: How INTERDEM Academy is preparing Europe's next generation of leaders



Fania Dassen and Sara Laureen Bartels

The INTERDEM Academy is a European training network for early- and mid-career dementia researchers affiliated with INTERDEM, a pan-European network of researchers collaborating in research on and dissemination of early, timely and quality psychosocial interventions in dementia. It aims to help young researchers develop their careers and build their capacity. Alzheimer Europe is proud to be a key partner of INTERDEM. In this article, Dr Sara Laureen Bartels and Dr Fania Dassen tell us more about the INTERDEM Academy.

Strengthening dementia research across Europe

Across Europe, dementia researchers are working to improve diagnostic processes, develop high-quality psychosocial interventions, strengthen care systems, and inform policies that support people living with dementia and their families. Yet, behind every scientific breakthrough or innovative care model stands a researcher whose own career also needed nurturing. Building scientific knowledge requires strong scientific capacity.

This is why the INTERDEM Academy was established in 2014, as part of the PRIDE project (PRomoting Independence in Dementia), funded by the NIHR/ ESRC, led by Prof. Dr Martin Orrell. This project aimed to identify how social and lifestyle changes may help reduce the risk of developing dementia and disability. PRIDE's workpackage 5 was to develop an INTERDEM Academy for career development and capacity building of researchers in psychosocial interventions and timely diagnosis in people with dementia, and to support pathways to senior academic posts. Maastricht University was appointed as the coordinating centre, with emeritus Prof. Dr Frans Verhey and Prof. Dr Marjolein de Vugt, the current chair of the INTERDEM network, initially in the lead.

As part of the INTERDEM network, the Academy nowadays supports 350+ early- and mid-career dementia researchers (EMCRs), including PhD candidates, postdoctoral researchers, clinicians pursuing research, and junior faculty members, from across Europe. Its mission is simple but ambitious: to strengthen research capacity in psychosocial dementia research by supporting talented researchers become future leaders of dementia care, research, and policy. Now lead by Dr Sara Laureen Bartels, coordinated by Dr Fania Dassen, and in collaboration with INTERDEM and Academy members, the membership continues to grow, and so does its impact.

Beyond scientific training

Beginning a research career is exciting, but it can also be overwhelming. Early-career researchers discover that conducting good science is only one part of the job. Navigating international collaborations, publishing papers, securing funding, developing leadership skills, communicating findings, and maintaining a healthy work-life balance are equally important—and often difficult to learn without guidance. As a beginning researcher, you enter the unique and also demanding world of international scientific research. In that world, certain rules, procedures, and expectations apply. Being part of an active network and making use of the knowledge, skills, and experience available can make the difference for your career. Importantly, the Academy welcomes researchers based on career stage rather than age. Whether someone has recently started a PhD, is completing postdoctoral training, or has moved into an independent research position, there is a place within the network for anyone still establishing their career in dementia research.

In-person and online masterclasses

The Academy's activities are designed around the evolving needs of EMCRs. Its in-person and online masterclasses combine scientific excellence with practical career development. Participants explore topics such as implementation science, innovative research methods, grant writing, leadership, science communication, and international collaboration. Networking is included in these masterclasses: participants and speakers exchange experiences, discuss challenges, celebrate successes, and shares what they call their "brilliant failures" - the setbacks that become valuable learning opportunities. Moreover, the online Spotlight Series allows the INTERDEM taskforces to highlight their innovative work taking place across Europe, always including at least one EMCR presenter.

> "The future of dementia research and care depends on the people who start their careers in it today."
> *Sara Laureen Bartels and Fania Dassen*



INTERDEM Academy session at Alzheimer Europe Conference, 6 October 2025, Bologna (Italy)

Annual Travel Fellowship

Knowledge exchange is further encouraged through the Annual Travel Fellowship, enabling researchers to visit colleagues in other psychosocial institutions for 1-3 months, to establish collaborations, learn new methodologies, and strengthen existing or new international partnerships. This year, the network congratulates Zsofia Szekeres, for her project "First steps towards an international citizen science active ageing programme". This one-month exchange, financially supported by INTERDEM Academy, establishes opportunities for knowledge exchange and future collaboration between researchers at the Centre for Health, Activity and Wellbeing Research, Cardiff Metropolitan University, and the PROmoting FITness and Health through Physical Activity (PROFITH) Research Group at the University of Granada.

Szofia commented: "*This Travel Fellowship will enable me to undertake an exploratory project that strengthens my research network, enhances my methodological expertise, and facilitates collaboration with European researchers and public health teams. Ultimately, this experience will support my ambition to lead innovative, solution-focused research addressing dementia prevention and health inequalities through community-based and systems-oriented approaches.*"

Publication Award

The Academy also celebrates excellence. Each year, the Publication Award recognises outstanding scientific publications by EMCRs, showcasing high-quality, wide variety in psychosocial dementia research, while increasing the visibility of emerging talent. The award is handed out during the Annual INTERDEM business meeting, preceding the Alzheimer Europe Conference, and the winner presents their article to the INTERDEM community.

Mentorship

Mentorship forms another cornerstone of the Academy. Through MENTORDEM, participants receive personalised career guidance from either an experienced senior researcher from the INTERDEM network, or a more advanced Academy member. These mentoring dyads are carefully matched on preferences and expertise by the executive office and last for at least one year. Mentorship provides an opportunity for strategic advice on career decisions, leadership development, juggling work-life balance, and navigating transitions that characterise an academic career.

The Academy's management board

Perhaps most uniquely, the Academy does not simply prepare researchers for leadership - it gives them opportunities to lead. EMCRs from the Academy can serve on the Academy's management board, contribute to the INTERDEM Board, participate in the jury of the publication award and travel fellowship, and co-lead thematic taskforces alongside senior colleagues. This shared leadership ensures that fresh perspectives are combined with experienced guidance and provide valuable leadership skills while enabling younger researchers to actively shape the future of the network itself.



INTERDEM Annual Meeting prior to Alzheimer Europe Conference, 5-6 October 2025, Bologna (Italy)

Understanding what researchers really need

The Academy continuously adapts its activities by listening carefully to its members. Dr Sara Laureen Bartels said: *"Our goal is to give everyone the best possible start and trajectory. We therefore continuously explore what early-career researchers need and tailor our activities accordingly."*

Research conducted within the INTERDEM Academy highlights EMCRs face significant challenges that threaten the sustainability of the workforce. Across Europe and internationally, researchers report a need for greater career stability, more secure funding, structured mentorship, and stronger support for professional development and collaboration. At the policy level, only few countries explicitly recognise and support EMCRs within national dementia strategies, resulting in considerable disparities in opportunities and resources. Evidence also points to mental health and wellbeing as critical concerns, with financial insecurity, career uncertainty, and imposter feelings being strongly associated with poorer mental health outcomes. Collectively, these studies underscore the need for a more supportive, inclusive, and sustainable research environment that not only attracts talented dementia researchers but also enables them to thrive and remain in the profession.

The value of belonging

For many members, the Academy's greatest strength is not only what they learn but also who they meet. Dr Esther Loseto-Gerritzen, the current conference manager at the INTERDEM Board, and an Academy member from the start of her PhD, reflects on her experience:

"INTERDEM Academy has played a very important role in my career as a PhD student and early-career researcher. Through the masterclasses, I didn't only learn a great deal about dementia, but also innovative research methods, grant writing, and how different professional disciplines work together. Perhaps the most valuable part has been becoming part of such a large network of peers. Through online World Café meetings, we brainstorm together, share experiences, and support one another. Meeting many of my Academy colleagues in person for the first time at the Alzheimer Europe Conference was an unforgettable experience."

Her experience illustrates that successful research careers are built through communities as much as through individual achievement. This focus has helped the Academy evolve into a vibrant and inclusive community rather than simply a programme of educational events. Alongside formal training, members regularly connect through the LinkedIn page, meet up at conferences and events to have both formal and informal discussions, and initiate collaborations.

For researchers working in smaller research groups, or in countries where opportunities for psychosocial dementia research are limited, an international network can provide essential support and a sense of belonging. Although the Academy has grown substantially over the past decade, its efforts continue to expand. One priority is increasing participation from Southern and Eastern European countries, facilitating that European researchers have equal access to high-quality training and international collaborations. Importantly, most Academy activities are free of charge. This commitment to accessibility reflects the belief that career development opportunities should be available based on motivation and potential rather than financial resources.

Meeting the community at the Alzheimer Europe Conference

INTERDEM's partnership with Alzheimer Europe is an important part of its success. The Alzheimer Europe Conferences provide a forum for researchers to discover the network, meet members, and explore opportunities for involvement. Dedicated INTERDEM sessions in the conference programme, bursaries supporting researchers from low- and middle-income countries, and opportunities for EMCRs to present their work creates a welcoming environment. Visitors to the INTERDEM booth can learn more about membership, share ideas about the needs of early-career researchers, and register to become part of the network.

Supporting INTERDEM Academy

The growing number of members demonstrates that EMCRs are increasingly finding their way to the INTERDEM Academy. Yet the need for investment in research capacity has never been greater. Europe's ageing population, the prevalence of dementia, and the urgent need for evidence-based psychosocial care all require a strong, skilled, and collaborative research community. Supporting EMCRs is therefore not simply an investment in individual careers, it is an investment in the future. As Sara and Fania conclude: "*If we help young researchers on their way and retain them in the field, dementia research and care will continue to improve and thrive.*"

Previously, Academy activities were supported by European initiatives such as the Marie-Curie networks INDUCT, DISTINCT and HOMEDEM, and current financial support comes from Alzheimer Nederland. For other Alzheimer Associations who wish to support the Academic practically or financially, please contact us at interdem-masterclass@maastrichtuniversity.nl.



INTERDEM Academy session at Alzheimer Europe Conference, 6 October 2025, Bologna (Italy)



INTERDEM stand at 35th Alzheimer Europe Conference, 6 October 2025, Bologna (Italy)

Marco Blom leaves Alzheimer Nederland after 29 years

After 29 years at Alzheimer Nederland, Marco Blom stepped down from his position as Scientific Director in early 2026, remaining in his role as Honorary Treasurer on the Board of Alzheimer Europe until June 2026. Upon his retirement, we asked him to look back over his time with Alzheimer Nederland and to share what it has meant to him to collaborate with Alzheimer Europe. We also spoke to Julie Meerveld, who is stepping down after 21 years working in communications, public affairs and advocacy at Alzheimer Nederland.



Marco Blom speaks at 29AEC, 23-25 October 2019, The Hague (Netherlands)

How long have you been the Scientific Director of Alzheimer Nederland and why have you decided to step down?

I started working at Alzheimer Nederland in March 1997. I changed my job from the national knowledge institute (NIZW) upon invitation from the director. My job title was Programme Manager, and I led a small team of project leads at that time. It also meant I could 100% focus on the topic of dementia. In the year 2000, I became deputy CEO and, since then, I was called scientific director in the international context. In Dutch it was "adjunct-directeur".

The decision to step down was totally on personal grounds. In the Netherlands, people retire when they are 67 years and 3 months (at least this is the case when you were born in 1961). I wanted to retire a bit earlier, though, to have enough quality time to share with my wife, children, grand-children, family and friends. And after this decision, the timing looked okay as I looked back on the organisational developments.

"The biggest achievement of Alzheimer Nederland? I think we managed to develop a great and diverse programme of activities and to grow substantially in income and number of staff."

Can you share some of your highlights from your time there and tell us what you think has been the biggest achievement of the organisation during that period?

Looking back on the period of 29 years, I'm very proud that I was able to contribute to:

- The development and growth of the Alzheimer Café initiative (also internationally)
- The start and development of six academic Alzheimer centres, including one on technology and dementia
- The numerous scientific programmes we granted, including prizes, travel grants and pilot grants for young dementia researchers
- The international activities of Alzheimer Nederland and especially the Alzheimer Europe conferences in Maastricht (2002) and The Hague (2019).

The biggest achievement of Alzheimer Nederland? I think we managed to grow substantially in income, number of staff and developed a great and diverse programme of activities on both sides of the organisation: the patient organisation (support activities, public affairs and lobbying), versus the health fund (fundraising, campaigning and scientific research). This balanced approach was visible in our corporate campaigns in which creating awareness goes hand-in-hand with creating understanding.

This was also crucial in fighting taboo and stigma.

As a member of the Alzheimer Europe Board since 2018 and as our Honorary Treasurer since 2020, how would you describe the benefits of the collaboration between Alzheimer Nederland and Alzheimer Europe?

I really enjoyed being part of the Board of Alzheimer Europe and making a contribution to the development of the organisation into an even more professional umbrella organisation for all the national members across Europe. The dedication of all the Board members and the staff of Alzheimer Europe brings a strong human factor into this work. This keeps you going.

> When I joined the Board back in 2018, I learned that Alzheimer Europe was a strong organisation both in its activities, as well as from a financial point of view. And this gives the organisation a crucial position in exchanging knowledge and ideas between national member associations and making a real difference in public affairs."



Alzheimer Nederland Dutch Dementia Researchers Conference 2026. Photo credit: Alzheimer Nederland

When I joined the Board back in 2018, I learned that Alzheimer Europe was a strong organisation both in its activities, as well as from a financial point of view. And this gives the organisation a crucial position in exchanging knowledge and ideas between national member associations and making a real difference in public affairs, setting the agenda and allowing the members to become stronger in their national activities. And all of this can be shared as well. Also, the great work of Alzheimer Europe in supporting the European Working Group of People with Dementia and the European Dementia Carers Working Group cannot be stressed enough! This approach can be a model for every member organisation.



Alzheimercafé. Photo credit: Alzheimer Nederland



Kim de Kleijn and Femke Feringa win RTA awards 2026. Photo credit: Alzheimer Nederland

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

When I left Alzheimer Nederland, the organisation was, after the Cancer Foundation and the Heart Foundation, the third leading health fund in the Netherlands. I really hope that within a few years we will be bigger than the Heart Foundation. Not because of competition, but because dementia is our biggest health issue nationally (as well as globally) in western society and is of growing importance in other societies. Within this future growth, I hope and expect that the balance between the patient organisation and

> The great work of Alzheimer Europe in supporting the European Working Group of People with Dementia and the European Dementia Carers Working Group cannot be stressed enough! This approach can be a model for every member organisation."

the health fund will be as successful as it has been until now. And more specifically for the research field: the growing research budgets must be spread between the patients of today and the future leading to breakthroughs in prevention, diagnosis, treatment (not only medical but also psychosocial) and innovative approaches in the dementia field. And who knows? Some of the breakthroughs might be brought about by Dutch researchers.

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

These last few months, I experienced what every retired person will tell you: I'm as busy as I was when working for Alzheimer Nederland, but with very different things on my agenda and with no real deadlines and less "must do's": Photography, long distance walking, a bit of travelling, seeing friends, reading and writing, and not to forget our five grandsons (ranging in age from 1-27 years!) keep us busy as well! My plan was to not have a fixed plan after retirement, and this works fine for me. I see what comes across my path. It feels as if "time is on our side", with the important thing to strive for being to stay healthy and active. And helping others when needed. That is also good to experience: to have enough time to invest in people around you.

A few words from Julie Meerveld



Julie Meerveld

Who would have thought? When I started at Alzheimer Nederland, 21 years ago, I was their first advocate for people with dementia. Nowadays, they have thousands of volunteers, active in all regions of the Netherlands, including as advocates. On 25 March 2026, I turned 67 and retired as head of the patient organisation of Alzheimer Nederland. I leave feeling melancholy and proud of the impact of our lobbying, 39 regional chapters with over 300 Alzheimer Cafés, the dementia friendly communities campaigning team and more than 1.3 million users of our online patient platform https://www.dementie.nl/.

Before working at Alzheimer Nederland, I worked as researcher at a knowledge institute. On behalf of the Ministry of Public Health, Welfare and Sports, I drew up the first National Dementia Plan (LDP) together with an expert panel (including Marco Blom!). The LDP was the first of four national strategies in the Netherlands. Alzheimer Nederland was given the role of advocating for people with dementia and their family carers, so I thought: what if I switch to work at Alzheimer Nederland to put this plan into action? The CEO at the time liked my idea and that's how I started at Alzheimer Nederland, with the assignment to develop advocacy and to increase the number of Alzheimer Cafés.

We went about this, step by step. We spent years building better support for people with dementia and their family carers. It required patience and perseverance. For example, we organised focus groups and our own "Dementia Monitor" (biennial questionnaire about experiences and needs of people living with dementia and carers, providing reliable data for Alzheimer Nederland's advocacy work), and we knew very well that people with dementia and their families needed a consistent, trusted, and knowledgeable guide throughout the whole disease process: a dementia case manager. It took time to make this happen. Important milestones included the moment that case managers became part of the basic insurance package, and when the first definition and recommendation on dementia case management was included in the "National Dementia Standard".

A lot has improved in dementia support in the Netherlands in the past 21 years. What has really helped is the growth and dual mission of Alzheimer Nederland: a future without dementia combined with action for a better life with dementia right now. Our donors increasingly supported us in that dual mission. This gave us the freedom to engage in issues and with partners we considered important, to follow our own agenda.

It gave us the opportunity to fund actions and research to boost interventions that really benefit people with dementia and their family carers, such as "Odensehuizen" (open, walk-in community centres for people with early-stage dementia and their families). It also made it possible to appoint a national Dementia Ambassador with authority to help municipalities and insurers understand the importance of timely deployment of dementia case managers.

The collaboration with Alzheimer Europe also helped a lot. Exchanging ideas is inspiring. We were able to share the concept of Alzheimer Cafés. We had access to Alzheimer Europe's studies on dementia policy. We learned from the European Working Group of People with Dementia as a powerful example of collaboration with people with dementia and family carers. And the exchange with the UK and Denmark about dementia-friendly campaigns basically empowered us to come up with our own Dutch programme: "Together Dementia-Friendly". Our special volunteers give loads of training sessions on how make life easier for and with people with dementia. We spread these trainings through the whole neighbourhood: community centres, supermarkets, hairdressers, restaurants, bus drivers, housing corporations, football clubs, etc. People with dementia tell us they want to keep participating as normally as possible for as long as possible, and a dementia-friendly neighbourhood is essential for that.

The coming years are going to be challenging. There are major issues in the world that will demand attention and budgets, alongside ageing populations and the increase in the number of people with dementia. It's up to Alzheimer organisations to keep advocating for the interests of people with dementia and their carers. I wish all the colleagues at Alzheimer Europe and Alzheimer Nederland lots of success!

A “changing of the guard” at Alzheimer Nederland

Wiesje van der Flier, former scientific director of the Alzheimer Center Amsterdam, joined Alzheimer Nederland as its new CEO following the departure of Gerjoke Wilmink in late 2025. We asked Professor van der Flier to share some thoughts on this new role and the future of the organisation.



Wiesje van der Flier

What made you decide to take the position as CEO of Alzheimer Nederland?

I have been active for more than 20 years in dementia research, the last four years or so as scientific director of Alzheimer Center Amsterdam. After all these years, I realised that as a researcher, it is very difficult to bring your innovations and new knowledge to society, to the people you designed them for. In fact, I think it is a pan-European characteristic that we are very good at science and developing innovations, but less expert in bringing these innovations to the end-users. Another realisation was that for true progress, we need large scale collaboration. Not only between different academic centres, but also cross-sectorally, with care and education, policy makers, industry, and societal organisations. When the position of CEO at Alzheimer Nederland became available, and I was invited to talk to them, I think it was these two reasons that make me decide to take the leap. Together, of course, with the fact that Alzheimer Nederland has done very well over the past years, that I have seen them grow as an organisation, and that there is an ambition to continue this growth, particularly as a health fund to support dementia-research. And with the fact that we are at a pivotal point in the Alzheimer’s field. With scientific progress continuing at an ever-increasing rate, this is the moment to take a leading role in the field. Making sure that we keep Alzheimer’s disease and dementia high up the agenda.



Left to right: Jean Georges, Wiesje van der Flier and Marco Blom, 30 June 2026, Senningerberg (Luxembourg)

You bring with you a wealth of scientific expertise. How is this helping you in your new role and how are you finding the transition from your previous role as Scientific Director of Alzheimer Center Amsterdam at Amsterdam UMC?

Slightly more than half a year into the new role, I am still discovering what the role of a patient organisation is, and what my personal role within that organisation can be, and this voyage of discovery has been a pleasure until now. I find that bringing the in-depth knowledge of the diseases that cause dementia as well as the scientific progress which is being made both in the Netherlands and worldwide, provides real value to the organisation. Progress and innovation come from the scientific field. As a patient organisation, it is our job to make sure that we provide access to this information and innovation, for people living with dementia and their families. Hence, knowing what is happening “out there” is crucial. As such, it is also proving a huge asset that the network in my former role largely overlaps with that of my new role, which sets the stage for a seamless transition.

To make sure that I remain sufficiently “nourished” scientifically, I hold an endowed professorship at Amsterdam UMC, department of Epidemiology and Data Science. I spend my Fridays in academia, and this makes for a very

nice combination and balance. Where in my former role I ensured that our centre would design the best and most helpful projects, ensuring maximum scientific progress; now, in my current role I see it as one of the most important tasks to make sure that on a national level, we make sure that we secure as many funds for dementia research as we can, dedicating these funds to the best projects. And in my view, these projects can best be executed collaboratively, in consortia. As such, I think of all dementia researchers together as "team NL".

What are your main hopes and aims for the organisation in the coming years?

My hope for the organisation is that we continue to thrive, as we have done before, and that we see real progress being made for people living with dementia. To achieve this, we need to act in two directions:

One is acting early; we need to move towards broad prevention, and by this, I mean prevention on three levels: (1) preventing brain disease, e.g. through lifestyle strategies and/or cardiovascular risk management; (2) preventing dementia, even when early brain disease has started, e.g. with pharmacological strategies, the first of which we see now emerging with both lecanemab and donanemab having been granted market access in the EU; (3) preventing high intensity care, e.g. by promoting care and wellbeing, supporting caregivers and leveraging technological developments.

The second broad direction of action is towards collaboration. The challenges posed by dementia are of such magnitude, that no organisation can solve these on their own. For this we need to embark upon large-scale and cross-sectoral collaboration. As such, we are building an Alzheimer's coalition of the "doing"; persons and organisations from all directions, who all realise the importance of acting collectively and boldly, to make sure that we move towards personalised medicine for Alzheimer's disease, at the same time as keeping care accessible, scalable and equitable.

alzheimer nederland

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Beyond memory: Keeping connected with the "shadow persons" of dementia

On 2 June 2026, a unique Round Table discussion on dementia took place under the chairmanship of His Majesty the King of the Belgians at the Royal Palace in Brussels. The central theme of this Round Table: "Maintaining Connections with the Shadow Persons of Dementia and Strengthening Informal Care". Alzheimer Europe was delighted and honoured to be at the table. The Round Table formed part of the Royal Palace's broader commitment to creating a dementia-friendly society and preceded the opening of the exhibition "The Royal Palace as a Memory Palace".

On 2 June 2026, a unique Round Table discussion on dementia took place under the chairmanship of His Majesty the King of the Belgians at the Royal Palace in Brussels (Belgium). The central theme of this Round Table: "Maintaining Connections with the Shadow Persons of Dementia and Strengthening Informal Care".

The Round Table brought together Alzheimer organisations, researchers, clinicians, policymakers, artists, people living with dementia and informal caregivers. The discussion was preceded by a heartfelt performance by De Betties, the intergenerational choir of Huis Perrekes (internationally acclaimed residential care centre for people with dementia, located in Oosterlo, Geel, Belgium). Through culture in its broadest sense, the choir raises awareness of dementia and the people whose lives it touches. The Round Table formed part of the Royal Palace's broader commitment to communicating the importance of creating a dementia-friendly society and preceded the opening of the exhibition "The Royal Palace as a Memory Palace" in the historic Mirror Room of The Royal Palace in Belgium.

The active participation of Alzheimer Europe, alongside the moral support of Alzheimer's Disease International, highlights the Royal Palace's leading role in promoting a forward-looking and inclusive approach to dementia. This initiative positions Belgium as a pioneer in fostering a dementia-friendly society and offers an example that could inspire similar efforts in other countries.

A round table symbolises equality, dialogue and shared responsibility. Around the King's table, representatives of Alzheimer organisations from across Belgium met as equal partners with professionals, researchers, civil society and lived-experience voices. The meeting itself became the birthplace of a new form of national collaboration, answering His Majesty the King's invitation for stronger and more innovative partnerships. It marked the official creation of the Dementia Alliance Belgium, a new network organisation whose beating heart consists of Belgium's patient organisations in the Alzheimer domain, united across linguistic and regional boundaries. Designed as an inclusive alliance with the potential to grow over time, the Dementia Alliance Belgium defines itself through a clear and explicit commitment to the often-overlooked "shadow persons" of all forms of dementia—recognising and empowering the families, loved ones and other informal caregivers whose lives are profoundly affected by the condition.

Dementia: the wider societal implications

Today, more than 220,000 people in Belgium and over 12 million people across Europe are living with dementia, highlighting the growing societal impact of the condition. Behind these figures are millions of families, friends, and communities whose lives are intertwined with dementia, yet they remain in the shadow—too often unseen in research, policy, and practice. By 2050, around 340,000 people in Belgium and nearly 20 million across Europe are expected to be living with dementia. How can we respond in ways that are evidence-based, hopeful and centred on enabling people with dementia, their families and their communities to continue living well?



Performance by De Betties (intergenerational choir of Huis Perrekes, Belgium)



Roundtable at the Royal Palace, 2 June 2026, Brussels (Belgium)

The message of the Round Table was unequivocal: dementia is not merely a medical condition, but above all a societal challenge. Responding effectively therefore requires collaboration across disciplines, sectors and communities. Although the search for effective treatments must continue, hope cannot rest solely on the prospect of a future cure. We must also invest in what already makes a difference today: evidence-based psychosocial interventions, the prevention of dementia, and communities that foster understanding, inclusion and human connection. This balanced approach offers a hopeful and realistic way forward for people living with dementia, their families and society as a whole.



Participants at the roundtable at the Royal Palace, 2 June 2026, Brussels (Belgium)

Bringing the "shadow persons" into the light

Around 70% of people living with dementia continue to live at home, supported primarily by family members and informal caregivers. This means that dementia affects far more people than prevalence statistics suggest. These relatives and friends are often invisible in policy, research and public debate. They carry emotional, practical and social responsibilities while enabling people with dementia to remain connected to daily life. The Round Table deliberately referred to them as the "shadow persons" of dementia. The term was introduced to draw attention to a broad group whose roles and experiences are not fully captured by existing terms such as informal caregivers, care partners or family members.

The term "shadow person" is both descriptive and transformative. In this context, "shadow persons" refers broadly to relatives, care partners, friends and others whose lives and relationships are substantially affected by dementia, whether or not they identify as caregivers. It acknowledges that these individuals are deeply embedded in the dementia journey, yet often remain unseen, while simultaneously reframing their role: they are not merely bearers of burden, but essential contributors to connection, continuity, and identity.

Beyond the pill and beyond the individual

Professor Manu Keirse (KU Leuven) reminded participants that dementia cannot be understood solely at the level of the individual. It affects not only the person diagnosed, but also their immediate social environment, which becomes an essential part of the lived reality of the condition. He therefore argued that responses to dementia require us not only to think beyond the pill, but also beyond the individual, recognising that care, meaning and resilience are fundamentally relational.

Within this broader perspective, attention was drawn to an often-overlooked group: children. Although seldom included in dementia discourse, they bring openness, spontaneity, playfulness and creativity that can be understood as essential social resources in how societies engage with dementia. Far from being mere observers, they play an active role in enabling more humane and imaginative forms of connection.

The pivotal moment after receiving a diagnosis

According to Peter Van Houtven (Alzheimer Liga Vlaanderen), one of the most overlooked moments in the dementia journey is the period immediately following diagnosis. It is precisely at this point that support is often insufficient, not only for the person receiving the diagnosis, but equally for their close environment. Yet this is the moment when guidance and relational support are most needed. Even in the presence of a difficult diagnosis, quality of life can remain meaningful for much longer than is often assumed, provided that people are placed in a position of strength rather than helplessness.

Without adequate support at this stage, an overwhelming sense of powerlessness can emerge, affecting both the individual and those around them. The objective should be to prevent this dynamic by ensuring timely, structured and compassionate support systems. At this crucial moment within the trajectory of the condition, it should not be understood as a moment of withdrawal, but as a moment of opportunity in which people can still be actively empowered and supported to maintain agency, confidence and connection.

Prevention of dementia and social connection

Professor Sebastiaan Engelborghs (Vrije Universiteit Brussel) emphasised that dementia is not an inevitable consequence of ageing and that this insight should move society away from fatalism. According to the 2024 publication of The Lancet Commission, addressing 14 modifiable risk factors could potentially prevent or delay around 45% of dementia cases. Several of these factors—including social isolation, hearing loss and depression—are closely linked to human connection.

He also pointed to progress in blood biomarkers and disease-modifying treatments, while warning that prevention, early diagnosis and innovation must remain accessible to everyone. Informal care is not an optional addition to professional care, but an essential link in prevention, early recognition and preserving dignity. Partners, relatives, friends, neighbours, volunteers and patient organisations often notice changes before formal services do and help people remain connected to their environment and to themselves. Research and treatment must go hand in hand with support

for caregivers, patient organisations and accessible community-based prevention. If we approach dementia only medically, we see the disease; by preserving connection, we continue to see the person.

Art as connection: when emotion speaks beyond dementia

Conceptual artist Sven Unik-ID offered a deeper reflection on human connection. Using DNA and biological networks as a metaphor, Sven Unik-ID described human beings as shaped by multiple layers of connection. Beyond this lies a more abstract, shared dimension of human existence: a world of emotion, perception and meaning that connects people beyond language and cognition. This "felt" dimension of connection allows human beings to remain linked far longer than communication alone would suggest. Even when speech and memory become fragile, a deeper relational space can continue to exist.

Within this space, art becomes essential. Through imagination, creativity and wonder, it enables people to reach the "shore" of the other, even when direct communication becomes difficult, sustaining connection beyond cognitive decline. Sven Unik-ID forms part of the artistic duo Unik-ID, responsible for the creative development of the exhibition "The Royal Palace as a Memory Palace."

Alzheimer patient organisations unite: Dementia Alliance Belgium

Sabine Henry (LINAL – National Alzheimer League) emphasised the strong commitment of the National Alzheimer League and its regional members in Flanders, Wallonia and the German-speaking community in Belgium, to the Memory Palace initiative at the Royal Palace. She highlighted the narrative of the exhibition, characterised by originality and artistic quality, as well as its capacity to connect stakeholders and the wider public. The project demonstrates how dementia can be brought into the cultural and societal centre rather than remaining at the margins.

"L'union fait la force" ("unity is strength") is one of the central credos of the Royal Palace. This principle finds concrete expression in the creation of a new entity, Dementia Alliance Belgium. Within this alliance, the country's



Exhibition at the Royal Palace, July 2026, Brussels (Belgium)

Alzheimer patient organisations come together as its beating heart. Such an alliance strengthens national collaboration and ensures that "shadow persons" are placed more centrally in the narrative on dementia in the coming years, both in policy and public discourse.

From national alliance to European urgency

Angela Bradshaw (Deputy Executive Director, Alzheimer Europe) placed the discussion within a broader European policy context, stressing that dementia represents one of the most urgent public health challenges in Europe. Prevalence is expected to nearly double by 2050, placing increasing pressure on health and social care systems across all Member States. In this context, it was emphasised that collaborative networks are indispensable to accelerate innovation, deepen understanding of social and relational determinants and improve the quality of life of those affected, while simultaneously preventing structural overload of care systems.

It was underlined that such collaborative networks must not only engage clinicians, researchers and policymakers, but also actively bring "shadow persons" out of their invisible positions, ensuring their roles, needs and lived realities are fully recognised. From this perspective, Alzheimer Europe welcomed the development of Dementia Alliance Belgium, describing network-based initiatives as essential building blocks for translating shared vision into concrete policy impact at the European level.

Mobilising for tailored support

Lydie Amici (Collectif Auguste et les autres) underlined that early-onset dementia can strike people as young as their forties or fifties, often while they are still leading active professional and personal lives. Spouses, children, and parents become both caregiver and voice for a loved one who fits no existing category: too young for services designed around the elderly, yet facing a condition typically associated with old age. This mismatch leaves families searching relentlessly for support genuinely tailored to the person's needs, rather than settling for what already exists. Timely planning, rather than passive waiting, helps families avoid choices later forced upon them by emergency. To keep going, caregivers must set aside what is lost and what will never be, focusing instead on what remains, day by day. The Collectif works to raise professional awareness of the distinct challenges of early-onset dementia. It also engages experts, contributes to psychosocial research, and builds activities responsive to families' needs.

The voice of caregivers and lived experience

The perspective of lived experience was shared by Christiane Gathoye (care partner) and Philippe Paquay (person living with Alzheimer's disease). They described how uncertainty in the wider social environment often shapes interactions after diagnosis. Many people do not know how to respond, leading to avoidance or emotional distance. When interaction does occur, it may be marked by pity or a sense of finality.

Against this background, they emphasised a crucial message: a meaningful and high-quality life with dementia often remains possible. They described how humour, shared experiences and a focus on remaining abilities shape their daily life. Rather than approaching dementia from a

perspective of loss, they start from strengths and capacities. This strength-based approach allowed them to maintain continuity in life, including participation in familiar activities such as tennis for as long as possible. Their testimony highlights a fundamental gap between societal perception and lived reality: where one sees decline, the other often experiences adaptation and continuity.

Resonance as a model for communication

Alessandra Clavello, Director of the nursing home Foyer de la Providence (ACIS asbl), highlighted the possibility of welcoming people living with dementia from home into a daycare centre integrated within a residential care unit. This approach provides much-needed respite for family caregivers while facilitating a gradual integration into a living environment for people with dementia, and maintaining their connection to the outside world. She also explained that communication with people living with dementia often requires adaptation rather than correction. Meaningful interaction, she noted, emerges through resonance: a process of attunement in which both parties adjust to each other's rhythm, rather than insisting on a rigid or conventional exchange.

She referred to the relational swing created by artists from Unik-ID and based on Kasper Bormans' "resonance method," highlighting that society must go beyond improving communication in dementia care and also prioritise intergenerational connection. A prototype of this swing has been donated by Ligue Alzheimer ASBL to one of its care facilities. Described as an "artwork that can be used," it encourages visits from nearby primary schools and attracts local residents who increasingly pause and pass through the garden. Like a shared movement on a swing, connection arises when both sides adapt rather than control. These moments of resonance help sustain dignity and emotional wellbeing.

Protection and support through collaborative policymaking

Pedro Facon, CEO of the Belgian National Institute for Health and Disability Insurance (RIZIV-INAMI), stressed the importance of continuously improving the care organisation and evidence-based reimbursement of innovation. People with dementia and their environment deserve a care organisation that is adapted to and supports their needs. Even if arrangements for reimbursement of medical costs caused by dementia already exist and financing of care via the memory clinics is guaranteed, the work is not yet finished. Offering integrated and person-centred care through care pathways is an important strategic objective of RIZIV-INAMI. These need to be designed in close collaboration with experts, health and care professionals, and – last but not least – with patient organisations and their environment. Promising innovative medicines are being developed by the pharmaceutical industry that go beyond the treatment of symptoms, trying to slow down or even prevent dementia. If these medicines can effectively prove their value for the patient, reimbursement will be considered, even if not all can be expected from medicines. Finally, the round table also stressed the importance of prevention through health lifestyle, as proven by scientific research.

The Memory Palace: bringing dementia into society

The Memory Palace exhibition at the Royal Palace demonstrates that dementia belongs not at the margins of society, but at its centre. Insights from participants at the Round Table converge on a central understanding: dementia cannot be fully grasped at the level of the individual alone. While person-centred care remains essential, it must be complemented by a stronger emphasis on relationships, since communication, dignity and quality of life depend not only on clinical care but also on the strength of human connection. This calls for a shift towards relationship-centred care, in which families, caregivers and communities are recognised as essential partners.

The future challenge can be summarised in two priorities: making "shadow persons" more visible and recognising them not only through the responsibilities they carry, but also as active makers of connection, continuity and meaning. While research continues to advance treatment and prevention, human connection remains one of our most powerful resources in dementia care.

More than 125,000 international visitors came to the Royal Palace this summer and visited the exhibition "The Royal Palace as a Memory Palace".

Some feedback about the Memory Palace exhibition



King and Queen of the Belgians at Memory Palace exhibition

"We live in an era in which individual independence and achievement take centre stage. But the strength of a community is also measured by the way it cares for its most vulnerable members. I am thinking in particular of those whose cognitive abilities are gradually fading away. I have the greatest admiration for the caregivers, the associations, and everyone who supports these patients and provides them with a safe environment – while respecting their dignity. Should we not take inspiration from them and bring more humanity and tenderness into our society? It is with this thought in mind that we chose to dedicate one of the exhibitions at the Royal Palace this summer to communicating with people living with dementia."
His Majesty the King of the Belgians

"The exhibition reminded me once again how much initiatives like these are enriched by the involvement of people living with dementia and family carers. Their lived experience brings a perspective that cannot be replaced by professional expertise alone. I was also struck by the fact that dementia has found a place within the Royal Palace. The involvement of both the Belgian Royal Family and the Flemish Minister for Welfare sends a powerful message, that dementia is not solely a healthcare issue, but rather a societal challenge that deserves visibility, understanding and political commitment."
Annick Germeys, member of the European Dementia Carers Working Group and carer for her husband, Geert

"As members of Alzheimer Liga Vlaanderen, we were grateful to contribute our voices to this conversation. Every opportunity to bring together policymakers, researchers, artists and people with lived experience helps build a more dementia-inclusive society."
Geert Mathys, living with dementia

Building "Strong Communities Without Age Barriers"

Alzheimer Bulgaria Association reports on its work, together with the Razvitie–1892 Community Centre in Byala Slatina, forming a Local Action Group to create dementia-inclusive communities in Northwest Bulgaria. The project is called "Strong Communities Without Age Barriers".



Local Action Group members are proud to hold their training certificates

Strong communities are not built only by projects. They begin when people get together, listen to one another, and decide that they can make a difference together.

A few months ago, Alzheimer Bulgaria and the Razvitie–1892 Community Centre in Byala Slatina launched the project "Strong Communities Without Age Barriers". Choosing this participant centre as a local partner was not incidental. It is a natural gathering place for community life, volunteering and civic engagement. In this place, people of different generations can meet, learn from one another and build meaningful connections.

The project's main objective is to encourage the active participation of people aged 65 and over in community life, while raising awareness of the challenges with which people living with dementia and their families are faced. The initiative is being achieved with the support of the Swiss–Bulgarian Cooperation Programme through the Civic Engagement and Transparency Facility (CETF) 2024–2029.

Local Action Group and training

The project has now entered its next phase, and after a series of introductory meetings and discussions, a Local Action Group has been established, bringing together participants from the town of Byala Slatina and the neighbouring communities. The group includes representatives of local authorities, health and social care services, the community centre, civil society organisations, volunteers and active citizens. Despite their different backgrounds, they share a common goal: to develop effective practical solutions that improve the support for people over 65, and to build a community where people with dementia are recognised, valued, involved, seen and included.

As part of the project, a series of training sessions has also begun for the members of the Local Action Group and volunteers. The first training took place in the city of Vratsa and combined theory in the form of expert presentations, practical exercises and real case-based learning. The aim was not only simply to increase the participants' knowledge about dementia but also to encourage them to exchange ideas, work collaboratively and develop initiatives that could be implemented within their own communities. Through an interactive "true or false?" game, the participants discussed common myths about dementia and compared them with evidence-based facts. The discussion naturally evolved into a conversation about stigma and its impact on people living with dementia and those who care for them.

Particular attention was given to the person behind the diagnosis. Real-life examples from the experience of Alzheimer Bulgaria illustrated the wide range of challenges families face and highlighted the importance of understanding, patience and timely support. Participants explored not only the problems but also practical solutions that could be developed at community level.

The second part of the training focused on communication with people living with dementia. Through role-play and paired exercises, participants experienced everyday situations from different perspectives—as a person with dementia, a family member or a volunteer. These activities made the discussions more personal and demonstrated how respect, empathy and calm communication can make a real difference in daily interactions.

Focusing on rights, dignity and respect

The rights of older people also prompted lively discussion. Using practical examples, participants explored ways to protect dignity, personal choice and the right of people living with dementia to remain active members of society. The conversation reinforced an important message: good care goes far beyond health and social services—it begins with respect for the individual.



Training session

Special attention was also paid to the role of communication in building strong local communities. Participants discussed different approaches to engaging volunteers, partners and supporters, emphasising the power of personal example, trust and authentic storytelling. They agreed that lasting change begins when more people recognise a cause as their own.

The training concluded with a practical simulation of a Local Action Group meeting. Taking on different roles, participants identified institutions and organisations that could support the initiative and outlined the first concrete steps for future action. For many, it was the first opportunity to sit around the same table, hear different perspectives and work together on a real community issue.

The importance of dialogue for understanding and change

The exercise clearly demonstrated the value of dialogue between people with different experience and expertise. When everyone has the opportunity to be heard, new ideas emerge—ideas that would rarely arise within the boundaries of a single institution. This is how communities gradually become places where people living with dementia and their families can count on greater understanding, stronger support and meaningful participation in community life. The project will continue with further training sessions, meetings and local initiatives that will expand the work of the Local Action Group. One of the next milestones will be the development of a Concept for the Participation and Support of People Aged 65+, based on the ideas and experience shared by the local community. ultimately, the project's success will not be measured by the number of meetings held or participants trained. Real change begins when people talk to one another, work together to find solutions and take personal responsibility for the wellbeing of their community. This is how inclusive communities are created—communities where people living with dementia and their families are treated with understanding, dignity and respect.

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Tallinn University students organise “memory cafés” in cooperation with Estonian dementia society

A group of students from Tallinn University recently organised a series of “memory cafés” in cooperation with the Estonian dementia society NGO Elu Dementsusega (Life with Dementia). Chris Ellermaa, Board member of NGO Living with Dementia, and Marten Sestverk, ELU project student (who contributed to communicating the experiences and needs of people affected by dementia and their families), tell us more.



Although memory cafés have been used in many parts of the world for years, such gatherings are still not very common in Estonia. At the same time, dementia and the need to support relatives and caregivers are being discussed more and more, and increasing attention is being given to finding ways to provide people with dementia and their loved ones with a supportive and safe environment outside traditional support services.

As part of the ELU (Interdisciplinary Innovation) project, students from Tallinn University organised three memory cafés in cooperation with the NGO Elu Dementsusega (“Life with Dementia”). The aim of the project was to give people with dementia and their loved ones an opportunity to come together, communicate, share experiences, and reduce the stigma and social isolation associated with the condition.

ELU is a course at Tallinn University designed to bring together students from different academic fields to solve a social issue collaboratively or carry out a community-supporting project. The memory café project also involved students from very diverse backgrounds, whose knowledge and skills helped create a supportive and versatile environment.

Students from journalism, psychology, social work, special education, youth work, health management, advertising, and public relations participated in the project. Some contributed more to communication and participant support, while others focused on organisation, activity planning, or increasing the project’s visibility. Collaboration between students from different disciplines made it possible to approach the topic from multiple perspectives and share knowledge among themselves. Before organising the events, the students familiarised themselves with scientific sources related to dementia and planned the café activities in a way that would be simple, calm, and safe for participants.



The goal of the memory cafés was not only to provide information but also to create an environment where people would feel that they were not alone in their situation. In addition to affecting memory and thinking, dementia often impacts communication, self-esteem, and everyday life. As a result, both people with dementia and their loved ones may experience loneliness, social isolation, and the feeling that they are not fully understood. During the project, organisers highlighted that stigma and low levels of awareness related to dementia are still significant issues in Estonia, and that some people may fear attending such gatherings because of possible judgment from others they know.

In total, three memory cafés were organised during the project. Although the number of participants remained relatively modest, the organisers felt that smaller groups created a more personal and peaceful atmosphere. The value of the project was measured not only by the number of participants but also by the emotional support and experience people gained from the meetings.

At the memory café in the town of Keila, participants played bingo, used kinetic sand, and were offered tea, coffee, and pancakes. There was also a small advice corner for

relatives and caregivers with practical tips. According to the organisers, this kind of direct interaction made the gathering special and gave them the feeling that the initiative truly mattered. Most importantly, participants were able to feel comfortable without fearing awkward situations or judgment. The calm atmosphere and small group size allowed people to communicate with one another and simply spend time together.

At another of the memory cafés, participants took part in various enjoyable activities. Together they made a biscuit cake, decorated cake boxes, and used kinetic sand as a relaxing activity. The organisers also created a small museum corner displaying vintage objects such as tableware, dolls, magazines, and an old telephone, which helped participants recall earlier times and share memories with one another. Guests were offered tea, coffee, sweets, and pastries, creating a warm and welcoming atmosphere. Such gatherings gave people an opportunity to socialise, gain new experiences, and simply spend time together.

At the other café, activity stations were created for participants. Each station had its own theme: a memory table with photographs of old objects, machines, and locations; a paper activity table with simple mandalas, sudoku puzzles, and proverb-matching exercises; as well as various board games. There was also a discussion corner with the project supervisors, where participants could talk about dementia-related topics and ask questions. Throughout the event, free snacks, fruit, and tea were offered.

According to the organisers, the cafés showed that even a small and peaceful gathering can mean a great deal to people. In addition to benefiting participants, the project also had a significant impact on the students themselves, whose understanding of dementia and its effect on everyday life increased considerably during the organisation process.

In the students' opinion, there should be more, similar initiatives in Estonia, as memory cafés help make conversations about dementia feel more natural and provide support for both people with dementia and their loved ones. Often, it is enough for a person to simply feel heard and understood.





Ten years of Dementia Friendly Communities in Italy: from local action to shared responsibility

More than 70 Dementia Friendly Communities active across 36 provinces in 13 regions, 10,000 people with dementia and family members involved, and 7,700 citizens trained. These achievements were highlighted at the National Conference "Ten Years of Dementia Friendly Communities: From Building to Collective Responsibility", organised by Federazione Alzheimer Italia on 22 May 2026.



Participants at the conference, 22 May 2026, Italy

Launched in 2016 with the pilot project in Abbiategrasso (Milan), over the past ten years the Communities have promoted hundreds of initiatives in different areas – public awareness and training, cultural, recreational and support activities – involving more than 700 volunteers and more than 220 initiatives co-designed with people living with dementia. The conference provided an opportunity to showcase some of these experiences, demonstrating how supportive relationships and welcoming environments can make a tangible difference in the lives of people with dementia.

"Over the past ten years, we have seen something emerge that goes beyond individual projects: communities that are learning, step by step, to recognise and embrace dementia while combating stigma and isolation", said Katia Pinto, president of Federazione Alzheimer Italia. *"The experiences we are hearing about today show that we can all play a role: public services, schools, cultural institutions, local businesses and individual citizens. Shared responsibility is something very concrete, taking shape every day in the way we choose to relate to people with dementia in our cities and towns".*

This message was echoed by Susana Inguil, a person living with dementia who shared her personal experience: *"It is important to involve people, because that way we feel valued and not excluded".*

Throughout the conference, a strong focus emerged on listening and participation, with initiatives addressing different aspects of everyday life. In Gavirate (Varese), the Atelier Rughe project uses creativity to promote participation, self-expression and wellbeing among people with dementia and their families, while in Ranica (Bergamo), Social Theatre workshops help participants rediscover new forms of empowerment and freedom. Collaborations with universities and research institutions are also playing an increasingly important role. These include the Daring project, promoted by the Dementia Friendly Community of Bari and focused on technological innovation in dementia care, as well as a partnership between the Dementia Friendly Community of Ivrea (Turin) and the University of Turin's School of Nursing to develop practical tools and educational activities.

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Another example is "Un cinema per Amico" ("A Cinema for a Friend"), a programme of dementia-inclusive screenings organised by Cinema Ariston in Trieste in collaboration with Fondazione Associativa Goffredo de Banfield and La Cappella Underground. The initiative received Federazione Alzheimer Italia's "Inclusive Realities" Award, which recognises outstanding experiences contributing to a more dementia-friendly society.

Many Communities also use cognitive stimulation activities as a way of creating opportunities for social interaction and participation. The Bottega dei Saperi ("Workshop of Knowledge") in Roverbella (Mantua) combines different approaches to enhance people's remaining abilities and support their active involvement, while initiatives in Sassoferrato (Ancona) are built around a broad local network involving citizens, volunteers and institutions. In Scanzorosciate (Bergamo), the walking groups "A S(p)asso Lento" are designed for people who are more vulnerable or at risk of isolation, bringing together physical activity, social engagement and neighbourhood networks through adapted routes and the support of trained volunteers.

The conference also featured the presentation of the Dementia Friendly Hospital Guidelines. Developed by Federazione Alzheimer Italia together with hospitals from across the country, the guidelines are intended for healthcare settings wishing to become more dementia-friendly and better respond to the specific needs of people with dementia and their families.

Throughout the day, conference participants and members of the public in Bari were able to visit the exhibition "10 Years Together", set up in the square outside the Kursaal Santalucia Theatre. Through photographs, words and testimonies collected from local communities, the exhibition illustrated how Dementia Friendly Communities are making a real difference in practice. Open to the public, it allowed stories, experiences and good practices to extend beyond the conference venue and connect with everyday life in the city, engaging visitors in a shared reflection on dementia.

Human Rights in Dementia Care: A Good Practice Guide

A book titled "Human Rights in Dementia Care: A Good Practice Guide" was launched some months ago at a special event held at Trinity College Dublin (Ireland). The book was co-authored by Prof. Suzanne Cahill, Dr Fiona Kelly and Dr Helen Rochford-Brennan. We asked all three authors to share their thoughts about the book, which aims to provide the tools required to enable paid and unpaid caregivers to use a human rights-based approach in dementia care.



Left to right: Helen Rochford-Brennan, Fiona Kelly and Suzanne Cahill.

Suzanne Cahill, TCD School of Social Work & Social Policy, Trinity College Dublin

Having worked in the field of dementia care for most of the last 35 years, I have over the years struggled to identify a useful theoretical framework to better understand the experiences of people living with dementia.

For example, in the context of dementia, theories on personhood are often open to interpretation. And person-centred care as an approach is not always easy to operationalise, nor is it informed by legislation.

It was during an Alzheimer Europe Conference hosted in Ireland in 2005 that I was first exposed to the human rights-based framework. This was through the powerful keynote presentation delivered by Gráinne Mc Gettrick who at the time received a standing ovation.

There and then, we were reminded that every aspect of dementia care has a human rights dimension and a person's human rights should never be surrendered simply because they have dementia.

Suddenly the penny dropped: the rights-based approach made a lot of sense for me. It built on personhood theory but in addition, it provided legal safeguards protecting the person's dignity, autonomy and right to participate. It ensured that best practice in dementia care complies with national and international legislation.

In fact, so important was this critical perspective that it inspired me to write my first book on Dementia and Human Rights. In that book, I argued that the voice of the person living with dementia must at all times be heard, facilitated and supported and that even minor human rights breaches that occur every day can erode dignity and identity.

This new book: "Human Rights and Dementia a Good Practice Guide" extends the debate further. It is, as the title suggests, a Practice Guide. Hence its target audience are those working with or caring for a person with dementia, who wish to advance their practice beyond the narrow constraints of more traditional biomedical approaches. It is hugely enriched by the input of my co-authors Dr Fiona Kelly, a nurse and social gerontological academic, and Dr Helen Rochford Brennan, a person living with dementia.

Throughout the chapters, we provide the reader with a down-to-earth translation of complex dementia-related topics, familiar to most family caregivers and health service professionals.

We identify many of the human rights most of us take for granted, but we know can be threatened during the course of dementia. We align these rights with principles set down in Conventions and legislation and we provide the resources needed to help practitioners and family caregivers ensure that the person's rights are always upheld and respected.

We identify some reasons why rights violations can occur. Examples include congregate care settings, inadequate staff/resident ratios in care homes, limited staff training and support, poor clinical leadership and restrictive organisational cultures.

We argue that human rights violations can be both macro or micro but regardless of their scale, any violation that affronts dignity and autonomy will be harmful to the person's physical and mental health and to their overall quality of life.

We hope that by bringing alive the research evidence and by drawing on practice and policy directives, this book may help the

reader better value and apply the human rights-based approach.

Throughout the chapters we provide real life case studies, review exercises, and wherever relevant, connections to on-line resources including research reports and scientific papers.

We believe that this book is greatly needed as despite advances in thinking about dementia, paternalistic practices along with myths and misunderstandings continue to exist. These place the person at risk of being mal-treated, neglected and, in extreme cases, abused. We hope you will find this book a useful guide to best practice.

> "Human Rights in Dementia Care powerfully illustrates how a rights-based approach can be applied from diagnosis through to end-of-life care. Grounded in lived experience, practical models, and the application of international conventions, this book is an essential guide. It challenges us all-constructively and positively-to reflect on and transform our approach to dementia care in Ireland."
> *Andy Heffernan, Chief Executive, The Alzheimer Society of Ireland*

Fiona Kelly, former Lecturer in Nursing, School of Health Sciences, Queen Margaret University, Edinburgh (Scotland)

This book is the result of many years of thoughtful, questioning practice and a growing understanding of the importance of embedding a human rights-based approach within everyday practice. There have been several inter-connected "lightbulb moments" during my time as a researcher and nurse working mainly with people with advanced cognitive impairment due to dementia, and many who were nearing the end of their lives. The first "lightbulb moment" was in 2003 when I read Tom Kitwood's seminal book "Dementia reconsidered: the person comes first" published in 1997. Here, he described types of behaviours from practitioners towards people with dementia that can either uphold (for example, through recognising, valuing or celebrating), or threaten (for example, through denying, disempowering or infantilising) their personhood. The second "lightbulb moment" was also in 2003 when I read Steven Sabat's book "The Experience of Alzheimer's Disease: Life Through a Tangled Veil" published in 2001. Here he described each person's aspects of self (Selfhood) and how they can be nurtured or damaged through interaction with other people. The third "lightbulb moment" was reading the Scottish Human Rights Commission practice guide "Care about Rights" published in 2010. This guide provides accessible, practical information on the human rights relevant to older people and the steps practitioners can (and should) take to uphold these rights. As I read each book, I reflected on how my nursing, research and everyday practice might impact either positively or negatively on the people I encountered, and I adjusted my interactions to promote positive experiences and outcomes and to role-model to others what a human rights-based approach looks and feels like within dementia care. Writing this book with my co-authors has been a natural next step in introducing and encouraging a human-rights based approach within practice.

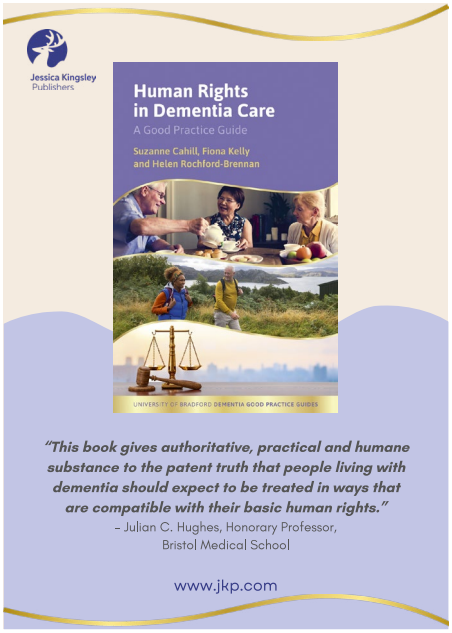
We hope our book will de-mystify a human rights-based approach by outlining the origins and evolution of human rights and by introducing human rights relevant to people with dementia from pre-diagnosis to death. We want to bring to life what a human rights-based approach might look like in practice, and we do this by providing examples from our research and practice of how human rights have been upheld or not. Importantly, in those cases where a person's human right was denied or infringed, we show how an alternative approach (for example focussing on upholding personhood or recognising and supporting selfhood) could have had a fundamentally different outcome. Finally, we want to empower and inspire practitioners, family members and people with dementia to role-model and advocate for a human rights-based approach wherever and whenever they can.

Helen Rochford-Brennan LLD, Global Dementia Ambassador and former member and Chairperson of the European Working Group of People with Dementia

Being invited to co-author Human Rights in Dementia Care: A Good Practice Guide has been one of the greatest privileges of my advocacy journey. Too often, as no doubt you are aware, people living with dementia are consulted after decisions have been made. This Good Practice Guide is different. It demonstrates the value of working together as equal partners, where lived experience sits alongside academic and professional expertise.

Human rights are not abstract legal principles. They are about everyday life: the right to be listened to, to make our own choices, to remain connected to our communities, and to continue contributing to society after a diagnosis (as I live everyday).

My hope is that this guide encourages professionals, families, policymakers and communities to see people living with dementia not for what we may have lost, but for what we continue to contribute. When we genuinely include lived experience, we create better practice, better policies and, ultimately, better lives.



Minister for Older People and Housing outlines the state of play for dementia policy in Ireland

Marking the occasion of the 36th Alzheimer Europe Conference, in Dublin, Ireland, we spoke to the Irish Minister for Older People and Housing, Kieran O'Donnell, about dementia policy in Ireland. In this article, he looks back on the progress made since the country's first national dementia strategy in 2014, the development of the Dementia Model of Care and working with The Alzheimer Society of Ireland as a key partner.



Minister O'Donnell (furthest right) in Waterford in June 2026

Ireland's National Dementia Strategy was published in 2014 – how has dementia policy in Ireland developed since then?

The National Dementia Strategy was developed to improve dementia care across the Irish health and social care system so that people with dementia can live well for as long as possible, and can have services and supports delivered in the best way possible.

The strategy focused on raising public awareness, reducing stigma, improving information, and enhancing training for health and social care professionals, frontline staff and family carers. It also highlighted the importance of timely diagnosis, integrated care, research, information systems and strong national leadership.

A National Dementia Strategy Implementation Programme supported key initiatives, including improved dementia diagnosis and management in primary care, pilot dementia intensive home supports, the national "Dementia: Understand Together" awareness campaign, a dementia research programme and the establishment of a National Dementia Office in the Health Service Executive (HSE).

The National Dementia Office, now National Dementia Services, has played a central role in driving reform of dementia care in Ireland. In 2023 it published the HSE Dementia Model of Care, providing a national framework for equitable access to assessment, diagnosis, post-diagnostic support and care planning, regardless of the type of dementia or where a person lives.

Since 2021, Government funding has supported the phased implementation of the Model of Care. The Department of Health's Statement of Strategy 2025-2028 also commits to its implementation. In addition, the Programme for Government includes commitments to expand dementia diagnostic and community-based services.

What are the next steps for the Government – is it envisaged that an updated strategy will be produced?

The National Dementia Strategy and Dementia Model of Care, together with the Programme for Government commitments on dementia, provide strong direction for national policy on dementia and for my work as Minister for Older People.

The Dementia Model of Care sets out 37 targets and recommendations covering assessment, diagnosis, treatment, care and support. A key priority is the development of a nationwide network of Memory Services. These include Memory Assessment and Support Services (MASS) for people with less complex presentations, Regional Specialist Memory Clinics (RSMCs) for more complex cases, including young-onset dementia, and a National Intellectual Disability Memory Service. Within the Model of Care, the GP remains the primary healthcare professional for the person with dementia and their family.

Since 2021, Government investment has supported the progressive development and expansion of these services, focusing on parts of the country that previously had few or no Memory Services. Three new Memory Assessment and Support services are now open, and HSE has committed to opening a further seven in 2026. In addition, the National Intellectual Disability Memory Service is operational, two new Regional Specialist Memory Clinics have been established, two existing services

have expanded, and HSE has committed to opening a fifth Regional Specialist Memory Clinic in Dublin this year.

Progress has also been made in expanding access to dementia day care, dementia day care at home, young-onset dementia supports and the National Dementia Adviser service, strengthening post-diagnostic supports nationwide.

The Department of Health is reviewing national dementia policy. As part of this review, a "best practice" comparative evidence brief on dementia strategies in other countries will commence in 2026. Additionally, the analysis and recommendations of the independent Commission on Care for Older People are expected to influence the future direction of dementia policy.

What actions is the Government taking to ensure the healthcare system is ready for recent developments in diagnosis and treatment?

The Government's primary focus is to expand access to high-quality dementia assessment and diagnosis in line with the Dementia Model of Care. Earlier and more accurate diagnosis allows people to access appropriate treatments, services and supports at the right stage of their condition.

In May last year, I announced the commencement of an Irish Dementia Registry. The Registry will collect consistent national data on diagnosis, treatment, support provision and patient outcomes. This information will help inform service delivery, planning and future policy decisions.

Advances in diagnostics are creating new opportunities. A blood test approved earlier this year can help confirm or rule out Alzheimer's disease pathology in people experiencing memory or cognitive symptoms. The test is non-invasive, will replace lumbar puncture in many cases, and has the potential to speed up diagnosis.

The Government's priority is to ensure the necessary infrastructure, workforce and services are in place so that people can access diagnosis, treatment, support and care on an equitable basis nationwide.

How does the Government work with ASI in the development and implementation of dementia policy in Ireland?

The Alzheimer Society of Ireland (ASI) is the Government's and HSE's key partner in the expansion of access to dementia-specific services in the community.

The 2025 Programme for Government contains several commitments that are being delivered in partnership with ASI over the lifetime of the Government. These include the development of additional dementia day care centres, expansion of dementia day care at home, growth of the national Dementia Adviser service and increased supports for people living with young-onset dementia.

The Government and ASI work closely to ensure that service developments funded through successive budgets are targeted to areas of greatest need and support equitable access across all regions.

ASI is also a key partner in the HSE-led "Dementia: Understand Together" campaign, which aims to improve public understanding of dementia and reduce stigma. Through its work with local dementia alliances, ASI also supports the development of dementia-inclusive communities across Ireland.

As an advocacy organisation, the ASI plays a vital role in ensuring that the voices of people with dementia and family carers are heard. It supports both the Irish Dementia Working Group and the Dementia Carers Campaign Network, helping to ensure that lived experience informs policy and service design.

ASI contributes valuable research on the experiences and needs of people living with dementia and their families. Its studies have enhanced understanding of the challenges faced by those affected by dementia, including during and after the COVID-19 pandemic. I look forward to the release of ASI's latest research on the experience of dementia in Ireland, which I understand will be published in November this year.

As 36AEC is hosted in Dublin this year, do you have a message for delegates attending the conference?

I would like to extend a very warm welcome to all delegates attending the 36th Alzheimer Europe Conference in Dublin.

As the age of our population increases, the number of people with dementia will increase and, I believe, this will ultimately become one of the greatest health and social care challenges facing Europe. Alzheimer Europe estimates that 9.1 million people were living with dementia in the EU in 2025, and this figure is set to increase by 58% to over 14.3 million by 2050. Over the same period, the number of people with dementia in Ireland is expected to more than double: from 70,000 in 2025 to 151,000 by 2050.

What makes this conference particularly valuable is the diversity of those attending. People with lived experience, family carers, clinicians, researchers, academics, voluntary organisations, service providers and policy-makers all bring unique perspectives and expertise. By learning from one another, we can strengthen our collective response to dementia.

Collaboration remains essential. Working together across countries, disciplines and sectors can help us accelerate progress in diagnosis, treatment, care and support, ensuring that people can receive an earlier dementia diagnosis, avail of effective pharmacological and non-pharmacological treatments, and receive evidence-based post-diagnostic supports and care that enable them to live as well and as independently as possible in their own homes and communities for as long as possible.

I am optimistic that by pooling our knowledge and expertise in dementia prevention and risk reduction, we can develop interventions that will continue the progress already made in preventing and slowing the progression of dementia.

I hope delegates find the conference both productive and inspiring. I hope that you enjoy your time in Dublin and Ireland, and experience the warmth, hospitality and *Céad Míle Fáilte* for which Ireland is renowned.

Four decades of The Alzheimer Society of Ireland: progress and work still to do in Ireland



Andy Heffernan

When The Alzheimer Society of Ireland (ASI) was founded in 1982, dementia was rarely spoken about publicly. Families often faced a dementia diagnosis with little information, limited support and few places to turn for help. In this article, Andy Heffernan, CEO of ASI, reflects on their work, highlighting progress and the challenges which remain.

The Alzheimer Society of Ireland (ASI) was established by Winifred Bligh and Imelda Gillespie in 1982, as they experienced the lack of support available in Ireland at the time, with scarce information about Alzheimer's disease and other dementias and services for people with the condition and their carers being virtually non-existent. Rather than accepting this reality, they set out to change it.

More than 44 years later, their vision continues to drive everything we do. Today, ASI supports thousands of people with dementia and informal carers, delivers specialist services nationwide, advances research and advocates for policies that improve quality of life.

Looking back, there is much to celebrate. Looking forward, there is even more to do.

Transforming dementia care in Ireland

One of the greatest achievements of ASI has been helping to transform public understanding of dementia. What was once a largely hidden condition is now recognised as a significant health and social care challenge. The voices of people with dementia and informal carers are increasingly heard and dementia is firmly on the national policy agenda.

Alongside this cultural shift, we have built practical supports and services in every county in Ireland, helping people to live well with dementia in their own communities. Today, ASI has more than 750 staff providing a wide range of services.

In 2025 alone, our day care services recorded over 81,000 attendances, while Day Care at Home delivered over 98,000 hours of support. Our Home Care Service provided almost 127,000 hours of dementia-specific care, enabling people to remain independent and connected to their communities for longer.

Across Alzheimer Cafés, social clubs, support groups and choirs, over 13,000 attendances were recorded last year, helping to reduce isolation and fostering social connections for people with dementia and their families.

Additionally, in 2025, our National Helpline responded to more than 6,400 contacts through phone, email and live chat services. Every call represents a person seeking understanding, reassurance and support during what can be one of the most challenging periods of their life.

Supporting people in the early stages of dementia has become an important priority. Last year, with dedicated Health Service Executive (HSE) investment, ASI launched 30 new Activity Clubs for people with young-onset and early-stage dementia, providing cognitive stimulation, social engagement and therapeutic activities to support wellbeing and quality of life.

In 2025, our Dementia Adviser (DA) service expanded, supporting almost 5,000 new clients during the year. For many families, DAs provide an invaluable link between diagnosis and available services, helping them navigate what can be a complicated and overwhelming system.

Informal carers remain at the heart of our work. Caring for a loved one with dementia requires extraordinary commitment, often over many years. Last year, our Family Carer Education programme experienced its busiest year, with more than 1,250 carers accessing training and education. This represents not only growing demand but also the recognition that carers need support, education and practical guidance to sustain their caring role.

Building on progress

Whilst we are proud of how far Ireland has come, as our population ages, the number of people living with dementia is projected to increase significantly, which will place increasing pressure on health services, social care systems and informal carers unless we act now.

The Programme for Government (2025) contains important commitments relating to dementia and delivering these must remain a national priority. We must reflect on our National Dementia Strategy, published in 2014, and how that meets current realities and prepares Ireland for future demand.

Investment in services that have proven their value is essential. DAs, day care services, activity clubs and dementia-specific home care all help people live independently for longer,

reducing unnecessary hospital admissions and premature entry into residential care.

The Model of Care for Dementia in Ireland (2023) presents significant opportunities to improve dementia care and support. However, to realise its full potential, it must be implemented with clear timelines and a dedicated budget. Faster access to diagnosis, specialist memory services and multidisciplinary teams can improve outcomes, support early intervention and help people plan for the future with confidence.

In parallel, social protection systems must keep pace with the realities facing people with dementia and families. The financial impact of dementia can be significant and long-lasting. No family should face unnecessary hardship because they are caring for a loved one living with the condition.

The challenges we still face

Perhaps the most pressing challenge is the increase in demand for dementia services and growth in waiting lists. Essential services such as DAs, day care centres and home services are under pressure in many areas.

Families consistently highlight a gap between the support available and the support required. Whilst personal care is essential, people with dementia often need much more than assistance with daily tasks. They need companionship, social connection, cognitive stimulation and opportunities to remain active within their communities.

Dementia-specific home care is particularly important, as it recognises the unique and evolving needs of a person with dementia and is delivered by staff trained specifically in dementia care. It focuses not only on practical assistance but also on maintaining independence, dignity, confidence and quality of life.

Rural communities face additional challenges, with access to specialist services and home support varying significantly depending on where a person lives. If Ireland is to become truly dementia-inclusive, we must address these geographical inequalities and ensure access to services is determined by need rather than postcode.

Access to emerging treatments is another key issue. Disease-modifying therapies such as lecanemab and donanemab have generated considerable interest and hope. However, access remains limited to the private sector, and significant financial barriers exist for many families. As Ireland assesses these treatments, equity and affordability must remain at the centre of discussions.

There are also broader policy changes that could make a meaningful difference. People under 65 with dementia do not automatically qualify for a Medical Card, despite often facing considerable healthcare costs. Similarly, dementia is not recognised within eligibility criteria for the Blue Badge parking scheme unless physical mobility issues are also present.

These may seem like small policy issues, but for individuals and families living with dementia, they can have a significant impact on daily life, independence and financial wellbeing.

The importance of lived experience

The most important voices in any conversation about dementia are those of people directly affected. At ASI, we are committed to ensuring people with dementia and informal carers are active partners in shaping services, policy and research.

Our Irish Dementia Working Group provides a platform for people with dementia to advocate, influence decision-makers and help shape a better future. The group demonstrates that a diagnosis does not diminish a person's ability to contribute meaningfully to society. The Dementia Carers Campaign Network performs a similarly important role for informal carers, ensuring their experiences inform policy and service development.

Through our Dementia Research Advisory Team, people living with dementia and carers contribute to research projects, funding decisions and public and patient involvement initiatives. Their expertise strengthens research and ensures it remains grounded in the realities of everyday life.

The principle is simple: nothing about people living with dementia should be decided without people living with dementia.

Bringing Alzheimer Europe back to Ireland

It is a special moment for ASI and the wider dementia community for Ireland to host the Alzheimer Europe Conference (AEC) this year. ASI plays an important role in Alzheimer Europe with Dr Kevin Quaid and Paddy Crosbie representing the organisation in its advocacy groups.

The last AEC held in Ireland took place in Killarney in 2005, making this a significant occasion and it is fitting, given Ireland's long-standing relationship with Alzheimer Europe.

The origins of Alzheimer Europe can be traced back to discussions between ASI's Michael Coote, Franz Baro of Belgium and Henk ter Haar of the Netherlands in 1990. Their shared vision led to the establishment of Alzheimer Europe in 1991, with ten founding member organisations, including Ireland, represented by ASI.

For us, hosting AEC is much more than welcoming delegates to Dublin. It is an opportunity to showcase Ireland's achievements in dementia policy, research and services. More importantly, it is a chance to learn from others, reinvigorating the efforts of those involved in dementia and defining Ireland's approach over the next decade.

The conference will place people with dementia and informal carers at its heart. Their experiences, expertise and insights must continue to shape the future of dementia care throughout Europe.

Looking ahead, the message is clear. Ireland has made enormous progress, but there is still much to do. By investing in services, supporting carers, advancing research and listening to lived experience, we can build a more dementia-inclusive society where every person affected by dementia is supported to live well, with dignity, purpose and hope.

That was the ambition of our founders in 1982. It remains our mission today.

More information on ASI is available at: https://alzheimer.ie/

I am proof there is life after a dementia diagnosis

In this article, Kathleen Farrell, Vice-Chair of the Irish Dementia Working Group (IDWG), shares her experience of being diagnosed with Lewy Body Dementia, her activities through her involvement with the IDWG and her advice to others on how to live well with the condition.



Kathleen Farrell

I was delighted to be asked to contribute to this magazine. A few years ago, my story was shared at the Alzheimer Europe Conference in Geneva, but due to physical limitations, I was unable to attend in person. This year is different. I am thrilled to have the opportunity to present alongside Dr Sarah Donnelly, sharing important work commissioned by the Irish Dementia Working Group (IDWG) on the human rights of people living with dementia in nursing homes. It is an honour and reminds me how far I have come since receiving my diagnosis.

My Journey to Diagnosis

I am 72 years young and I live in Tallaght, Dublin, with my sister and aunt. In 2021, I was diagnosed with Lewy Body Dementia with Parkinson's disease. If someone had told me then that I would go on to become Vice-Chair of the IDWG, I would never have believed them.

My journey to diagnosis was far from straightforward. Looking back, there were warning signs, but neither I nor my family recognised them.

I spent several months in hospital. It was frightening and confusing for me and my family. Thankfully, there was a consultant geriatrician who believed something else was happening. She reassured me that she would get to the bottom of it and arranged specialist scans that confirmed I had Lewy Body Dementia with Parkinson's disease.

I felt terrified, helpless and overwhelmed. I knew very little about Lewy Body Dementia and thought my life was over.

For a while, I believed I would spend the rest of my life sitting at home waiting for the worst to happen. I struggled to imagine a future where I could still contribute to society.

A Turning Point

Then I made a phone call that changed everything.

I contacted The Alzheimer Society of Ireland's (The ASI) National Helpline. Elaine, who answered, listened to me with patience, kindness and understanding. For the first time since my diagnosis, I felt heard.

During that conversation, she told me about the IDWG. Joining that group was one of the best decisions I have ever made.

Today, I am proud to serve as Vice-Chair of the IDWG. Through this role, I have spoken at policy events, contributed to The ASI's Pre-Budget Submission, participated in dementia awareness training and media engagement, appeared on podcasts, joined the Understand Together Working Group and contributed to national campaigns.

One of my proudest moments was taking part in the Irish Human Rights and Equality Commission's Ageism Campaign. When I realised my photograph was displayed on the largest billboard in Dublin, I could hardly believe it. Standing there, looking up at my face on that billboard, was an emotional moment. The woman who once thought her life was over was now helping to challenge stigma and change perceptions about dementia.

Living with Lewy Body Dementia is not easy. My days can be unpredictable. My mobility has declined and I now use a walking stick and rollator. There are times when I struggle to process information, follow conversations or remember things.

I'm still me

But despite these challenges, I remain the same person I have always been.

I enjoy life. I still love meeting people. I still enjoy being part of my community. I still laugh, joke and find mischief wherever I can.

Most importantly, I have incredible support around me. My family is my greatest strength, particularly my sister Bernadette, who supports me every day.

If there is one thing I would like readers to take from my story, it is that there is life after a diagnosis of dementia. There is hope. There is support. There is purpose.

My advice is simple: find your people. Find the people who believe in you when you no longer believe in yourself. Find people who will see your abilities rather than your disabilities and who walk beside you when life feels difficult. I call this finding your "Power Within".

Dementia may be part of my story, but it is not the whole story. My story is about resilience, advocacy, community and hope. Most of all, it is about continuing to live, contribute and be heard. That is the power I found within myself, and I hope others can find it too.

Finding a voice through advocacy

In this article, Ray Cregan, who cared for his father, Paddy, tells us about his activities as a member of the Dementia Carers Campaign Network (DCCN), including his advocacy work pushing for better supports for people with dementia and their carers, as well as how he continues to support the dementia movement through fundraising and as a member of ASI's Dementia Research Advisory Team.



Ray Cregan

I cared for my father, Paddy, for almost nine years. Paddy had vascular dementia and sadly passed away in 2015. The nature of vascular dementia for my father involved a series of small strokes, and over time we began to notice the changes.

Paddy was quite the character. He was jovial, outgoing and had a large circle of friends. During the 1960s and 1970s, when I was growing up, he took great pleasure in cooking and baking and began trying his hand at quite advanced culinary delights. I am not in the same cooking and baking league as Paddy, but this is where my love of all things culinary began, and I have a few signature dishes I enjoy making for family and friends.

Amplifying the voices of carers

I have been involved with the Dementia Carers Campaign Network (DCCN) since it began in 2013. I have served on the Committee for four years, and I was Vice-Chair for a few years. I understand how important supports and services are for people living with dementia, their carers and their families, and I want to lend my voice to the call for better dementia supports, which I can do through the DCCN. My advocacy work has taken me to Leinster House, home of the Houses of the Oireachtas in Ireland, where I have advocated for carers' rights.



Ray and Paddy Cregan

I have also appeared on television and radio, featured in newspapers, and spoken at conferences and events to highlight the lived experience of caring and the distinct needs of family carers.

I have taken part in many other engagements over the years, including focus groups, policy consultations, and several arts initiatives, which I enjoy, as the arts offer an innovative way for carers to share their stories.

The power of the arts

The most recent arts engagement I took part in was a screening of "Yes, But Do You Care?" at the Irish Museum of Modern Art (IMMA), where I spoke alongside visual artist Marie Brett. This filmic artwork was created by Marie with dance artist and choreographer Philip Connaughton. DCCN members shared their experiences at the beginning of this project to help shape and inform the work. It was lovely to have the opportunity to speak about the work with Marie, especially in the beautiful surroundings of IMMA, as the artwork is now part of the museum's National Collection.

We have also had the opportunity to engage with other arts professionals, including a film director, a playwright and several authors. These engagements are very important as they help carers to tell their stories and feel seen and heard.

Giving back

I have also taken part in fundraising events for The Alzheimer Society of Ireland, including an event with KBC Bank a few years ago with my DCCN pal Richard. I also organised a Tea Day event at Christ Church Cathedral, Dublin, in 2023 and 2025 with my DCCN friend Una.

I started my career as an engineer for railway suspensions. I then worked on the engineering for manufacturing of mainframe computer cabinets. Subsequently, I moved into engineering sales, selling predominantly to the architectural community, before I gave up work to look after my dad.

I love playing football and supporting Ireland at matches. For the last 20 years, I have gone with a group of friends to villages in Czech and Slovakia to play in a small annual football tournament. I like cycling, but don't do as much of it as I used to. However, I have a desire to cycle around the breweries of Belgium.

Ringing master and conference volunteer

I am the Ringing Master at Christ Church Cathedral in Dublin. In 2028, Christ Church Cathedral will celebrate its millennium as an institution. Whatever church stood on the site over nearly one thousand years has always had a bell. I take pleasure in the sound of well-rung bells. Ringing Master is a role I really enjoy and that I hadn't anticipated would become such a significant part of my life.

I am volunteering at the Alzheimer Europe Conference this year as I enjoy meeting and helping people. My appetite for volunteering was whetted when I was involved in the Special Olympics World Games in Ireland in 2003. I am looking forward to the conference and to meeting carers and people with dementia from all over Europe.

Shaping the future of dementia research in Ireland

In this article, Dr Laura O'Philbin and Dr Sally Yalley of The Alzheimer Society of Ireland (ASI), and Professor Sean Kennelly of Dementia Research Network Ireland (DRNI), talk about the strengths in dementia research in Ireland, the value of collaboration and lived experience, as well as the need for sustained research investment.



Dr Laura O'Philbin

Interview with Dr Laura O'Philbin, Research & Policy Manager, The Alzheimer Society of Ireland (ASI)

What do you see as Ireland's greatest strengths in dementia research?

Ireland may be a small country, but we consistently make important contributions across disciplines; basic science and clinical research to psychosocial interventions, technology and health services research. Our researchers and clinicians are world-class and internationally respected, making a significant contribution despite relatively limited resources.

Our size is an advantage, enabling collaboration between researchers, healthcare providers, policymakers, charities and people with lived experience. This helps to develop partnerships and translate research into practice. To build on this, greater investment, sustainable research careers and more opportunities to lead European research programmes are needed.

What role do you believe organisations like ASI play in dementia research?

Research has the greatest impact when it extends beyond academia and improves the lives of people affected by dementia. National Alzheimer's associations are uniquely placed to help make that happen. We work at the intersection of research, policy, practice and lived experience, helping to ensure that research is scientifically robust, but also relevant to the people it is intended to benefit.

We help shape the research environment by championing investment, strengthening research participation and public and patient involvement (PPI), translating evidence into policy and practice, and building the partnerships needed to maximise the impact of dementia research.

One of the priorities in your Research and Policy Strategy is advocating for investment in dementia research. Why is that becoming increasingly important?

Dementia research is entering an exciting era, but continued progress requires sustained investment. ASI has always supported research, but our new Research and Policy Strategy also positions us to champion it. We need to make the case to governments, funders and the wider public that investment in dementia research is the key to better diagnosis, care, treatments and support.

As Ireland prepares to co-host the Alzheimer Europe Conference, it's an exciting opportunity to strengthen these discussions both at home and across Europe.

Looking ahead, what would success look like for dementia research in Ireland?

For me, success is about research leading to a tangible impact on the lives of people affected by dementia, whether through improved interventions, changes in policy, clinical innovations or better awareness and training.

I would like to see dementia recognised as the research priority it deserves to be. As our population ages, the personal, social and economic impact of dementia will continue to grow. We need to be equally ambitious in how we respond through sustained investment, supporting the next generation of researchers and ensuring people with dementia remain at the centre of everything we do.

More information on ASI's research and policy team is available at: https://alzheimer.ie/creating-change/research/

Interview with Dr Sally Yalley, Research Officer, ASI

How has your professional background shaped your perspective on dementia?

Having worked in clinical practice, academic research and now as Research Officer, I have come to appreciate the contribution of each sector to dementia research, as well as the importance of the connections between them. My work within ASI has offered an opportunity to engage with a broader range of people than would be possible through clinical practice alone, while allowing for a depth and continuity of engagement that can be difficult to achieve through individual research studies. Working with ASI has also given me a greater



Dr Sally Yalley

appreciation of how research can be connected to the experiences and priorities of people affected by dementia.

Many people first encounter dementia research through media coverage. What role can charities play in public education?

For many people, particularly following a dementia diagnosis, charities are a trusted source of information about dementia and the evolving research landscape.

When major research findings attract public attention, there can be a gap between scientific publications and how findings are understood by the public. Organisations such as ASI can help provide context, ensuring that developments are communicated accurately, accessibly and proportionately.

People with dementia and their families understandably want to know what emerging research means for them. Supporting informed interpretation, signposting to reliable sources and helping people navigate uncertainty are therefore important aspects of public engagement.

What does this interconnected approach mean for the future of dementia research?

Ultimately, progress in dementia research depends not only on generating new knowledge, but on ensuring that knowledge remains relevant to the people it is intended to serve, and keeps people affected by dementia central.

Interview with Professor Sean Kennelly, Tallaght University Hospital and Lead Investigator, Dementia Research Network Ireland (DRNI)

Can you tell us a bit about DRNI?

DRNI is a multidisciplinary network of researchers working in the area of dementia across the island of Ireland, funded by the Irish Health Research Board and based in the School of Medicine, Trinity College Dublin. With nearly 250 members on both sides of the border, DRNI connects clinical researchers, allied healthcare professionals, basic researchers and social science and policy researchers, providing engagement and exchange across the entire spectrum of the dementia research landscape. Most of our members are active researchers based in universities and clinical research sites across Ireland and Northern Ireland, however, we also have members from less "typical" areas such as law and the creative arts.

What does DRNI do?

DRNI works to provide a national-level dissemination platform, including research seminars, newsletters, policy-linked channels and national academic forums, as well as supporting knowledge translation. DRNI works closely with PPI representatives and ASI to ensure PPI work is providing impact across multiple levels. DRNI plays a strong role in supporting Ireland's next generation of researchers by creating opportunities for early career researchers to present their work, meet their peers and engage with established researchers.

A new and exciting development has been the creation of Trasna na dTonnta (Across the Waves), a network for the Irish dementia research diaspora, or any researcher who has an Irish connection. Trasna na dTonnta aims to strengthen links between Irish dementia researchers at home and abroad; to support Irish dementia researchers emigrating to new countries and those returning home; and to strengthen Irish dementia research by supporting international collaborations.

What would you like to see happen in dementia research in Ireland going forward?



Prof. Sean Kennelly

An increase in investment, both nationally and internationally, is crucial for research in dementia to move forward. This is a very exciting time in research with the recent breakthroughs in disease-modifying therapies; however, research needs more investment across the board. Ireland possesses world-class expertise in dementia research and is widely respected internationally, yet its ranking in pan-European research initiatives remains average. Increased national funding could enable Ireland to align more closely with European and global research efforts, enhancing its competitiveness and impact. Increases in funding would also create a career pathway for early career researchers where staying in Ireland is a realistic option, thereby preventing them leaving due to a lack of opportunities.

More information on DRNI is available at: https://dementianetwork.ie/

Building political momentum for dementia: The vital role of Ireland's cross-party parliamentary group

In this article, Cormac Cahill and Philippe Carr of The Alzheimer Society of Ireland (ASI), talk about the work of the All-Party Oireachtas Group on Dementia in building cross party support to prioritise dementia as policy issue, as well as fostering collaboration between decision makers and civil society.

In a political landscape often dominated by competing priorities, dementia has remained firmly on the agenda of Ireland's lawmakers, thanks in large part to the work of the All-Party Oireachtas Group on Dementia. Since its formation in 2016, the group has become an influential forum for discussion, advocacy and collaboration, ensuring that the voices of people living with dementia and their families are heard at the highest levels of government.

As Ireland's population ages and life expectancy increases, the number of people living with dementia is rising rapidly. This demographic shift makes informed and sustained political attention more important than ever.

The group brings together parliamentarians, healthcare professionals, advocacy organisations and people with lived experience so that policy discussions are informed by the realities of those most affected.

The Alzheimer Society of Ireland (ASI) has invested heavily in building relationships with parliamentarians to raise awareness of key issues relating to dementia, health, research and social policy.

Before going further, it is useful to know that the Oireachtas is Ireland's national parliament, made up of two houses: Dáil Éireann, the House of Representatives, and Seanad Éireann, the Senate. For the past decade, an informal alliance of parliamentarians, including Teachtaí Dála (TDs) and Senators, has met regularly to focus on issues affecting the dementia community. Known as the All-Party Oireachtas Group on Dementia, it brings together representatives from both houses and from government and opposition parties.

Membership of the group typically consists of around 20 parliamentarians, mostly backbench representatives who have greater flexibility to engage in policy-focused initiatives. Some join because of a strong interest in health, ageing, disability or social policy. Others have a personal connection to dementia through family members, friends or constituents living with the condition.

Over the years, several members have gone on to serve in senior ministerial and government positions, strengthening awareness of dementia within wider political and policy discussions.

The group is currently co-chaired by Deputy George Lawlor of the Labour Party and Senator Fiona O'Loughlin, Deputy Chairperson of Seanad Éireann and a member of Fianna Fáil, one of the governing coalition parties. Leadership drawn from both Government and Opposition helps ensure balanced discussion and shared ownership of the issue.

Senator O'Loughlin has been a member of the Oireachtas since 2016. Alongside chairing important parliamentary committees dealing with education and disability-related matters, she also serves as head of the Irish delegation to the Parliamentary Assembly of the Council of Europe.



Minister Mary Butler TD was a co-founder of the Group in 2016

Senator Fiona O'Loughlin said: *"The expert input from people with lived experience of dementia, clinicians and researchers facilitated through ASI has guided and informed our All-Party Group's agenda and priorities, has highlighted support gaps and has helped Oireachtas members understand dementia from an informed perspective, helping TDs and Senators speak with accuracy and empathy, keeping dementia on the political agenda. It has been both insightful and informative to work with ASI, who do an incredible job advocating for those living with dementia, their families and carers."*

Deputy Lawlor joined the group following his election to Dáil Éireann in 2024 and has shown a strong commitment to addressing issues relating to social exclusion and community wellbeing.

Meeting approximately four times each year, the group receives regular briefings from ASI, the Irish Dementia Working Group, the Dementia Carers Campaign Network and a range of clinical, academic and policy experts. These sessions provide politicians with direct insight into emerging issues, challenges within services and opportunities to improve the lives of those affected by dementia.

In the past, the group has also undertaken interparliamentary visits to Scotland, combined with visits to local dementia



All-Party Oireachtas Group Co-Chairs Senator Fiona O'Loughlin (front row, centre) and George Lawlor TD (front row, second from left) with ASI team members in Leinster House in March 2026

groups and healthcare providers. Closer to home, group members have visited hospitals and services in Dublin and elsewhere to better understand developments in dementia care.

The group also plays an important role during Ireland's annual budget process. Throughout the year, parliamentarians engage with ASI to discuss areas requiring investment and support. Government representatives can then raise these issues within their parties and departments, highlighting priorities such as community services, financial supports for people living with dementia and family carers, and increased investment in research.

Members of the All-Party Oireachtas Group on Dementia were also instrumental in welcoming Jordan and Cian Adams, better known as the FTD Brothers, to Leinster House in July 2026. The brothers played a key role in highlighting the impact of frontotemporal dementia and helping to secure statements and a dedicated debate on dementia in Dáil Éireann. The discussion in the main Dáil debating chamber included 22 contributions from Government and Opposition TDs examining how Ireland can respond to one of the country's most significant health and social challenges.

A Partnership That Requires Commitment

One of the group's original convenors was current Government Chief Whip and Minister for Mental Health Mary Butler TD, who was first elected to Dáil Éireann in 2011 and has previously held ministerial responsibility for Older People. From the outset, she recognised the need to strengthen political understanding of dementia and the challenges faced by individuals and families affected by the condition.

When the group was established, there was a clear need to focus policymakers on the growing number of people living with dementia and the everyday challenges they encountered. While dementia was not being ignored, it often received insufficient attention compared with other health and social policy issues.

Government Chief Whip and Minister for Older People, Mary Butler TD said: *"I co-founded the Oireachtas Group on Dementia in 2016 alongside Senator Collette Kelleher. I did so having been appointed Fianna Fáil Spokesperson for Older People.*

It truly was a cross-party effort as we left politics at the door and sought to raise awareness in both Houses on the long-term care needs of the people and their families living with dementia in Ireland at that time.

I worked closely with ASI who provided secretariat to our committee. We were conscious of the postcode lottery in relation to services. We held many events for Oireachtas members including dementia training and awareness. We also worked closely with the respective Minister in the lead up to Budgets.

Upon my appointment to the office of Minister for Mental Health and Older People in 2020, I became the first Minister to ringfence funding specifically for dementia supports which previously relied on dormant accounts funding and philanthropy."

The parliamentary group provided an important platform for discussion and awareness-raising. It helped maintain momentum behind policy development and contributed to wider support for a national dementia care pathway and the Dementia Model of Care, which was launched in 2023. Its experience also shows that access to parliamentarians must be matched with strong evidence, practical proposals and sustained advocacy if it is to translate into meaningful policy change.

The Value of Political Engagement

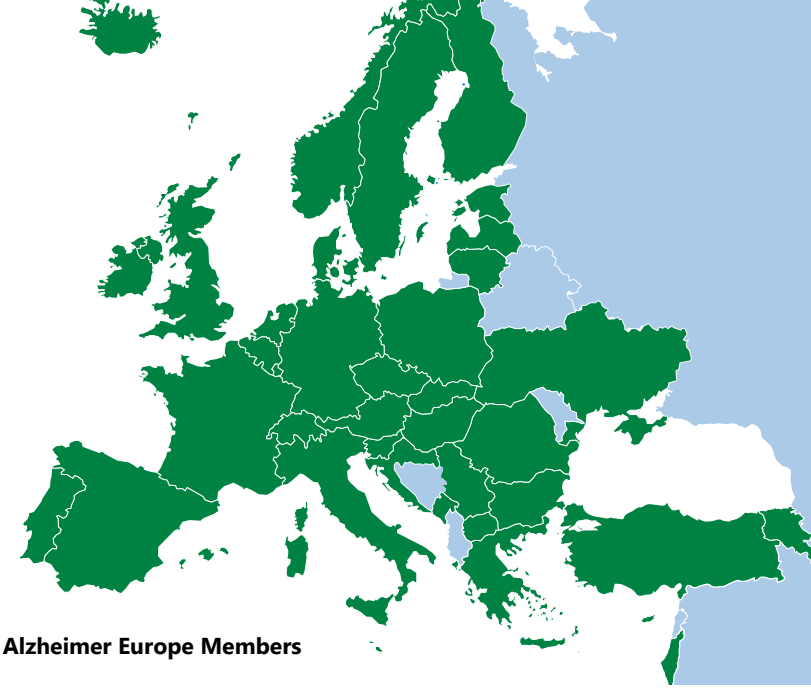
Ireland's political system is among the most representative in the European Union, with voters directly electing local representatives who are often closely attuned to community concerns. This creates valuable opportunities for organisations such as ASI, which provides dementia supports and services across the country, to engage directly with policymakers.

The All-Party Oireachtas Group on Dementia continues to shape its priorities for the years ahead. Current areas of focus include improving access to community supports, innovative medicines and therapies and addressing the distinct challenges faced by people living with young onset and early-stage dementia.

Looking ahead, collaboration between civil society and parliamentarians will remain essential. The group's experience shows how sustained engagement, grounded in lived experience and practical evidence, can help drive meaningful policy change for people affected by dementia.

More information on the group is available at: https://alzheimer.ie/creating-change/policy-on-dementia-in-ireland/all-party-oireachtas-group-on-dementia/

Our members are helping people with dementia and their carers in 39 countries



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POLAND – WARSAW
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