Borut Pohar
Former President of Slovenia reflects on progress on dementia policy during his time in office

Philippe Close
Mayor of Brussels tells us why new dementia friendly city charter is so important and what challenges it poses

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Welcome

Maria da Rosária Zincke dos Reis, Chairperson

It is with great pleasure that I introduce the 41st edition of our Dementia in Europe magazine – my first as newly elected Chair of Alzheimer Europe. The latter part of 2022 was full of activity and the beginning of 2023 has continued apace!

We open the Alzheimer Europe section by recounting our European Parliament lunch debate held in September 2022, which examined the role of artificial intelligence (AI) in dementia research. We are incredibly grateful to Sirpa Pietikäinen MEP (Finland) for chairing the session.

Alzheimer Europe has recently launched a number of important publications, which are presented in the following two articles. The first of these is the Dementia in Europe Yearbook 2022, which focused on employment and social protection for people with dementia and their carers. The second article looks at the two new guides which have been produced, one on ethical and respectful communication about dementia and the other on sex, gender and sexuality in the context of dementia.

The 32nd Alzheimer Europe Conference (32AEC) in Bucharest, Romania, saw many changes for our organisation, which we cover in the following articles. Firstly, we introduce the new Alzheimer Europe Board, after which I share my thoughts on the future of the organisation as its new Chairperson, and then we present the new European Working Group of People with Dementia (EWGPWD) for the 2022-2024 term. The collaboration between Alzheimer Europe and Roche for World Alzheimer’s Day is the subject of our next article, looking at the “What makes you, you” campaign. Still on the theme of collaboration, the new year brings three new projects: ADIS, eBRAIN-Health and PatternCog, in which Alzheimer Europe is delighted to be involved.

We wrap up this section by looking at the winners and runners up of our inaugural Anti-Stigma Award, presented at 32AEC, with their inspiring work to lessen the stigma associated with dementia.

Moving to the Policy Watch section, we are delighted to feature an interview with the European Commissioner for Jobs and Social Rights, Nicolas Schmit, on the European Care Strategy and what this means for people living with dementia and carers. We are also pleased to share an interview with the former President of Slovenia, Borut Pahor, with whom our colleagues in Spominica worked closely to prioritise dementia as a political matter and to make progress on a new dementia strategy.

At a European level, we report on the European Day of Persons with Disabilities conference, hosted by the European Commission and the European Disability Forum, in which Alzheimer Europe was delighted to participate, together with a number of members of the EWGPWD.

We then hear from colleagues in the World Health Organization (WHO) Europe on their ongoing work on mental health and dedicated workstream on older person’s mental health, whilst colleagues from the Organisation for Economic Cooperation and Development (OECD) share views on key areas for the future of dementia policy from diagnosis to end-of-life.

The final article of the section is of particular professional interest to me, as a lawyer. We hear from the Hague Convention following their recent Special Commission on the Convention for the Protection of Vulnerable Adults.

We open the Dementia in Society section with a report from the Organisation for Economic Cooperation and Development (OECD) on the role of artificial intelligence (AI) in dementia policy. We then hear from colleagues in the World Health Organization (WHO) Europe on their ongoing work on mental health and dedicated workstream on older person’s mental health, whilst colleagues from the Organisation for Economic Cooperation and Development (OECD) share views on key areas for the future of dementia policy from diagnosis to end-of-life.

The final article of the section is of particular professional interest to me, as a lawyer. We hear from the Hague Convention following their recent Special Commission on the Convention for the Protection of Vulnerable Adults.

We open the Dementia in Society section with an interview with the Mayor of Brussels, Philippe Close, who recently signed a charter pledging that the city will become dementia friendly – a most welcome development, especially since Brussels is the capital of Europe, the headquarters of the European institutions and also the location of many Alzheimer Europe meetings!

In the following article, Ukrainian charity Nezabutni (“Unforgettable”), a new member of the Alzheimer Europe family, shares details of the ongoing challenges faced by persons living with dementia, as a consequence of the Russia’s invasion of the country and the changes the charity has made in incredibly difficult circumstances, the actions of Nezabutni in continuing to offer support in the most difficult circumstances.

Our next article examines the recent research developments in disease-modifying therapies for Alzheimer’s disease. We interviewed Nicolas Villain, who has published two reviews on anti-amyloid immunotherapies, and asked three other experts in the field for their perspectives on the recent phase III results of lecanemab.

From there we move on to the Older Adults Mental Health Awareness week, coordinated by the International Psychogeriatric Association, which included the perspective of a person living with dementia, input from Alzheimer associations, as well as the involvement of the Chair of the Alzheimer Europe Alliance, Sirpa Pietikäinen MEP (Finland).

In the final article in this section, Kevin Quaid, Vice-Chairperson of the EWGPWD, tells us about how living with Lewy body dementia has impacted on his sleep.

In the final section, we revisit our Annual Conference, 32AEC, in Bucharest, Romania, including the plenary sessions, special symposia and the involvement of the INTERDEM network. It was wonderful to be able to attend the conference in person after two years of online conferences. I am deeply saddened, however, to inform you of the passing of our distinguished keynote speaker Alexander Kurz, on 23 January 2023. Alexander served on the Board of Alzheimer Europe from 1998 to 2004 and was a vital part of our big European family. He will be very much missed.

I wish you all a healthy and happy 2023 and look forward to seeing and working with many of you in the year ahead!
Alzheimer Europe hosts lunch debate on “The role of artificial intelligence and big data in dementia research”

Alzheimer Europe welcomed attendees to the final lunch debate of the year on 27 September 2022 in Brussels, Belgium. The session explored how technology was driving changes in dementia research, with stakeholders representing national member organisations, civil society representatives, industry partners, policy makers and members of the European Working Group of People with Dementia (EWGPWD).

Sirpa Pietikäinen MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA) hosted the session and opened by highlighting the opportunities that exist for big data and artificial intelligence to develop more effective treatments for dementia. She noted that considerable amounts of data were generated daily, yet much of it was not analysed or made use of, despite it having potential to improve understanding of the condition. Furthermore, she spoke of the need to balance the opportunities of big data and artificial intelligence, with the need to respect the rights of individuals in relation to their personal data. In a pre-recorded video message, Deirdre Clune MEP (Ireland) welcomed participants to the meeting and highlighted her membership of the Internal Market and Consumer Protection Committee, noting that she would be keen to hear ideas and suggestions about the steps the EU can take to facilitate the use of data and artificial intelligence to support research into dementia. Furthermore, she highlighted the barriers identified in Alzheimer Europe’s “Data Sharing in Dementia Research – the EU Landscape” report, outlining the role of the EU in addressing issues around infrastructure and regulation.

Jesper Kjaer, Co-Chair of the Big Data Steering Group (BDSG) in the European Medicines Agency, highlighted some of the previous work of the group on this subject, including...
a report in 2021 which issued recommendations to improve the use of big data for public health. He set the context of the use of big data as one of supply and demand, noting that implementation requires a stepwise approach, with gradual changes over time. He further explained that real world evidence supported regulators’ decision-making by helping support planning and validity, the understanding of the clinical context, and the investigation of the associations and impacts. A key ongoing project is the Data Analysis and Real-World Interrogation Network (DARWIN EU), a federated network of data, expertise and services that will support better decision-making throughout the product lifecycle by generating reliable evidence from real world healthcare data.

Andrzej Rys, Director for Health Systems, Medical Products and Innovation in the European Commission, spoke about two key pieces of legislation: the Organisation of Health Data (European Health Data Space - EHDS) introduced May 2022 and the Development and Deployment of trustworthy AI systems (the AI Act), introduced in April 2021. He noted that the EHDS set out the manner of collection and registration of health data, as well as the obligations of data holders to make health data available e.g. for research or the development of medical devices. He explained that high-risk AI systems, including AI-based medical devices, were governed by the AI Act, which set out data governance obligations, as well as mandating human oversight, a robust risk management system, as well as transparency and information to users.

Göedze Susuzlu Briggs, Project Coordinator for the DataSavesLives (DSL) initiative, outlined how the multi-stakeholder initiative (led by the European Patients Forum) aims to raise patient and public awareness about the importance of health data and how it is used. She noted that the fundamental principle of the initiative was transparency, ensuring patients were informed and meaningfully involved in processes related to the use of health data. DSL has undertaken a number of activities to spread knowledge and understanding, including the development of a toolkit, as well as a training programme for “ambassadors”, who will be given the information, skills and guidance to take actions to promote the use of health data in their countries. She also shared that work is underway by the Ministry of Health in Germany in this area.

During the open discussions, a number of contributions were made, including from members and supporters of the EWG-PWD, who shared their poor experience of hospitals in rural areas, as well as their hopes for the development of a cure or new treatment in the near future.

EAA member Tilly Metz MEP (Luxembourg) closed the session, sharing how this subject related to her work as a member of the Environment and Health Committee, as well as shadow rapporteur for the Greens on the EHDS. She thanked the speakers and those who had shared their personal experiences during the debate.

Ms Metz noted the need for coordinated involvement of all stakeholders to drive change in this area, by public, private, research and civil society organisations. She highlighted that where discoveries and outputs were developed from public-private partnerships, the public needed to benefit from the investment made, with good practices and developments translating into improvements in health systems and clinical practice.

The videos of the presentations from the lunch debate can be watched here:

https://www.youtube.com/watch?list=PLo-PgQHiWQV3T102zB4c9yyXgj2B&v=b9bcxv8pPhi&feature=youtu.be
Snapshots from the lunch debate
Alzheimer Europe launches 2022 Yearbook on employment and related social protection for people with dementia and their carers

The Dementia in Europe Yearbook 2022 examines how the rights of people with dementia and their carers are outlined in policy at the European and international level, before examining the extent to which these are implemented at a national level. Good practice examples are identified across a number of countries, whilst the experiences of people with dementia and carers are also included.

On 30 January, Alzheimer Europe published its Dementia in Europe Yearbook 2022, focused on employment and related social protections for people with dementia and their carers.

The Yearbook provides an overview of the provisions of the Charter of Fundamental Rights, the European Pillar of Social Rights, the United Nations Convention on the Rights of Persons with Disabilities, as well as examples of EU legislation and policy initiatives in the area of employment and social protection. The Yearbook found that the rights of persons with dementia were well articulated in this regard (as a disability), whilst carers rights were less specifically acknowledged.

In addition, based on the responses of 21 Alzheimer’s associations across Europe, Alzheimer Europe was able to collate information on the current policies and legislation at a national level, identifying common strengths and weaknesses of different systems, as well as the extent to which they upheld the rights of people living with dementia and carers, as set out in the aforementioned European and International accords.

Across European countries, policies and legislation related to employment and social protection varied considerably. Of the countries with a dementia strategy, only a small number contained references to employment or social protection for either people with dementia or carers, whilst others reported relevant policy drivers in the areas of older persons, disabilities or employment, which included resources and schemes relevant to persons with dementia.

Alzheimer Europe was surprised not to see greater reference to the European Work Life Balance Directive in the responses of members, despite the requirement for it to be transposed by August 2022. It is not clear whether this was due to countries inaction on the matter (e.g. where they already met or exceeded the minimum criteria of the Directive) or a lack of awareness of the changes in legislation.

Despite the considerable differences in social protection systems between countries, common criticisms emerged. These included the overly complex structures of systems, the restrictiveness of eligibility criteria and the insufficient levels of financial support provided. For people with dementia, few social protection systems considered the specific nature of dementia as a progressive and life-limiting condition (most measured against the level of disability or ability to work), whilst for carers, benefits were often assessed by the level of disability of the cared-for person, not the level of care provided or the needs of the carer themselves.

The Yearbook also contains testimonies from a number of past and present members of the European Working Group of People with Dementia, as well as other people living with dementia, who shared their experiences of receiving a diagnosis of dementia whilst employed or those who accessed social protection systems. These experiences are unfortunately broadly negative and illustrate that there is much work to be done to ensure that the rights of people with dementia and their carers are upheld. To this end, the conclusion of the report contains a number of recommendations aimed at both National and European decision-makers, to encourage them to take actions to improve legislation and policies around employment and social protection.

For more information, the Dementia in Europe Yearbook 2022 can be downloaded at: https://bit.ly/AE2022Yearbook
Alzheimer Europe launches resources on ethical and inclusive communication about people with dementia and a guide on sex, gender and sexuality

Alzheimer Europe has long worked to reduce the stigma associated with dementia and to uphold the rights of people living with this condition. To support these aims, Alzheimer Europe has published two resources. The first is a set of guidelines on the communication and portrayal of people with dementia, whilst the second aims to raise awareness of issues surrounding sex, gender and sexuality in dementia.

Guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia

In 2013, Alzheimer Europe set up an ethics working group to explore the different ways that people with dementia are perceived and portrayed within society and to consider the ethical implications of this. On the basis of an extensive literature search, the group explored the perceptions and portrayals of dementia of different groups in society (e.g. the general public, people with dementia, carers and healthcare professionals, to name but a few), the use of language and the influence of the media and film-makers.

This ethical reflection focused on ways in which various ways of perceiving and portraying dementia are likely to be beneficial or potentially harmful to people with dementia (e.g. in terms of their dignity, wellbeing, autonomy, rights, personhood, relationships and role in society). Now, almost a decade later, members of the European Working Group of People with Dementia (EWGPWD) have revised and built on this work to develop a set of guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia. These guidelines are targeted at the media, researchers, journalists, policy makers and indeed anyone responsible for the portrayal of or communication about dementia in the public domain.

The guidelines are aimed at provoking greater reflection and increasing awareness about this issue. The members of the EWGPWD were keen to emphasise that they did not want to act as the “word police” and that their guidance goes beyond the choice of individual words. This is important because preferences and objections to certain words, whilst important, vary greatly, not only between different countries but also within different communities and social groups. Rather, their goal was to offer constructive and friendly guidance to help raise awareness of the need to communicate in an ethical and inclusive manner. This means paying attention to messages and images that we communicate and use, and trying to ensure that they convey respect for people with dementia, that they are not harmful (e.g. stigmatising, insulting or degrading) and that they both reflect and promote the inclusion of people with dementia from all walks of life, including those from marginalised groups, in society.

People with dementia use language, sometimes including metaphors, to convey their personal experience of dementia at a particular moment in time and it is important that they have the freedom to express their experience and feelings in whatever way they see fit. Words and images communicated by others, however, tend to be understood as representing or summing up the experience of all people with dementia, reducing people with dementia as a group to sufferers or patients, or portraying every aspect of dementia as a devastating natural catastrophe. This is why it is important for people who do not have dementia to pay particular attention to the words and images that they use and the underlying messages that they may be conveying.

The guidelines are structured around 14 statements, each constituting a piece of advice and followed by a more detailed explanation, and in some cases by a few quotes from members of the EWGPWD and one from a supporter.

Chris Roberts, Chairperson of the EWGPWD, said: “Our diagnosis should not define us but words and images sometimes do. Respectful communication costs nothing but means everything.”

The new guidelines can be downloaded from the Alzheimer Europe website, at: https://bit.ly/AEGuide_EthicalCommunication
Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers

Sex, gender and sexuality are fundamental aspects of our lives, which influence how we see ourselves, how others see us and our position in society. In recent years, there has been increasing awareness about sex, gender and sexuality and the many different gender identities and sexual orientations that people have. Unfortunately, there is still a lack of information on this topic in dementia care where this central part of our identity is all too often invisible. Europe is still highly influenced by heteronormative assumptions (i.e. that everyone is heterosexual, identifies with the sex attributed to them at birth and lives in a close-knit biological family) and this is also the case in dementia care and support.

The societies we live in have developed structures of care and support around these assumptions, which, unfortunately, also often reflect homophobia, transphobia, ageism and ableism. This is reflected in negative stereotypes about the sexuality of older people and people with dementia, and broad generalisations about what men and women with dementia want or need in life, and what is considered “normal” or acceptable behaviour.

In 2021, Alzheimer Europe set up a working group with expertise in this area to look closely at these issues. The working group included men and women with and without dementia, and with different gender identities and sexual orientations, from the fields of dementia, gender studies, ethics, ageing, service provision, training of healthcare professionals, nursing and psychology. The group produced a comprehensive report on the topic, which can be obtained at:


Following on from this work, a short guide was developed in 2022 to raise awareness and provide health and social care workers with recommendations on how to provide sensitive, appropriate and good quality care and support to people with dementia and their carers or supporters of different sexes, gender identities and sexual orientations.

The guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. We draw attention to inequality, discrimination and lack of sensitivity towards their needs and wishes, both from other people and through structures and procedures within society, also towards their families, carers and in some cases health and social care workers. The guide is not limited to the experience of LGBTQ+ people but their experience is often qualitatively different to that of non-LGBTQ+ people and they encounter several issues that others do not, hence the frequent reference to this group in the guide.

Dianne Gove, Director for Projects at Alzheimer Europe commented: “We need to ensure that everyone with dementia feels accepted and valued for who and what they are, that they feel safe to be open about their gender identities and sexual orientations, and that they can all enjoy the same rights, respect and opportunities as other members of society.”

We hope that this guide will provoke reflection, contribute towards challenging assumptions and inequalities and help ensure that everyone is free from violence, discrimination and harassment irrespective of their sex, gender identity or sexual orientation.

The new guide can be downloaded from the Alzheimer Europe website, at: https://bit.ly/AEGuide_SexGenderSexualityinDementia

Recognition of contributors

Alzheimer Europe would like to thank the former and current members of the EWGPWD and their supporters, as well as the members of the earlier ethics working group, for all the work they put into developing the communication guidance in 2022.

We would like to thank the members of the working group who were co-authors of one or both of these reports on sex, gender and sexuality in the context of dementia:

Dianne Gove, Chair (Luxembourg), Simone Anna Felding (Denmark), Aileen Beatty (United Kingdom), Andrea Capstick (United Kingdom), Patrick Ettenes (United Kingdom), Jean Georges (Luxembourg), Fabrice Gzil (France), Phil Harper (United Kingdom), Helga Rohra (Germany), Linn Sandberg (Sweden), Anthony Scerri (Malta), Charles Scerri (Malta), Annemarie Schumacher Dimech (Switzerland) and Karin Westerlund (Sweden).

Acknowledgement

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 elects new Board and Chairperson and welcomes new members

On 17 October 2022, Alzheimer Europe held its Annual General Meeting (AGM) in Bucharest, Romania, voting on new membership applications and electing a new Board and Chairperson for the term 2022-2024.

On 17 October 2022, Alzheimer Europe organised its Annual General Meeting (AGM), with representatives of its national member organisations. 33 out of 34 full members were in attendance or were represented. The AGM voted on new membership applications and elected a new Board and Chairperson for the term 2022-2024.

Existing provisional member MTÜ Elu Dementsusega (Estonia) was welcomed as a full member of Alzheimer Europe, while Alzheimer Polska (Poland) and Demenz Selbsthilfe Austria (Austria) were welcomed as new full members.

Alzheimer’s Care Armenia (Armenia), Demencija Lietuvoje (Lithuania), Institute for Alzheimer’s disease and neuroscience (North Macedonia), O Srpskom udruženju za Alchajmerovu bolest (Serbia) and Nezabutni (Ukraine) were voted in as provisional members of Alzheimer Europe. Going forward, Alzheimer Europe will represent 41 members from 37 European countries.

The 2022-2024 Board

Office bearers

- Chairperson: Maria do Rosário Zincke dos Reis (Portugal), newly elected to this position
- Vice-Chairperson: Charles Scerri (Malta), re-elected
- Honorary Secretary: Mario Possenti (Italy), newly elected
- Honorary Treasurer: Marco Blom (Netherlands), re-elected.

Members

- Stefanie Becker (Switzerland), re-elected
- René Friederici (Luxembourg), re-elected
- Lorène Gilly (France), newly elected
- Andy Heffernan (Ireland), newly elected
- Martina Mátlová (Czech Republic), newly elected
- Mary-Frances Morris (Scotland, UK), newly elected
- Chris Roberts, re-elected as Chairperson of the European Working Group of People with Dementia (EWGPWD).
- Katarina Suomu (Finland), newly elected
- Jochen René Thyrian (Germany), newly elected.

Congratulations to all of them and a warm welcome to all new Board members.

Outgoing Chairperson Iva Holmerová (Czech Republic), outgoing Honorary Secretary James Pearson (United Kingdom – Scotland) and outgoing Board members Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen, MEP (Finland) and Karin Westerlund (Sweden) did not stand for re-election. Alzheimer Europe and its Board would like to thank all of them for their service and important contributions and wish them all the very best.

Maria do Rosário Zincke dos Reis (Portugal) - Chairperson

Maria do Rosário Zincke dos Reis has been practicing law in Portugal since 1987, with a focus on family law and the legal rights of people with diminished capacity. She is also a trainer on these same issues. She served as Chairperson of Alzheimer Portugal during 2001-2012 and currently she is the Vice-Chairperson. She is the Chairperson of “Plataforma Saúde em Diálogo” an umbrella organisation of 62 organisations, mostly of patients organisations of people living with chronic diseases.

She is also a member of CEIC - National Ethics Committee for Clinical Research.

She has been a member of the Alzheimer Europe Board since 2008, was the Honorary Treasurer from 2010-2020, and was elected as Chairperson in October 2022.
Charles Scerri (Malta) - Vice-Chairperson

Charles Scerri is a graduate from the University of Dundee in Scotland and lectures in neuropharmacology and dementia studies at the Faculty of Medicine and Surgery, University of Malta. He is the Chairperson of the Malta Dementia Society and is the National Focal Point on Dementia in Malta.

He is also a member of the European Union Joint Programme for Neurodegenerative Diseases (JPND) Scientific Advisory Board and Early Detection and Timely Intervention in Dementia Group (INTERDEM).


He has been Vice-Chair of Alzheimer Europe since October 2016. Prior to this, he was the organisation’s Honorary Secretary.

Marco Blom (Netherlands) - Honorary Treasurer

Marco Blom is Scientific Director of Alzheimer Nederland. He is psycho-gerontologist since 1987, is involved in organisations and projects on dementia. He started his career at a Community Mental Health Centre in The Hague and, in 1991, was appointed at the National Institute of Care and Welfare (now called Vilans) in Utrecht. In March 1997, he joined Alzheimer Nederland.

At Alzheimer Nederland, he was involved in the development of the Alzheimer Cafés, the academic Alzheimer Research Centres and the online platform for people with dementia and their family caregivers. He was a board member of the “Delta Plan Dementie”, the national programme on dementia in the Netherlands (2013 – 2020). In 2021, he was invited to chair a mission team on the topic of dementia within the Topsector Life Sciences and Health. He is also a member of the editorial board of the Netherlands journal of Psycho-geriatrics (Denkbeeld). He joined the Alzheimer Europe Board in 2016 and was elected as Honorary Treasurer in 2020.

Stefanie Becker (Switzerland)

Stefanie Becker is the Director of Alzheimer Switzerland. A trained psychologist and gerontologist, she holds a PhD in Psychology from the Karl-Ruprecht University of Heidelberg in Germany. For more than 20 years, she has been working on the question of stabilising and promoting quality of life for people with dementia. Former employers in the field of Gerontology were the German Centre for Research on Ageing and the research group of Psycho-geriatrics at the Centre of Mental Health, Germany, as well as Director of the Institute of Aging at the University of Applied Sciences in Bern, Switzerland. She has also worked with professional caregivers in providing stress management assistance and training. In addition, she has handled several consultancy projects, such as developing and implementing dementia strategies and concepts in different nursing homes and in a hospital, developing curricula for training caregivers, designing specialised dementia care units and quality evaluation in different gerontological fields.

In Switzerland, she held the presidency of the Swiss Society of Gerontology and Geriatrics from 2012-2016 and was founder and chief editor of the bilingual (German-French) journal, “Applied Gerontology”.

She is a member of different strategic boards, such as the Swiss national platform on dementia. She joined the Alzheimer Europe Board in 2016.

René Friederici (Luxembourg)

Since 2015, René Friederici has been an Executive Board Member of Association Luxembourg Alzheimer (ALA). Formerly, he worked for an engineering and project management company, headquartered in Luxembourg, where he held the position of Senior Vice-President, responsible for Global Human Resources of the Group.

As a member of Rotary International, he was District Governor for Belgium and Luxembourg and, since 2021, he has been a regular member of the Rotary International Parliament. In these functions, he is also focusing on financially supporting Alzheimer’s academic research in Luxembourg. He has been a Board member of Alzheimer Europe since 2020.

Lorène Gilly (France)

Lorène Gilly has been working for Alzheimer since March 2017 and is the Head of Public Affairs there, since January 2018. She holds a degree in health system economics (2011) and has also studied public health issues. She represents France Alzheimer in other national bodies and also manages
Andy Heffernan (Ireland)

Andy Heffernan is currently the Chief Executive of the Alzheimer Society of Ireland, having previously served as the National Secretary of the Society of St. Vincent de Paul (SVP), which is one of the largest voluntary charitable organisations in Ireland. Prior to his role at the SVP, he was Chief Executive of Saint John of God Community Services, an organisation providing a range of services to those with learning disabilities and mental health issues across Ireland. He also served in the Defence Forces for 19 years, holding a range of training, command and staff appointments. He also served abroad, including three trips in the Middle East with the United Nations, Central Africa with Goal and the Balkans with the European Union.

He has a BSc from NUIG, an MSc from the University of Ulster and a certificate in Charity Law, Trusteehip and Governance from the Law Society of Ireland.

He was elected to the Alzheimer Europe Board in October 2022.

Mary-Frances Morris (United Kingdom - Scotland)

Mary-Frances Morris spent a number of years at Oxford University Department of Psychiatry, researching anxiety in mainly elderly populations and teaching psychology to undergraduate students of psychology and of medicine. She later studied law at Oxford University (New College) and was subsequently called to the Bar of England and Wales, in 2004.

She divided her time between London and Scotland for over a decade to allow her to play a very active part in caring for her parents, who both had vascular dementia. While this was of course a personal tragedy, it gave her a great deal of experience of dealing with dementia and everything that goes along with it, at very close quarters. This has also informed her passion for helping the currently ill and their carers, as well as looking to the future of dementia care and prevention/cure. Mary-Frances Morris is Vice Convenor of Alzheimer Scotland, Chair of its Human Rights and Public Policy Advisory Group, which helps steer the campaigning arm of the organisation and also sits on the Research Advisory Forum and Advisory Group to the University of Edinburgh Alzheimer Scotland Dementia Research Centre. She was recently an invited speaker at the World Congress on Adult Capacity 2022. She was elected to the Alzheimer Europe Board in October 2022.

Katarina Suomu (Finland)

Katarina Suomu joined the Alzheimer Society of Finland (Muistiliitto) in March 2019, when she was appointed as Executive Director of the association. She has completed her Master’s degree in Social Sciences and has also studied pedagogy, coaching and has qualifications in leadership and management. She has over 20 years of work experience in different NGOs and has also volunteered and worked as a board member in various organisations. Currently, she is a member of Human Rights Delegation of The Human Rights Centre in Finland, a board member of the Finnish Brain Council and a council member of SOSTE, the Finnish Federation for Social Affairs and Health (the European Working Group of People with Dementia (EWGPWD) for four years, since joining the group in October 2016.

Chris Roberts (United Kingdom – England, Northern Ireland and Wales), Chairperson of the European Working Group of People with Dementia

Chris Roberts is the current Chairperson of the European Working Group of People with Dementia (EWGPWD) and an ex-officio member of the Board of Alzheimer Europe, with full voting rights. He is from Wales, United Kingdom, and was diagnosed with mixed dementia (Alzheimer’s type and vascular dementia) in early 2012, but has not let this diagnosis get in the way of leading a full life.

He spends a lot of his time raising awareness of dementia to dispel the stigma that is associated, promoting the development and continuation of better services and support. Chris campaigns to uphold the rights of all people affected by dementia. He has spoken at events, nationally, as well as in Europe and beyond and is supported by his wife Jayne Goodrick. Chris also represents people with dementia as an Ambassador for Alzheimer’s Society (UK), Co-Founder and active member of the 3 Nations Dementia Working Group (England, Northern Ireland and Wales, UK), Prime Minister’s Dementia Challenge Group for Air Transport, Honorary Fellow and Lecturer in MSc Dementia Studies, School of Healthcare Sciences, Bangor University, Salzburg Global Fellow (International Seminar 587), Ambassador for the National Association of Care Caterers, member and former Board member of Dementia Alliance International, member of the Expert Working Group for the Wales Dementia Action Plan 2018 and of the Dementia Oversight of Implementation and Impact Group.

Prior to his role as Chairperson, he was the Vice-Chairperson of the EWGPWD for four years, since joining the group in October 2016.
A few words from our new Chairperson Maria do Rosário Zincke dos Reis

Alzheimer Europe’s new Chairperson, Maria do Rosário Zincke dos Reis, has been a Board member since 2008 and has now been elected as Chair, in October 2022. She tells us a bit about her experience of working with the organisation, so far, and about her hopes for the future.

How and when did you first come into contact with Alzheimer Europe?

I think, I am right in saying that it was in 2004, at the Alzheimer Europe Conference, in Prague, Czech Republic. That was the first Alzheimer Europe Conference that I attended. It was a very special conference for me, not only because it was my first one, but also because it was there, at Alzheimer Europe’s Annual General Meeting, that Alzheimer Portugal presented its application to host the 2007 Alzheimer Europe Conference. The application was successful and the 2007 conference took place in Estoril (Cascais, Portugal) under the banner “The Sound of Silence”.

What has your experience been of working with the organisation, so far? Can you list some personal highlights from your time on the Board?

I did not start off as a Board Member. That only happened in 2008, when I became the Honorary Treasurer. I remember, I was involved in Alzheimer Europe’s project “European Collaboration on Dementia – EuroCoDe” (2006–2008) and in Lawnet II in 2009 (inventory of existing legislation regarding the legal protection and rights of people with dementia). It was a very rich experience to know what was happening in very different countries especially in what concerns legal issues. For instance, I learned a lot about Advance Directives and Guardianship.

Some other very special moments I would highlight include the signature of the Paris Declaration (2008) and the moment when Nicolas Sarkozy, the French President at the time, launched the French National Plan for Dementia, in Paris.

My experience as a Board Member has also been very rich. The Alzheimer Europe team and staff are always fantastic. All the decisions are very well prepared and discussed among the Board members, so everyone feels involved in the decision-making process.

Why did you decide to accept this position and what are your hopes for the future of Alzheimer Europe?

It was not something I had planned, but the circumstances made me feel comfortable to accept the position, as I immediately received my colleagues’ support. My predecessor, Iva Holmerová, has always been such a kind and competent person and it is a great honour for me to succeed her. It is an exciting challenge for me, to be the Chairperson of Alzheimer Europe, the leader of the European Dementia Movement. I believe that Alzheimer Europe will strengthen its position as a reference point, bringing together so many national organisations, with a common goal – to improve the quality of life of people with dementia and contribute to a society that really involves and listens to their voices. The organisation will also strengthen its role, influencing European and national policy and being deeply respected among European Institutions and many different partners and stakeholders.

What do you see as the main priorities of the organisation, going forward?

The main priorities of Alzheimer Europe are very well described in our strategic objectives, which are:

- providing a voice to people with dementia and their carers;
- making dementia a European priority;
- changing perceptions and combating stigma;
- raising awareness of brain health and prevention;
- strengthening the European dementia movement and supporting dementia research.
European Working Group of People with Dementia welcomes new members for 2022-2024

The European Working Group of People with Dementia (EWGPWD) began its new term of office, on 19 October 2022, at the close of the 32nd Alzheimer Europe Conference.

The group operates independently and members elect their own Chairperson and Vice-Chairpersons. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe, with full voting rights. During the group’s previous terms of office, members have actively participated in Alzheimer Europe’s annual conferences and contributed towards public involvement (PI) work for EU-funded research projects in which Alzheimer Europe is involved, as well as to other areas of Alzheimer Europe’s work.

They have also contributed to research on a wide variety of topics including the use of technology in dementia, Artificial intelligence-based dementia risk prediction and the respectful communication and portrayal of dementia, and have attended a number of international events, including at the European Parliament, as representatives of the group.

The Alzheimer Europe team would like to express its gratitude to departing members from the previous group, Idalina Aguiar, Stefan Eriksson, Tomaž Gržinič, Danny McDonald, Helen Rochford-Brennan and Geert Van Laer (Geert has sadly, since, passed away, in January 2023) for their important contributions. They will be missed!

The EWGPWD for 2022-2024 is composed of the following 15 members:

Chairperson
- Chris Roberts, United Kingdom

Vice-Chairpersons
- Margaret McCallion, Scotland, United Kingdom
- Kevin Quaid, Ireland

Members
- Bernd Heise, Germany
- Nigel Hullah, United Kingdom
- Erla Jónsdóttir, Iceland
- Marguerite Keating, Ireland
- Lieselotte Klotz, Germany
- Pia Knudsen, Denmark
- Petri Lampinen, Finland
- Real Larnou, Belgium
- Stephen John McCleery, Italy
- Angela Pototschnigg, Austria
- Shelagh Robinson, United Kingdom
- Věra Ryšavá, Czech Republic
- Marguerite Keating, Ireland
- Lieselotte Klotz, Germany
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The 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.

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The Members

Bernd Heise

Bernd Heise is married and lived in Munich with his wife. For 34 years, he worked as a development engineer of semiconductor devices in the telecommunications industry, until his dementia diagnosis. He is also a member of the Advisory Board of People Living with Dementia, founded by the German Alzheimer association (Deutsche Alzheimer Gesellschaft). Bernd Heise was nominated to join the EWGPWD in 2018, by the Deutsche Alzheimer Gesellschaft Selbsthilfe Demenz, and was the group’s Vice-Chairperson for the term 2020-2022.

Nigel Hullah

Nigel Hullah was diagnosed with early-onset dementia in 2012. He has a lot of experience of working with groups at a regional and national level. He is the Chair of the 3 Nations Dementia Working Group (3NDWG) and has gained exposure to the development of services and helping with innovation of strategies. He has also supported the rights of all disabled people (including those with a dementia diagnosis) for equitable services, the fulfilment of statutory and civil rights and the promotion of their preferences and a right to be heard. He was nominated to join the EWGPWD by Alzheimer’s Society, UK, in 2020.

Erla Jónsdóttir

Erla Jónsdóttir is from Reykjavík in Iceland but lives in Garðabær. She and her husband Emil have two daughters and four grandchildren. She was diagnosed with early onset Alzheimer’s disease in 2020, and immediately joined Alzheimer Iceland’s working group of people with dementia, called “Frumkvöðlar” (Pioneers). She has a broad spectrum of working experience in the private and public sector including as a member of the town council in Garðabær and as a board member of UNIFEM (United Nations Development Fund for Women). She was nominated to join the EWGPWD by Alzheimer Iceland in 2020.
Marguerite Keating was nominated to join the EWGPWD by The Alzheimer Society of Ireland in October 2022.

Marguerite Keating lives in Cashel, County Tipperary, Ireland. Her partner is James Brown and she has three grown-up daughters and eight grandchildren. She was diagnosed with early onset Alzheimer’s disease in February 2019 and now she tries to give hope to newly-diagnosed people and their carers. She is involved with groups including The Alzheimer Society of Ireland (ASI) steering group, the Understand Together working group and two local Memory Cafés. She also gives talks for the Health Service Executive (HSE) ASI.

Marguerite Keating was nominated to join the EWGPWD by The Alzheimer Society of Ireland in October 2022.

Pia Knudsen is from Aarhus, Denmark. Though she lives alone, she has a son in Barcelona and a daughter in Copenhagen. She studied art and design and has given exhibitions in many places in Europe. She also worked as a teacher and always loved her work. Now, she loves being a spokesperson for people with dementia. She has spoken at the Parliament in Denmark and is also an ambassador of dementia in Aarhus, where she works with the councillor of health and care to try to make Aarhus a dementia-friendly city. She has appeared in the media, discussing her experience of dementia and has participated in several lectures with the Danish Alzheimer’s association. In her daily life, she focuses on preserving her physical and cognitive ability and strength, and enjoys many social activities.

She was nominated by Alzheimerforeningen to join the EWGPWD in October 2022.

Pia Knudsen

Real Larnou worked in a bank for more than 30 years, and for the last ten years of his career, was a relationship manager for the agricultural sector, responsible for credit applications of farmers.

Three years ago, while driving to one of his clients, he suddenly experienced a loss of orientation, which was the first sign that something was wrong. A year later, he made a mistake in a daily routine file and so made an appointment with his doctor. His diagnosis of Alzheimer’s disease came six months later in July 2021. On the one hand, the diagnosis was a relief for him, because he finally knew what was wrong, but on the other hand, it was very difficult, because he had always hoped to end his career in a more positive way.

Real Larnou was nominated by Ligue Nationale Alzheimer Liga to join the EWGPWD in October 2022.

Margaret McCallion, Vice-chairperson

Margaret McCallion lives in Glasgow and has been a member of the Scottish Dementia Working Group (SDWG) since 2019, following a diagnosis of Frontotemporal dementia in 2016. Prior to this, she enjoyed a varied PA career at director level. Her final position was with a large well-known organisation with whom she worked for 11 years. Following problems with her memory, she was told by her employer that she could not continue her work. Because of this upsetting experience, she is passionate about improving the working environment for people living with dementia. She then discovered the SDWG and welcomed the opportunity to have her voice heard and to campaign for the rights of people with dementia. She was nominated to the EWGPWD by Alzheimer Scotland in 2020 and became Vice-chairperson in October 2022.

Margaret McCallion

Petri Lampinen was diagnosed with Frontotemporal dementia in 2015, but he refuses to let the difficulties associated with his dementia to defeat him. In spite of them, he continues to live an active life, working in his garden, cycling and playing ping-pong and badminton.

He finds that being open about his condition and remaining as calm as possible in any situation helps him navigate life with dementia, with the support of others when needed.

He has been a member of the EWGPWD since his nomination to the group by the Alzheimer Society of Finland (Muistillitto) in 2017.

Real Larnou

Margaret McCallion

Lieselotte Klotz (Lilo) is a wife, mother, daughter, sister, aunt and friend and a passionate sailor. She was diagnosed with Lewy Body Dementia in April 2017. She is from a small town near Cologne in Germany and lives with her little dog Dorie in Kuehlungsborn, on the German Baltic Sea. She has three children who live and work in Cologne, Berlin and Tokyo. From 2010 to 2016, she sailed many oceans with different sailboats and crews, where women are still considered a “fringe group”, and she hopes to inspire other women to take to the water as active sailors.

She began her professional career in the healthcare sector before moving to the IT sector and during her 30 years as a single mother, she always had a full-time job and even founded her own successful IT service company. She also worked as a managing director and strategic manager in other IT companies in Germany. Since her diagnosis, she volunteers as actively as possible at Deutsche Alzheimer Gesellschaft, which nominated her to join the EWGPWD in October 2022.

Lieselotte Klotz

Pia Knudsen

Petri Lampinen
Stephen John McCleery

Stephen McCleery was born in Belfast, in 1967 and graduated in law from Cambridge University in 1990. Following internships in Sydney and in Brussels at the European Commission, he began work in London as an anti-trust lawyer, then in Milan, where he holds an MBA from the SDA Bocconi Business School. He speaks Italian and French and has been living and working in Milan since 2000.

In 2020, during the pandemic, he was diagnosed with Alzheimer’s disease and joined the EWGPWD in October 2022, as an “Italian” member.

He was nominated by Federazione Alzheimer Italia to join the EWGPWD in October 2022.

Angela Pototschnigg

Angela Pototschnigg lives in Vienna and has been living with dementia since 2015. She is an ambassador for inclusion and the rights of people with dementia and holds peer-talks twice a month for those with memory problems, organised and supported by Alzheimer Austria.

In the past few years, she has been invited to speak in committees about the concerns, needs and wishes of people with dementia, such as in the Austrian Dementia Strategy and the adopted care reform. She gives talks in dementia-friendly communities, to family carers and professional caregivers and engages in projects that focus on participation of and information about people living with dementia.

Since 2022, she is on the board of the national umbrella organisation Demenz Selbsthilfe Austria. In 2018, she was nominated by Alzheimer Austria to join the EWGPWD.

Kevin Quaid, Vice-chairperson

Kevin Quaid was first diagnosed with Parkinson’s disease, just over six years ago, and then with Lewy body dementia. He is Chairperson of the Irish Dementia Working Group, Vice-chairperson of the EWGPWD and co-founder of Lewy Body Ireland. He is the author of two books about Lewy body dementia, and is currently writing a third book.

In 2022, he received the Presidential Award from Longford International College, Ireland, for outstanding achievements in bringing awareness of Lewy Body dementia to people not just in Ireland but around the world.

He was nominated to the EWGPWD by the Alzheimer Society of Ireland in 2020.

Chris Roberts, Chairperson

Chris Roberts is the Chairperson of the EWGPWD and an ex-officio member of the Board of Alzheimer Europe. He is from Wales and was diagnosed with mixed dementia (Alzheimer’s and vascular dementia) in early 2012.

He spends a lot of his time raising awareness of dementia to dispel the stigma that is associated with it, and promoting the development and continuation of better services and support. He campaigns to uphold the rights of all people affected by dementia and has spoken at national events, as well as in Europe and beyond, supported by his wife Jayne Goodrick.

Prior to his role as Chairperson, he was the Vice-chairperson of the EWGPWD for four years, since joining the group in October 2016. He was nominated by Alzheimer’s Society, UK.

Shelagh Robinson

Shelagh Robinson is living with Alzheimer’s dementia. She says she was fortunate to have a doctor who really listened to her, as this helped her get a quick and early diagnosis. She has been a volunteer for the Alzheimer’s Society (UK) since they sought her out following a Facebook post, and she has since discovered a talent for public speaking that is well used. Like all those living with dementia, she is aware that she has a limited time to be active and wants to do all she can to improve life for those who live with dementia.

She is passionate about good support at the time of diagnosis, and good end-of-life care and of the course all the rest of the journey too. Shelagh has discovered it is possible to live a full and rich life with dementia, rolling with the bad days and is grateful for the wonderful support that the Alzheimer’s Society offers her.

For more information, see: https://www.bit.ly/EWGPWD

On the occasion of World Alzheimer’s Day 2022, Alzheimer Europe was proud to collaborate with Roche on an initiative called “What Makes You, You?”. Members of the European Working Group of People with Dementia took part in a series of videos looking beyond an Alzheimer’s diagnosis, to celebrate the person.

World Alzheimer’s Day is marked each year by organisations and individuals around the world, raising awareness of Alzheimer’s and other types of dementia, as well as challenging the stigma surrounding dementia.

To mark this important day, in 2022, Alzheimer Europe was proud to launch an initiative called “What Makes You, You?” a collaborative effort between Roche, the European Working Group of People with Dementia (EWGPWD) and Alzheimer Europe. The aim of this initiative was to help create a world where people living with diseases that affect the brain, like Alzheimer’s, can live life to the fullest and it stressed the importance of looking beyond a person’s diagnosis and of valuing them for who they are.

Short videos (approximately three minutes each) were created, featuring three members of the EWGPWD, all living with Alzheimer’s disease, together with some of their family members. Each told the story of who they are in their words. In the first video, Bernd Heise, Vice-Chairperson of the group at the time (now a group member), who used to be an engineer and is still very keen on technology, appears alongside his wife Hilde, who is amazed at his continuing ability to work with technology, though she notes that it takes him much longer than it used to. Bernd says:

“I try to be as much as I was before, but I was an engineer and very attached to technical solutions. This has changed a bit. Now I talk to and learn from other people more, rather than trying to do everything by myself. I change, but I am still me. You have to carry on and just try to live life as well and as enjoyably as possible.”

The second video features Helen Rochford-Brennan, a member of the EWGPWD at the time who has since left the group. She stresses that it is vital for her to keep focusing on the same things she always has:

“Working for the rights of all people is important to me to this day. Equality for all. I am also a political activist and I think I must keep doing that, to keep being the person that I am. All that has changed is that I have a short-term memory problem. Of course I forget, but that’s ok. That has not changed at all my passion about rights, about my rose garden and about the things that I believe in and the things that I love, like getting out in my car, walking my dog and enjoying my life. That’s Helen.”

Stefan Eriksson (also a member of the group at the time, who has since left) and his daughter Janni Ahlgren feature in the third video. Janni shares her father’s and the rest of the family’s positive outlook on life and the importance they all place on Stefan continuing to enjoy life as much as possible and staying as active as he always has been:

“Even though he has Alzheimer’s now, he still has goals in his life and he still wants to achieve them and continue doing the things he loves. My dad is always going to be dad, he’s always going to be Stefan. Just because he has Alzheimer’s doesn’t mean he is going to become a totally different person. He still has his vision in life, his goals, his hobbies and interests that he loves to do. We always try to encourage him to stay the Stefan that he is.”

You can watch the videos on our YouTube channel, here:
https://www.youtube.com/playlist?list=PLo-PqQHiiWQUEfadlt9s2LupMB_AgDHN

Alzheimer Europe is delighted to have worked on this initiative in collaboration with Roche. We would also like to again express our gratitude to Bernd, Hilde, Helen, Janni and Stefan for sharing their stories to help raise awareness, combat stigma and create a world where people with dementia can continue to be who they are, this World Alzheimer’s Day and every day.
Alzheimer Europe partners in three new projects linked to Artificial Intelligence

Alzheimer Europe is pleased to partner in three new projects. In this article, we present a brief overview of ADIS (JPND funded), eBRAIN-Health (Horizon Europe funded) and Pattern-Cog (ERA PerMed funded). The perspective of each project’s coordinator is presented, regarding the rationale behind the projects and the concrete actions being undertaken.

ADIS

ADIS stands for “Early Diagnosis of Alzheimer’s Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances”. The project is funded through the EU Joint Programme - Neurodegenerative Disease Research (JPND). JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases.

The ADIS project will run for a period of three years with a budget of 1.3 million, distributed among seven collaborators.

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

What is the problem you are aiming to address with ADIS?

ADIS focuses on the question of how we could achieve earlier diagnosis of Alzheimer’s disease (AD) in the future. This is important, because the disease likely starts decades before the manifestation of first symptoms. The success of any future medical treatment critically depends on starting as early as possible, because the damages to the brain that are initiated by the disease are irreversible. Another reason why earlier diagnosis is so important is the strongly increasing number of patients with AD. The diagnosis, treatment and care of each of these patients is very expensive. So, it would help, if in the future a higher percentage of patients could be diagnosed in primary care institutions rather than in specialised memory clinics.

For both these reasons, we need measurements (biomarkers), and these biomarkers should be sufficiently easy to assess so that this can also be done by general practitioners. In the ADIS project, we thus focus on blood-based biomarkers as well as sleep disturbances.

What are the concrete objectives and actions which will be undertaken by ADIS?

Our two concrete objectives are to evaluate whether blood-based biomarkers derived from special types of immune cells and sleep disturbances allow us to reliably distinguish AD patients at different stages of the disease from healthy subjects; and to understand, in how far sleep disturbances might influence blood-based biomarkers. This is important, because we need to know which type of measurements are most effective and most efficient.

Our concrete actions include running a clinical study with 75 participants (25 with AD, 25 with mild cognitive impairment and 25 cognitively normal participants), that we carefully assess via standard questionnaires, a smartwatch (worn at home), an augmented reality game (to monitor cognition) and via blood sampling.

From each of the blood samples we measure many different molecular markers, even on the level of individual cells. We use statistical as well as advanced computational approaches (including Artificial Intelligence) to find patterns in the data generated by our study. This will help us to evaluate whether blood-based biomarkers and sleep disturbances might allow us to detect AD at an early disease stage.

“ADIS will leverage cutting-edge science and technology with clinical expertise to explore biomarkers for earlier diagnosis of Alzheimer’s disease, which is essential to enhance success chances of any treatment.”

Acknowledgement

This project is supported by the Luxembourg National Research Fund (INTER JPND21/15741011/ADIS) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu
**eBRAIN-Health**

eBRAIN-Health is a Horizon Europe-funded research project that was launched in July 2022, with a total budget of almost 13 million EUR. Involving 20 partners including Alzheimer Europe, the project will run for four years, until July 2026. Alzheimer Europe is leading the public involvement activities and contributes to communications and outreach work for the project.

**Interview with Project Coordinator Prof. Petra Ritter, Berlin Institute of Health at Charité University Hospital, Germany**

What is the problem you are aiming to address with eBRAIN-Health?

Brain health costs in Europe are estimated to exceed EUR 800 billion per year. However, we still lack effective, disease-modifying treatments for Alzheimer’s disease (AD) and dementia, which affect over 10 million people in Europe alone. There are many factors that contribute to this. Firstly, there are still gaps in knowledge about the specific biological processes in the brain that cause these diseases, which often affect people with multiple health problems. In addition, we lack precise, highly-accurate tools and systems for modelling, diagnosing and monitoring the progress of AD, which may take decades to develop. Together, these and other factors mean that people with AD can wait years to be diagnosed, and lack effective treatments that could change the course of the disease.

Many research studies have been collecting data and information to better understand the biological basis of AD, assess diagnostic and monitoring biomarkers and test potential treatments. These individual studies can be limited by the range of tests and assessments used, and by the number and diversity of participants that are included. In addition, while large investments in dementia research have been made over the last decade, there are technical barriers that hinder progress: such as a lack of integration, and insufficient computational exploitation and re-use of research data. In eBRAIN-Health, we are aiming to address these barriers, by developing a secure research platform for accurate “digital twins” of the brain, created by assembling a large range of data sources. Using these digital versions of individuals to model disease progression could accelerate brain research, and improve clinical decision-making for patients with Alzheimer’s and other neurodegenerative diseases.

What are the concrete objectives and actions which will be undertaken by eBRAIN-Health?

As mentioned above, our project is built around the concept of “digital twins”. Digital twins are virtual representations of individuals, created based on vast quantities of clinical data and scientific knowledge. Using artificial intelligence, this information can be integrated into a “digital twin”, personalised to resemble the clinical characteristics of individual people. As our real-time, virtual representations, digital twins have the potential to support more accurate and personalised decision-making, for example by allowing doctors to simulate the future outcomes of different treatment options.

In eBRAIN-Health, a large variety of data sources will be brought together in a GDPR-compliant research platform, to support the development of digital representations of the brain. These data sources will include brain scans, behavioural studies and lifestyle surveys, as well as clinical data from thousands of patients and healthy peers. The data will be combined with biological information from scientific research on the brain, helping to build complete and highly-detailed simulations of the brain.

These simulations can then be personalised to resemble individual people, creating a brain “digital twin”. These “digital twins” will allow a large number of researchers to conduct innovative brain research within a powerful digital platform that keeps patient data secure and confidential. In addition, the digital twins have the potential to improve our understanding of brain function and disease at an individual level; improve diagnosis and risk prediction and optimise potential therapies.

Digital twins that simulate individual brains have the potential to accelerate research, and improve clinical decision-making for patients with AD. In eBRAIN-Health, we are working together to realise this potential, by developing a powerful digital platform that will keep patient data secure whilst driving innovation.”

**Acknowledgement**

eBRAIN-Health has received funding from the European Union’s Horizon Europe research and innovation programme, under grant agreement No. 101058516.
Pattern-Cog

Pattern-Cog stands for “Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals.” The European project officially started on 1 June 2022 and has a duration of three years. The project has a budget of 1.7 million from ERA PerMed, distributed across a total of six partners: University of Eastern Finland, Jena University Hospital, Karolinska Institutet, Fundación Centro de Investigación de Enfermedades Neurologicas, Charité Universitätsmedizin Berlin and Alzheimer Europe. In this project, Alzheimer Europe co-leads the work packages dedicated to public involvement and communication/dissemination.

Interview with Project Coordinator Jussi Tohka, University of Eastern Finland

What is the problem you are aiming to address with Pattern-Cog?

The overarching goal of the Pattern-Cog project is to improve dementia prevention strategies by developing and validating a personalised medicine methodology for the detection of earliest signs of impending cognitive decline and markers, to enable early and personalised multidomain interventions. Effective disease modifying drugs are not yet widely available, but a multidomain lifestyle intervention (FINGER randomised controlled trial, RCT) has been shown to improve cognition and other related outcomes in older adults from the general population with elevated risk for developing dementia.

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

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

What are the objectives and actions taken when implementing the Pattern-Cog project?

The primary objectives of Pattern-Cog are: 1) to develop an innovative methodology for predicting future cognitive decline indicative of high risk for clinical transition, 2) to test the methodology in ongoing RCTs for dementia prevention and 3) to develop solutions to the ethical, legal, and social issues associated with computer-assisted dementia risk prediction.

Pattern-Cog will combine data from several existing databases, including a large observational study of healthy aging (“Vallecas Study”) and dementia intervention/prevention trials (e.g., FINGER, MIND-AD mini). Ethical, legal, and social aspects of dementia prediction and prevention are essential components of the project.

Pattern-Cog will help answer relevant questions about the management of research data in multinational studies of personalised medicine in dementia. Equally important is understanding the views and concerns of people with cognitive impairment and dementia regarding algorithm-based prediction of future cognitive decline. Even as clinical tools are being developed, Pattern-cog will organise public engagement activities to understand how best to communicate the results of risk assessments based on algorithmic approaches.

Acknowledgement

This project was supported through the following funding organisations: Finland, Academy of Finland (AKA); Germany, Federal Ministry of Education and Research (BMBF); Germany, Federal Ministry of Health (BMG); Luxembourg, National Research Fund (FNR); Spain, National Institute of Health Carlos III (ISCIII); Sweden, Swedish Research Council (SRC) under the frame of ERA PerMed.
Dutch “Adoption project” wins Alzheimer Europe’s Anti-Stigma Award

At the closing ceremony of the 32nd Alzheimer Europe Conference the “Adoptieproject: Jong adopteert Oud” (Adoption project, young adopts old) was announced as the winner of Alzheimer Europe’s new Anti-Stigma-Award.

On 19 October 2022, at the closing ceremony of the 32nd Alzheimer Europe Conference in Bucharest (Romania), the “Adoptieproject: Jong adopteert Oud” (Adoption project, young adopts old) of the Alzheimer Centrum Limburg (Maastricht, Netherlands) was announced as the winner of Alzheimer Europe’s new Anti-Stigma-Award. The award, together with a cash prize of EUR 3,000 was presented by Iva Holmerová, outgoing Chairperson of Alzheimer Europe and Treasurer of the Alzheimer Europe Foundation. The second place award with a cash prize of EUR 1,500 to “Changing perceptions of dementia in the Punjabi community” by Alzheimer’s Society, UK.

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Biogen, Lilly and Roche had launched a call for applications in June 2022, with the aim of recognising an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. Applications were open to individuals and organisations established in a member country of Alzheimer Europe, for projects, campaigns, films, videos, publications or books developed and/or implemented in the past three years (2019-2022). 52 applications were received and reviewed by the Jury. Promising and innovative campaigns were included on a special website on the Alzheimer Europe website: https://www.alzheimer-europe.org/our-work/anti-stigma-award/ Anti-Stigma-initiatives-2022

The three finalists were invited to present their initiatives during the Alzheimer Europe Conference with the winner and runners-up announced during the closing ceremony (you can read all about the conference on pages 50 - 55 of this magazine).

The winning initiative was presented by Niels Janssen, from Alzheimer Centrum Limburg during the afternoon plenary on 18 October. The “Adoptieproject: Jong adopteert Oud” is an initiative aiming to connect generations, by bringing together children from a primary school with people in a nearby care home, who have dementia. The three main goals of the project are to reduce stigma and taboo by “opening up the conversation”; to help children to “understand the world of people with dementia” and to enhance social participation and increase wellbeing. The project began at a regional level and is now being carried out nationally, in close collaboration with Alzheimer Nederland.

Niels Janssen thanked Alzheimer Europe for the opportunity to present this project and expressed his gratitude for the project being shortlisted. “We’re honoured to be shortlisted for this award. It wouldn’t have been possible without the brave and honest sharing of stories of dementia of the Punjabi community”, he stressed, and explained that the aim of the initiative “Non ti scordare di volermi bene” is to give life to a new more dementia-friendly, inclusive generation.

Ellie Jerman, Marketing Executive at Alzheimer’s Society, UK introduced her organisation’s initiative “Changing perceptions of dementia in the Punjabi community”, during morning plenary on 19 October. She highlighted that, within the Punjabi community, the stigma associated with dementia means many people do not access the vital support they need. “Through these culturally bespoke resources, we want to bring help and hope to those who need us most”, she said. “We’re honoured to be shortlisted for this award. It wouldn’t have been possible without the brave and honest sharing of stories from members of the Punjabi community, who ensured our resources were truthful and impactful”, she concluded.

More information about the Anti-Stigma Award, and about some of the initiatives and campaigns which applied in 2022, can be found at: https://www.alzheimer-europe.org/our-work/anti-stigma-award

Acknowledgement

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, Biogen, Lilly and Roche.
Commissioner Schmit outlines European Care Strategy

Following the adoption of two recommendations relating to European Care Strategy by the Council of the European Union, Commissioner for Jobs and Social Rights, Nicolas Schmit, has spoken to Alzheimer Europe about the development of the strategy and what it means for people living with dementia, their families and carers.

Can you tell us about the development of the European Care Strategy and, in particular, the Recommendation on Long-Term Care?

The EU places a high value on care work, both professional and informal. We should never take for granted the huge sacrifices that millions of people – mostly women – make every day to care for children, persons with disabilities and the elderly. And yet this has often been an undervalued sector, with low pay and poor working conditions leading to a huge shortage of care workers. With that in mind, the European Care Strategy aims to bring about a shift in policy-making which will be felt by both receivers and givers of care.

People in need of long-term care must be guaranteed access to affordable services of good quality so they can live a dignified life. This has to be our starting point. Currently around a third of households in the EU with long-term care needs do not use home care services because they cannot afford them. On average, nearly half of older people with long-term care needs are estimated to be below the poverty threshold after meeting the out-of-pocket costs of home care. Half of children with disabilities are cared for by their parents alone. There can often also be a lack of options when it comes to long term care services, whilst residents of rural areas have even less choice available to them. This means that around 52 million Europeans are providing unpaid, non-professional long-term care to family members or friends.

We should never take for granted the huge sacrifices that millions of people – mostly women – make every day to care for children, persons with disabilities and the elderly.

If long term care services were more affordable, more accessible and quality-assured, it could make a huge difference to all those taking care of friends and family on top of their other jobs and responsibilities. It would also go a long way to ensuring independence and dignity for those in need of care. And it could have a big impact on gender equality: 92% of women in the EU regularly care for someone and due to their care responsibilities, have reduced to part time work or left employment altogether.

What is the potential benefit for people living with dementia, their families and carers?

The Council Recommendation on long-term care will improve the adequacy of long-term care so it is timely, comprehensive and accessible to those who need it, for example people with dementia. It also recommends increasing the offer of long-term care, as well as providing a balanced mix of services in all care settings (for example, home care, community-based care and residential care) which could have a big impact on people living with dementia and those caring for them.

A major issue we need to address is the pay and working conditions of care workers. The number of people in need of long-term care is on the rise – it is expected to reach 38 million by 2050. More than 1.6 million long-term care workers would have to be added by 2050 to keep long-term care coverage at the same level. At the same time, there is a shortage of care workers, with low pay and challenging working conditions make it difficult to attract and retain staff. Only in few Member States are almost all long-term care workers covered by collective agreements. In other Member States, social dialogue is almost absent from the long-term care sector. There is also the issue of training. The skills required in the care sector are increasingly complex. In addition to traditional skills and competences, carers often need to have advanced digital and communication skills, sometimes in a foreign language, and be able to handle complex and changing needs.

The Council Recommendation will guide Member States in improving working conditions, increasing wages, and promoting
social dialogue. It also encourages Member States to provide continuous training opportunities for workers in the long-term care sector; building career pathways through upskilling, reskilling, skills validation, and guidance services; and to support informal carers, through training, counselling, psychological and financial support. Member States should also make sure that the highest standards in occupational health and safety are in place, as well as ratifying and implementing ILO Convention 189 on domestic workers.

Principle 18 of the Pillar of Social Rights says: Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.”

How does this align with other EU policy areas, such as the European Pillar of Social Rights and the European Semester process?

The Care Strategy will help to advance the implementation of the European Pillar of Social Rights and the 2030 EU headline targets on employment, skills and poverty reduction. Principle 18 of the Pillar of Social Rights says: “Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.”

The Guidelines for the Employment Policies of Member States provide the basis for monitoring key employment and social developments in Europe within the framework of the European Semester. Guideline 12 contains specific provisions on long-term care. It states that Member States should ensure timely and equal access to affordable long-term care and healthcare services. Furthermore, country-specific recommendations provide guidance on improving access to care services, including to support the participation of informal carers in the labour market.

The Commission will continue to monitor closely via the European Semester the affordability and quality of long-term care in the Member States, as well as the fiscal sustainability of long-term care systems, and women’s labour market participation through access to long-term care services.

The Recovery and Resilience Facility via the national recovery and resilience plans envisages 33% of the social expenditure for health and long-term care (around EUR 45 billion), another 33% for education and childcare (around EUR 45 billion), and 14% for social policies (EUR 19.7 billion). Member States have used their national recovery and resilience plans to include long-term care related investments. For example, Portugal will use RRF funding to support the National Health Service in the fields of primary, mental and long-term care to anchor them strongly in local services and community-based care.

To bring the Care Strategy to life, Member States will require the input and collaboration of a wide range of partners, including NGOs and other civil society actors, social partners, social economy entities, and so on. Some of the specific follow-up actions where NGOs could play a role include improving data collection and evaluation, gathering lessons learned, seeking feedback on long-term care policies and practices, developing a mechanism for forecasting long-term care needs and strengthening contingency planning and capacity. Their expertise and commitment will be needed to keep up the momentum – we now have to really see a shift in how we value the critical work of carers, both informal and professional.

What are the next steps for the European Care Strategy?

On 8 December, Ministers of labour and social affairs at the EPSCO Council adopted the Recommendations on both early childhood education and care and on affordable high-quality long-term care.

Member States will now appoint long-term care coordinators to oversee implementation of the Recommendation, and within 18 months they will inform the Commission of the measures taken or planned to implement it.

What role can NGOs play, both nationally and at an EU level, to ensure that Member States implement the European Care Strategy?

To bring the Care Strategy to life, Member States will require the input and collaboration of a wide range of partners, including NGOs and other civil society actors, social partners, social economy entities, and so on. Some of the specific follow-up actions where NGOs could play a role include improving data collection and evaluation, gathering lessons learned, seeking feedback on long-term care policies and practices, developing a mechanism for forecasting long-term care needs and strengthening contingency planning and capacity. Their expertise and commitment will be needed to keep up the momentum – we now have to really see a shift in how we value the critical work of carers, both informal and professional.

More information on the European Care Strategy is available at: https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=10382&furtherNews=yes#navItem-4
Slovenia prepares to launch new dementia strategy

A new dementia strategy will soon be launched in Slovenia, overseen by a Council for Dementia Management. The Slovenian strategy will address ten priority areas to improve the lives of people living with dementia in the country. Our Slovenian colleagues in Spominčica - Alzheimer Slovenia, have been involved in the development of the strategy and spoke to the President of the Republic of Slovenia (until December 2022), Borut Pahor, about the new strategy and Council.

Background to new Slovenian dementia strategy

After the meeting of the Slovenian Council for Dementia Management, on 2 November 2022, at the Office of the President of the Republic of Slovenia, the Ministry of Health of the Republic of Slovenia launched a public debate on the proposed Slovenian dementia management strategy 2030. The second strategy was prepared by an interdisciplinary working group which was appointed by the Minister of Health in 2019. The members of the working group are experts from the Ministry of Health, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, the University of Ljubljana, Psychiatric Clinic of Ljubljana, the Neurology Clinic of Ljubljana, the National Institute for Public Health, General Practitioners and Spominčica – Alzheimer Slovenia.

The proposed strategy builds on Slovenia’s first national dementia strategy, as well as reflecting European Union and World Health Organization (WHO) commitments, as well as strategies in the field of dementia management in other countries, aiming to ensure preventive measures, early detection and appropriate standards of medical and social care for people with the condition. The ten objectives of the strategy, are:

1. Promotion of preventive programmes to reduce risk factors and to maintain and strengthen health in the community with different approaches to groups and individuals.
2. Diagnosing the early stages of neurocognitive disorders, improving access to quality, safe and effective health care and treatment.
3. Improving access to appropriate and coordinated post-diagnostic multidisciplinary treatment for people with dementia, including integrated treatment, long-term care, social services, support for families or caregivers in the local environment, and access to palliative care.
4. Using modern information and communication technologies for the treatment and support of people with dementia.
5. Respecting the dignity of people with dementia, reducing stigma and raising awareness among the wider society and the professional public for the development and establishment of dementia-friendly communities.
6. Educating professional groups in the field of dementia management.
7. Establishing national dementia data collection.
8. Promoting modern dementia research.
9. Establishing a National Dementia Centre.
10. Appropriate treatment of persons with dementia during epidemics and other emergencies.

The strategy had been developed already in March 2022, however, its adoption was delayed by the COVID-19 pandemic and the change of the government in April 2022. The draft strategy is available at: https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/ DJZ-Preventiva-in-skrb-za-zdravje/Demenca/demenca-Strategija-o-demenci-javna-razprava-021122.pdf

Council for Dementia Management

The Council for Dementia Management is a recently established consultative body to the President of the Republic of Slovenia and was founded on the initiative of Spominčica - Alzheimer Slovenia President Štefanija Zlobec, the Chairman of Spominčica’s expert Council Prof. Dr. Zvezdan Pirtošek and the President of the Republic of Slovenia (until December 2022), Borut Pahor. The purpose of establishing the Council in the President’s Cabinet was to ensure his participation in issues regarding dementia and his support in the process of adoption and implementation of the Slovenian national strategy until 2030.
The following experts were appointed to the Council:

- Danijel Bešič Loredan, Minister of Health of the Republic of Slovenia
- Mr Luka Mesec, Minister for Labour, Family, Social Affairs and Equal Opportunities of the Republic of Slovenia
- M.A. Tamara Kozlovič, Chair of the Committee on Health in the National Assembly
- Mr Peter Svetina, Human Rights Ombudsman
- Dr Božidar Volič, Chairman of the Slovenian Medical Ethics Commission
- Štefanija Lukič Zlobec, President of the Association Spominčica - Alzheimer Slovenia
- Dr Nena Kopčavar Guček, General practitioner, Community Health Centre Ljubljana
- Dr Milica Gregorič Kramberger, Neurologist, Department of Neurology, University Medical Centre Ljubljana, Ljubljana, Slovenia
- Dr Zvezdan Pirtošek, Neurologist, Department of Neurology, University Medical Centre Ljubljana, Ljubljana, Slovenia
- Dr Polona Rus Prelog, Psychiatrist, University Psychiatric Clinic Ljubljana, Ljubljana, Slovenia
- Dr Mercedes Lovrečič, Psychiatrist, National Institute of Public Health
- Denis Sahernik, Community of Social Institutions of Slovenia

Presidential palace of the President of the Republic of Slovenia becomes a new Dementia Friendly Point

Following the meeting of the Council in November 2022, the Presidential Palace of the President of the Republic of Slovenia joined the network of Dementia Friendly Points that Spominčica is establishing across Slovenia. Dementia Friendly Points are established in wide range of different organisations, after Spominčica provides training for the employees. Members of the Dementia friendly points network are various organizations like the Ombudsman for Human Rights Office, Lidl, the Post Office of Slovenia, Unicredit Bank, the Medical Chamber of Slovenia, pharmacies, libraries, museums etc.

The main goal of Dementia friendly points is to enable people with dementia to remain in their local environment as much as possible and to empower them to maintain an active and high-quality lifestyle. To date more than 400 organisations have joined.

President of the Republic of Slovenia (until December 2022), Borut Pahor, speaks on the developments in the past decade and the role of the new Council

In 2014, when the first Dementia Management Strategy was being prepared in the Republic of Slovenia, you expressed your support for the creation and adoption of a strategic document for dealing with dementia in Slovenia. In 2015, took place in Ljubljana under your Patronage. How much do you think has changed in the field of dementia since then?

I can certainly say that the perception and awareness of dementia has changed in these ten years. Today, it is clear that it is a serious and ubiquitous health problem, which medicine is currently unable to cope with, and therefore all of us, medical staff, carers, relatives etc. need to put in so much more effort, because a person with dementia cannot. If I was able to contribute to this as the President of the Republic, I am satisfied, I tried my best.

I remember my first visit to the Institute of Neurology UKC Ljubljana, this was right at the beginning of my first term as president. From this first meeting, a long-lasting brilliant collaboration developed with Professor Zvezdan Pirtošek and Štefanija Zlobec, President of Spominčica. I admire their dedication and commitment, I think they have really done a lot, and in 2018 I awarded them both with the state award for the work on dementia.

Also, with their help and support, the first strategy was adopted in June 2016. Similarly, this year the Spominčica initiative establishing the Council for Dementia Management was adopted, to which you all key stakeholders were invited. Thanks to the Council, the strategy was submitted for public consideration in November 2022.

I thought it was important that such a Council was established and operates under the auspices of the President of the Republic. We established it in the last year of my presidency, and in a short period of time we had two meetings and perhaps really significantly contributed to the faster adoption of the Strategy. From this perspective, dementia is also a political challenge.

How do you see the role of the President of the country in connecting civil society, professions and politics in the field of dementia and what message would you like to convey to other organisations based on this good practice from Slovenia in the field of dementia?

In our country, the President does not have great powers in such matters, he cannot decide on strategies or policies by himself. But he can help, I’m sure. He can listen to experts more unburdened, than the executive power, if he is able to openly cooperate with other politicians, he can connect all three in a broad discussion that can have beneficial effects.
This is how I worked: In the thematic debates, I invited experts and the interested public, politicians from all parties, both government and opposition, who always joined at my invitation.

In November 2022, the Cabinet of the President became a member of the network of Dementia Friendly Points. The first Dementia Friendly Point was the Office of the Ombudsman for Human Rights in 2017, and a wide variety of organisations joined the network since then. With these Dementia Friendly points, we spread awareness of dementia in local environments, and in addition, these points offer their services in a dementia-friendly way and so encouraging people with dementia to remain active members of society and the community.

**What is your view on creating a dementia-friendly and inclusive society?**

In fact, I think that society is much more aware of the dementia problem than it was years ago, and it is now easier to instigate initiatives than in the past, when they seemed unnecessary or invented. I think that people accept them very well, because, unfortunately, nowadays almost everyone has a personal experience with dementia in their family or in the environment where they work or live.

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I thought it was important that such a Council was established and operates under the auspices of the President of the Republic. We established it in the last year of my presidency, and in a short period of time we had two meetings and perhaps really significantly contributed to the faster adoption of the Strategy."
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European Day of Persons with Disabilities highlights need for continued work on rights

On 24 and 25 November 2022, the European Commission hosted the European Day of Persons with Disabilities conference, co-organised with the European Disability Forum (EDF). The event took place at the Commission’s Charlemagne Building in Brussels (Belgium) and was attended by a number of stakeholders working in the field, including disability organisations and disability advocates.

Alzheimer Europe was pleased to support a number of people with dementia to attend the European Day of Persons with Disability conference, including Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD). Kevin Quaid, Vice-Chairperson of the EWGPWD and Helen Rochford-Brennan, former Chairperson of the EWGPWD, together with their respective supporters, Jayne Goodrick, Helena Quaid and Carmel Geoghegan. Alzheimer Europe Project Officers Daphné Lamirel and Soraya Moradi-Bachiller, and Communications Officer, Kate Boor Ellis, also attended the event, whilst Director for Projects Dianne Gove joined the event online.

Opening Session

At the opening session, Alison Crabb, Disability and Inclusion Head of Unit at the European Commission welcomed delegates and speakers to the conference. Helena Dalli, European Commissioner for Equality, highlighted the persistent disability employment gap, whilst noting that the Commission had adopted the EU Disability Rights Strategy, in line with the European Pillar of Social Rights and the United Nations Convention on the Rights of persons with Disabilities (UNCRPD). She also highlighted the Disability Employment Package which aims to help reduce the employment gap. She noted that everybody has the right to live independently, whilst also explaining that one in three people with disabilities are at risk of poverty and going on to express the importance of supporting persons with disabilities fleeing the war in Ukraine. Additionally, Commissioner Dalli mentioned the upcoming EU Disability Card, which the Commission expects to launch in 2023.

Martina Štěpánková, Deputy Minister of Labour and Social Affairs, Czech Republic, reaffirmed the commitment of the Czech Presidency of the Council of the European Union to the EU Disability Rights Strategy and to the Disability Employment Package. She echoed Commissioner Dalli’s comments on employment issues noting that: “Persons with disabilities are more likely to fall into inactivity or long-term unemployment. When employed, they work often in sheltered employment, rather than in the open labour market, or in less paid and less secure jobs”.

Yannis Vardakastanis, President of the European Disability Forum (EDF), stressed that “in times of crisis, persons with disabilities are the first to be left behind and have their basic rights neglected”, whilst thanking EDF’s members for working tirelessly to support persons with disabilities affected by the war in Ukraine. He highlighted that persons with disabilities were disproportionately affected by the pandemic and now by the cost of living crisis, calling on the EU “to take swift action to address this dramatic situation”. Finally, he noted that: “It is crucial to mainstream disability rights, strong legislation to tackle violence against women with disabilities and create strong legislation for accessibility including the AccessibleEU Centre and the EU Disability Card”.

Members and supporters of the European Working Group of People with Dementia attended the conference

EDF President, Yannis Vardakastanis, spoke during the opening of the conference
Global instruments to protect the rights of person with disabilities

Inmaculada Placencia Porrero, Senior Expert in Disability and Inclusion at the European Commission, opened the session on “Global instruments to protect the rights of person with disabilities”. The speakers were: Kata-rina Ivanovic-Knezevic, Director for Social Rights and Inclusion at the European Commission, Gerard Quinn, UN Special Rapporteur on Disability, Jorge Araya from the Secretariat of the UNCRPD Committee, Marine Uldry, Senior Human Rights Officer at EDF, Patri-cia Otvos, Adviser to the Commissioner for Human Rights at the Council of Europe and Giuseppe Palmisano, General Rapporteur and former President of the European Committee of Social Rights at the Council of Europe. Some of the instruments discussed included the EU Disability Rights Strategy, the Euro-pean Pillar of Social Rights and the UNCRPD.

The speakers highlighted that people with disabilities should be included in tackling big challenges such as armed conflict and cli-mate change, that European civil society is doing great work (e.g. contributing Alterna-tive Reports to the UNCRPD Review process) and that there is still much work to be done for the EU’s internal services to fully move away from the medical model.

Ms Uldry stated that “EDF strives to ensure the EU is protecting persons with disabilities in all their diversity - including ethnic, racial, gender, sexual orientation and types of dis-ability” and noted that EDF is happy that the UN Treaty Bodies’ Committee on the Rights of Persons with Disabilities had taken note of many of the issues it had brought to their attention. She also highlighted that EDF is closely following the Disability Employment Package of the European Commission.

During the questions and discussion ses-sion, Chris Roberts commented that it is important, that where organisations or individuals are unsure of a person’s needs, to ask instead of making assumptions. He stated: “People affected by dementia feel that society treats them very differently to people with other health conditions or dis-abilities, which significantly impacts on our ability to participate in our communities. This will continue unless we all take action to ensure people with dementia can access the legal protections and rights that we are entitled to, such as found in the UNCRPD. We must not be left behind!” He also spoke about the importance of keeping in mind that not all disabilities are visible and won-dered what strategies could be used to overcome the daily obstacle of “not look-ing like you have a disability”.

Helen Rochford-Brennan raised the issue of countries like Ireland not having signed or ratified the Optional Protocol to the UNCRPD, and asked the panel what could be done about it. The Optional Protocol estab-lishes an individual complaints mechanism for the UNCRPD, similar to those of other accords, such as the International Covenant on Civil and Political Rights. She also asked how we can ensure that dementia is recogn-ised as a disability, to allow people with dementia to access their rights and to access supports, where needed.

Violence against persons with disabilities

Day two of the conference coincided with the International Day to End Violence Against Women, opening with a panel on violence against persons with disabilities. This session was chaired by Gunta Anca, Vice-President of EDF, with panellists Bianca Faragau, European Commission (DG JUST, D.2. Gender Equality) who discussed gender-based violence; Independent expert Claudia Mahler, who focused on the human rights of older persons; Sabine Coppens, Coordinator of “Alles over Pesten” (anti-bullying project, Flanders, Belgium), who discussed the prob-lem of bullying at school and Yevheniya
Pavlova, Member of the Ukrainian National Assembly of Persons with Disabilities, who talked about violence against persons with disabilities in or fleeing Ukraine, during the war.

Ms Faragau highlighted that the risk of suffering violence is higher for women, older people and other people with disabilities with intersecting identities, and that the upcoming End Violence Against Women Directive would have some measures to help tackle this. Ms Mahler called for action to protect older persons with disabilities, noting that deaths in residential institutions during the pandemic showed the need for change. She stressed that more support is needed for older persons with disabilities, especially for those that acquire disabilities later in life.

Concluding remarks

Concluding remarks were made by John Patrick Clarke, Vice-President of EDF, Camilla Waltersson Grönvall, Swedish Minister for Social Services at the Ministry of Health and Social Affairs and Alison Crabb. Mr Clarke insisted that “every day should be a day to advance the rights of persons with disabilities”, whilst Ms Grönvall echoed her Czech counterpart, affirming Sweden’s commitment to the EU Disability Rights Strategy, noting that the Swedish Presidency of the EU would host a seminar on this topic when Sweden assumes the rotating EU Presidency from 1 January to 30 June 2023. Ms Crabb closed by stressing the importance of disability rights throughout the whole life course, mentioning national targets for education and speaking about the EU as a signatory of the UNCRPD.

More information about the conference is available at: https://ec.europa.eu/social/main.jsp?langId=en&catId=88&eventId=2031&furtherEvents=Yes

Chris Roberts, Chair of the EWGPWD, (in the pink shirt) spoke on the importance of recognising invisible disabilities.
WHO Europe hosts second Pan-European Mental Health Coalition meeting addressing mental health and well-being of older adults

Reflecting on the successful second Pan-European Mental Health Coalition meeting in November 2022 in Ankara, Turkey, Yongjie Yon and Cassie Redlich from WHO Europe provide insight to one of the six work packages, mental health and well-being of older adults, why it is a key priority, as well as some of its key areas of focus.

Background

Populations across the European Region are ageing at a faster pace than in the past. Already, the Region has the highest median age of all the World Health Organization (WHO) regions and by 2024, the Region will have more older adults aged 65 years and older than young adults under aged 15 years. This demographic transition has an impact on every aspect of our society. That is why, at the technical consultation in February 2021, mental health and well-being of older adults was identified as a priority action and one of the six working packages under the broader Coalition membership: 1. mental health leadership; 2. mental health and well-being of children, adolescents and young people; 3. mental health and well-being of older adults; 4. mental health in the workplace; 5. mental health in emergencies and 6. mental health service transformation. The focus on older adults also aligns with the UN Decade of Healthy Ageing 2021-2030 that brings together a range of government and non-governmental stakeholders to improve the lives of older people, their families and the communities in which we live.

Pan-European Mental Health Coalition

The Pan-European Mental Health Coalition is a flagship initiative of WHO Europe launched in September 2021 in response to requests to address the mental health challenges and disparities faced by communities across the 53 Member States of the WHO European Region, particularly in the wake of the COVID-19 pandemic. The Coalition functions as the operationalising instrument of the European Framework for Action on Mental Health 2021-2025 (EFAMH). The EFAMH offers a structure for the planning and implementation of mental health services, programmes and policies throughout the European Region by laying out the needs and objectives that, if met, would position mental health as a crucial facet of a healthy society and achieve improved population mental health outcomes.

Accordingly, the membership of the Coalition aims to reflect the diversity of action needed to implement a whole-of-society approach to mental health system reform. Besides Member State representatives, researchers and health care professionals and organisations, the Coalition includes non-governmental and international non-governmental organisations, charities, people with lived experience and more. With the Mental Health Flagship team at the WHO Regional Office for Europe as facilitator and central node, the Coalition aims to create a network of stakeholders to implement comprehensive and sustainable change throughout the Region.

Work package on mental health and well-being of older adults

Central to the work package on mental health and well-being of older adults is combating ageism, which prevents older persons from seeking and accessing mental health services. It is not uncommon to hear some variations of the same story: An older person telling a healthcare professional about feeling severely depressed but was told each time that depression is a normal part of the ageing process - something along the line of “what do you expect? You’re getting older, you got aches and pains. Your friends are dying. This is what happens in older age.” Such a response is wrong, and it is yet another example of ageism that affects our society at large.
Unsurprisingly, a recent study shows that 62% of healthcare practitioners also believe that dementia is a normal part of ageing and it is estimated that globally 75% of people with dementia are not diagnosed. Strengthening training and professional development to equip the healthcare workforce with new knowledge and age-friendly competencies such as addressing ageism along with the intersection of sexism and ableism would be crucial to ensure effective diagnoses and treatment for older adults especially those living with dementia.

"Strengthening training and professional development to equip the healthcare workforce with new knowledge and age-friendly competencies such as addressing ageism along with the intersection of sexism and ableism would be crucial to ensure effective diagnoses and treatment for older adults especially those living with dementia."

Over a series of meetings in 2022 bringing together members of the Coalition working package on mental health and well-being of older adults, some clear priority actions have emerged which will be taken forward by the group and WHO Europe in 2023. To this end, WHO Europe has undertaken a mapping exercise to highlight the overarching challenges facing older adults as well as the systemic and individual barriers that prevent their mainstream access to high quality care. The work package deliverables will be developed in collaboration with people with lived experience of dementia, as well as their caregivers, to ensure their voices are always heard.

Social isolation and loneliness (SIL) among older adults are both risk factors for and consequences of mental health conditions including dementia. SIL are a growing public health and public policy concern which have been made more salient by the COVID-19 pandemic. While SIL are now known to impact negatively on life expectancy, mental and physical health and quality of life amongst older people, we also know that they can be reduced by improving infrastructure (e.g. transport, digital inclusion, built environment) and promoting age-friendly communities.

The importance of cities and communities

One of the topics where WHO Europe is at the forefront is our cooperation with cities and communities in promoting age-friendly environments. Cities and communities provide powerful influences on how we experience ageing. Thus, enabling age-friendly environments, such as dementia-friendly communities, can support longer and more independent lives for everyone. At the second Coalition meeting, representative from the city of Metamorfosis, Greece, shared an award-winning programme “Friendship of all ages” to combat depression and loneliness among older people during COVID-19. By creating age-friendly environments, we can enable older people to age safely in a place that is right for them, continue to develop themselves, be included, and contribute to their communities while retaining their independence and health.

"Cities and communities provide powerful influences on how we experience ageing. Thus, enabling age-friendly environments, such as dementia-friendly communities, can support longer and more independent lives for everyone."

There is no line in the sand between young and old, growing and ageing. Being part of the Coalition within the UN Decade of Healthy Ageing is our opportunity to work together across all six work packages to create a world where all people can live long and healthy lives. Indeed, to achieve the lofty goals of EFAMH, WHO Europe stands ready to work with Coalition members, including Alzheimer Europe, by adopting all-of-government and all-of-society approaches to change the way we prioritise and support mental health across the life course. To this end, the WHO Europe will assist countries to improve older people’s mental health and well-being, in collaboration with individuals as well as cities and communities, through:

- Actions to support the mental health of people living with dementia or other forms of cognitive decline, who may be victims of ageist attitudes and/or experience violations to their human rights
- Actions to improve the mental health and well-being of those caring for people living with dementia or other forms of cognitive decline
- Coordinating policy support to strengthen ageing policies including dementia policies in Europe
- Development of technical products including evidence-based toolkits to address ageism and stigma for those seeking mental health care
- Actions to support health and care professionals through improved working conditions and the necessary age-friendly competencies to provide the best care for older adults
- Actions to improve the mental health and well-being of older people who are at risk of loneliness and/or social exclusion.

Further information on the WHO Europe’s work in relation to mental health and healthy ageing is available at: https://www.who.int/europe/teams/mental-health
https://www.who.int/europe/health-topics/ageing
Supporting people with dementia from diagnosis to the end of life: what challenges and policy options in OECD countries?

The Organisation of Economic Cooperation and Development (OECD) recently published its findings into end-of-life care in OECD countries. In this article, Paola Sillitti and Ana Llena-Nozal of the OECD set out some of the policy implications for dementia.

Background

As populations age across Organisation of Economic Cooperation and Development (OECD) countries, the challenge posed by dementia continues to grow. The share of the population aged over 65 years increased from less than 9% in 1960 to 17% in 2019 and is expected to reach 27% in 2050. This will see the number of people living with dementia rise from 21 million in 2021 to 42 million in 2050. Beyond the personal and emotional toll, dementia has significant associated financial expenditure, due to high out-of-pocket costs. The annual household cost attributable to dementia varies greatly across 11 European countries, ranging from EUR 109 million in Estonia to EUR 24,548 million in Germany in 2018. The increase in the number of people living longer with dementia and other chronic conditions is expected to result in a growing need for end-of-life care (defined as the care provided to people who are in the last 12 months of life and who receive palliative and curative care). The OECD estimates that 2.4 million people who die due to Alzheimer’s disease and other dementias (those coded as ICD-10 F00-F03, G30, R54, and R54) will need end-of-life care by 2050, compared to 1.5 million in 2020. These estimates do not include the relatives of people at the end-of-life, despite this caregiving role at the end-of-life being physically, psychologically and financially exhausting. The actual need for end-of-life care is therefore likely to be even higher when considering the psychosocial and financial support for family members during the dying and grieving process.

Policy focus and impact of COVID-19

Policy attention towards dementia has increased in recent years, yet people living with dementia still do not receive the adequate support, from prevention and diagnosis through to the end of life. While there is growing evidence that addressing risk factors for chronic conditions is effective in preventing dementia, OECD countries devote less than 3% of their health spending to prevention. Countries also experience delays and gaps in the diagnosis of dementia, with fewer than 40% of OECD countries able to estimate national diagnosis rates. After diagnosis, care for people with dementia is often inadequate and can result in poor health outcomes, due to inappropriate prescribing of medications and lack of specific training for health and care professionals. Finally, less than half of people aged 65 or older discuss their care preferences ahead of the end of their life, ranging between 12% in France and 78% in the US.

The pandemic has had a profound impact on people with dementia, who are usually older and have comorbidities, falling within the category of patients most at risk of death due to COVID-19. Furthermore, social distancing and other measures to reduce the spread of contagion represented a particular challenge for people with dementia and a source of frustration for carers. During the pandemic, people living with dementia within healthcare settings experienced prolonged isolation which caused or exacerbated feelings of loneliness, depression and stress, often translating into worsening of cognitive symptoms and lower levels of independence. Furthermore, COVID-19 patients with dementia often had to be isolated and treated in intensive care units. Isolating people with dementia and treating them in unfamiliar environments, provoking reactions that in some cases required sedation and caused post-traumatic stress disorder.

Policy recommendations for the future of dementia care

The pandemic has caused considerable hardship among people with dementia and their carers but has also highlighted
the need for better care and support, from diagnosis to the end-of-life. Building on the lessons learnt during the pandemic and in light of the growing numbers of people living with dementia, the following policy recommendations outline the way towards better care:

- **Improving early diagnosis of dementia.** Identifying dementia as early as possible is paramount to access the most adequate care. Primary care plays a crucial role in identifying dementia as it usually represents the first contact point between people concerned about memory issues and the healthcare system. Nevertheless, primary care doctors lack adequate dementia training and correctly identify dementia in only about 50–75% of cases. Across the OECD, 25 countries have memory clinics to provide a diagnosis of dementia, but access varies widely across countries. Denmark, France, the Netherlands, Switzerland and the United Kingdom (England) have developed guidelines and standards of care for such memory clinics.

- **Improving care pathways.** After diagnosis, people with dementia often experience poor quality care and coordination of support. Furthermore, the European Federation of Pharmaceutical Industries and Associations reports that healthcare systems lack capacity for timely delivery of treatment when new therapies are developed. Countries should strive to improve access to care and coordination of support, whilst ensuring professionals have disease-specific competencies, to adequately support people from prevention to the end of life. For instance, electronic notes sharing and multidisciplinary conversations can support care coordination and improve the patient experience. Electronic note sharing is currently in place in 60% of OECD countries.

- **Developing guidance and special programmes to treat people with dementia during emergencies.** During the COVID-19 crisis, countries faced the challenge of protecting people with dementia from contracting COVID-19 while ensuring their psychological wellbeing. In most cases, decisions on how to treat people with dementia were taken at the clinician level with little guidance available, while some countries had specific programmes in place for people with cognitive impairment (e.g. Korea) or issued guidelines on the treatment of long-term care patients with dementia (e.g. Ireland, Italy and New Zealand).

- **Supporting informal caregivers.** According to the 2020 SHARE survey (Survey of Health, Ageing and Retirement in Europe), informal caregivers provide the bulk of care among OECD countries, with between 46% and 86% of people who died aged 65 or over receiving some form of informal care. Furthermore, informal caregivers bear a significant physical, psychosocial and financial pressures when caring for people living with dementia.

    Although informal caregivers can benefit from work leave, flexible work arrangements, respite care and cash benefits, previous OECD analysis shows that these are not yet widespread across countries and could be improved.

    

![Projections of number of deaths due to frailty (including Alzheimer's disease and other dementias) requiring end-of-life care until 2050.](image)

![Note: The data include 33 OECD countries. Greece, Ireland and Turkey are excluded for insufficient data. Source: OECD, Time for better care at the end of life, 2023.](image)

![Figure 1. 2.4 million people who die because of Alzheimer's and other dementias will need end-of-life care across OECD countries by 2050.](image)
• Developing compassionate communities. Compassionate communities and dementia-friendly communities are a relatively new phenomenon which have been developed over the past decade to support people with life-limiting conditions to live as independently as possible, though these are at different stages of development across OECD countries. Although evidence on their effectiveness is not yet widespread, compassionate communities have the potential to support people living with dementia and their loved ones. For instance, communities can increase awareness on chronic diseases among the population, provide social support to people with diseases to maintain their independence and improve public spaces.

• Enhancing the use of Advance Care Planning (ACP). As people with dementia approach the end of life or as the disease progresses, the ability to make decisions is likely to decrease greatly. Having conversations around preferences of care early on before the end of life is therefore of particular importance for people living with dementia. While 77% of OECD countries have regulation allowing people at the end of life to designate an attorney for decision-making, discussion around care preferences rarely happens. Stigma and difficulty to talk about death is often reported as a barrier to ACP. Canada, Japan and the United States have implemented specific training for healthcare staff around conversations at the end of life.

Further information on the findings and policy recommendations can be found in the OECD’s "Time for Better Care at the End of Life" report, available at: www.oecd-ilibrary.org/social-issues-migration-health/time-for-better-care-at-the-end-of-life_722b927a-en

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Hague Conference on Private International Law (HCCH) looks to make progress on protection of vulnerable adults

Following a Special Commission of the HCCH in November 2022, Alzheimer Europe spoke to Assistant Legal Officer, Nietta Keane, to discuss the future of the HCCH 2000 Protection of Adults Convention and why it remained highly relevant for people with dementia.

Could you give a brief background and overview of the HCCH 2000 Protection of Adults Convention?

The international protection of adults has been a recurrent area of interest for the HCCH, dating all the way back its Fourth Session in 1905. For the next few decades, the outbreak and aftermath of the World Wars shifted the priorities of the international order. While a 1967 study by Bernard Dutoit, then Secretary at the Permanent Bureau of the HCCH, renewed interest in the international protection of adults, the level of interest in the area has ebbed and flowed over the last few decades.

In more recent years, increased international mobility and, consequently, the spread of personal assets, interests and relationships across borders brought with it an increase in cross-border situations involving adults with mental, intellectual, physical or sensory impairments. These developments, in conjunction with the adoption of the United Nations Convention of 13 December 2006 on the Rights of Persons with Disabilities (UNCRPD), led many States to reform their domestic systems for the protection of adults whose personal faculties are impaired. In the light of these reforms, an opportunity arose to begin examining the feasibility and desirability of a private international law instrument in the area, in order to achieve a level of international harmony in this area.

During the 17th and 18th Sessions of the HCCH in 1993 and 1996, the first substantive discussions on the development of a draft instrument on the international protection of adults took place, with the final text of the Convention being adopted by a meeting of the Special Commission of a diplomatic character in late September 1999.

The 2000 Protection of Adults Convention provides a comprehensive body of rules on jurisdiction, applicable law, and recognition and enforcement of protective measures. It also establishes mechanisms for cooperation between the authorities of Contracting Parties.

The Convention also reinforces provisions of the UNCRPD, in particular Article 12 on equal recognition before the law, Article 18 on the liberty of movement and nationality, and Article 32 on international cooperation.

What are the practical implications of the Convention, for example, for a person living with dementia?

The international protection of adults can very often give rise to complex legal questions and practical challenges when there are conflicts between the legal systems of the States involved. The 2000 Convention aims to prevent and resolve such difficulties by connecting legal systems and facilitating cooperation between Contracting Parties. The Convention is drafted, and should be applied, with practicality and efficiency in mind, in order to facilitate the swift and effective implementation of its rules, for the benefit of all adults falling under its scope, including those living with dementia.

Through its rules on jurisdiction and cooperation, the 2000 Convention establishes a “complete and closed system”, which applies as an integral whole to Contracting Parties. This system does not allow for conflicting jurisdictions and necessitates co-ordination between competent authorities in this regard. Therefore, only one competent authority may take jurisdiction at a given time, over a specific matter.

This way, the Convention avoids conflicting decisions being issued on matters falling under its scope, preventing practical difficulties and complications which can be time consuming and costly to resolve.

Since the adoption of the Convention, the area of the international protection of adults has evolved considerably and continues to evolve, as paradigms shift in the global community.
But flexibility and adaptability are built into the text of the Convention, affording it a great capacity for organic growth, which is why the Convention remains just as relevant, if not more relevant, today than it was at the time it was drafted. Although the 2000 Convention applies to all persons over the age of 18 who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests, the Convention is particularly relevant to persons who live with neurodegenerative disorders such as dementia.

When an individual living with dementia travels across borders for any reason (e.g. a permanent relocation to be closer to their family or a short-term stay abroad to receive medical treatment) and finds themselves in need of protection, the Convention provides for the taking of short-term and long-term measures of protection regarding the adult and/or their property as well as for the recognition and, if necessary, the enforcement of such measures abroad.

The Convention also provides a framework of cooperation between the two relevant States, thus contributing to the smooth relocation of the adult and the elimination of any protection gaps. If needed, the cooperation provisions and Central Authority system of the Convention could also assist with the repatriation of this person to their State of habitual residence.

The 2000 Convention can also assist in cases where an adult living with dementia has fled or has been taken from an assisted-living facility or other place where protection, support and care is being provided (for more information, see pages 109 - 110 of the draft Practical Handbook, available on the HCCH website).

A particularly important element of the 2000 Convention for persons living with dementia is...
The SC was a promising step towards the harmonisation of private international law rules in the area of the international protection of adults.

becoming Parties to the Convention. The SC also approved, in principle, implementation tools such as the Practical Handbook, an Implementation Checklist and a Country Profile.

The SC also confirmed that ex lege representation as well as the instructions given and wishes made by an adult in anticipation of a future impairment fall within the general scope of the 2000 Convention under Article 1 and are subject to the cooperation provisions in Chapter V.

The SC recommended that the Council on General Affairs and Policy (CGAP) consider extending the scope of the International Hague Network of Judges to matters pertaining to the 2000 Convention, along with the Emerging Guidance and General Principles on Direct Judicial Communications. The SC also invited CGAP to discuss the possibility of amending the 2000 Convention to include a clause allowing Regional Economic Integration Organisations, such as the EU, to become Contracting Parties.

The SC was a promising step towards the harmonisation of private international law rules in the area of the international protection of adults.

Further information on the interpretation and implementation of the 2000 Convention, is available by accessing the following resource at https://www.hcch.net:

- Explanatory Report on the 2000 Protection of Adults Convention
- Revised draft version of the Practical Handbook: Prel. Doc. No 4 of July 2022
- Revised draft version of the Country Profile: Prel. Doc. No 7 of June 2022

Dementia and other neurogenerative disorders are powers of representation, provided for under Articles 15 and 16. A power of representation is to be understood as a document (unilateral act or agreement) which enables the adult to plan, in advance, how they want to be supported in the exercise of their legal capacity and autonomy when the adult is no longer in a position to protect their interests. The Convention allows for such voluntary, anticipatory acts to be given effect across borders, through the applicable law rules of the Convention.

Giving effect to powers of representation issued by an adult provides an excellent means to support their dignity and autonomy and to ensure respect for their rights, will and preferences. In this regard, Articles 15 and 16 have the potential to become one of the most important features of the Convention.

In addition, under Article 38 of the Convention, it is also possible for a person entrusted with the protection of the adult to obtain a certificate attesting to any measures of protection taken or powers of representation which have been confirmed (for more information on the confirmation of powers of representation, please refer to Prel. Doc. No 11 of October 2022, available on the HCCH website).

How many European countries are currently signatories of the Convention – are more expected to sign?

The total number of Contracting Parties to the 2000 Convention is currently 14, of which 11 are EU Member States, with Greece being the most recent to become a Contracting Party. In November 2022, Malta signed the Convention during the first meeting of the Special Commission on the practical operation of the Convention (SC). The Convention will enter into force for Malta following the deposit of its instrument of ratification in 2023, making Malta the fifteenth Contracting Party.

It is hoped that, in the light of the successful outcome of the first meeting of the SC and in the light of the upcoming publication of several useful implementation tools such as the Practical Handbook and Country Profile, more States, including EU Member States, will become Contracting Parties to the Convention.

What work is currently underway in the EU in this area and how can the EU encourage more countries to become signatories?

Over the years, the European Union has been regularly encouraging its Member States to become Contracting Parties to the 2000 Protection of Adults Convention. Such efforts include but are not limited to making the Explanatory Report available in all official EU languages and the Joint EC-HCCH Conference on the Cross-border Protection of Vulnerable Adults, jointly organised by the European Commission and the HCCH, which took place in Brussels in December 2018.

The international protection of adults was one of the priorities of the Portuguese Presidency of the Council of the European Union during the first half of 2021. The High Level Conference on Protecting Vulnerable Adults across Europe – the Way Forward was held virtually in March 2021, hosted by the Portuguese Presidency with the support of the European Commission and the European Union Agency for Fundamental Rights. During the conference, experiences with the 2000 Convention at the regional level were exchanged and the utility and importance of the Convention was highlighted. In the first half of 2023, the European Commission plans to make a legislative proposal concerning the protection of vulnerable adults within the EU.

In November 2022, the HCCH held a Special Commission on the practical operation of the 2000 Convention – what were the key developments and outcomes?

The SC resulted in the adoption of over 70 Conclusions & Recommendations, which provide guidance to (prospective) Contracting Parties on a wide range of issues relating to the implementation and practical operation of this Convention. Most notably, the SC confirmed that, in general, the 2000 Convention is operating smoothly and is fit for purpose. It also stressed the importance of more States
Brussels signs “Dementia-Friendly City” charter

On 21 September 2022 – World Alzheimer’s Day – Brussels signed the “Dementia-Friendly City” charter, along with Alzheimer Liga Vlaanderen (Flanders) and Ligue Alzheimer (Wallonia and Brussels) and has become the 50th Dementia-Friendly City. In doing so, the capital of Europe committed to focusing on the quality of life of residents with dementia. In this interview, Mayor Philippe Close tells us why the charter is so important and what challenges it poses for his city.

Why is it important for Brussels to be a Dementia-Friendly City?

In Brussels, everybody matters. Brussels used to be a small city but has now become the capital city for 500 million Europeans, the world’s leading diplomatic city and the most multicultural city on the planet after Dubai, with 184 nationalities and 104 languages spoken. That’s why the important thing in Brussels is not where we come from but what we do together. A mayor’s primary task is to ensure that every inhabitant receives particular attention. This obviously includes older people, people with disabilities and people with long-term illnesses.

The City of Brussels became aware of these issues earlier than other cities due to the presence of the University of Brussels inside the city, and because of the major hospitals it manages. Brussels has always paid particular attention to general health problems, mainly through the work of our Public Centres for Social Welfare (Centres Publics d’Action Sociale - CPAS).

Another equally important aspect is nursing homes. The City of Brussels owns five such homes, since it has always intended to have a nursing home in each district. The good news is that we are living longer; the bad news is that healthcare is going to cost more. After all, people use 50% of their healthcare budget in the last five years of their lives. The current challenges are to take everyone’s needs into account and to reflect upon the end of life. Unfortunately, this subject is taboo. Many questions remain: how do we manage the end of life? How do we manage palliative care? What type of support can be offered? Good end-of-life management is a fundamental need when we talk to families, who explain how comforting it can be, and how it can help them in their grief.

Dementia generally occurs as part of the last phase of a person’s life, and you have to know how to talk about it. So why have we opted for a Dementia-Friendly City? It is because we believe that sharing experiences, and having people to discuss good practices with, is extremely important. We intend to share our experiences in the existing networks, as well as benefit from the experiences of others. Incidentally, we have seen the extent to which Maison Vesale has set a standard, and how many people in the world come to visit it.

Philippe Close, Mayor of Brussels, signs the Charter

The fact that Brussels is the capital of Europe sends a strong message. Can Brussels become a model Dementia-Friendly City for other cities and capitals?

I think the opportunity we have today is that when you want to be heard, speaking in Brussels has an impact. Brussels is the headquarters of all the European institutions, more than 1,800 international organisations are here, and there are huge numbers of lobbyists and journalists. Brussels can really bring an issue into focus even though, of course, it is not the only place that can do so. But I believe that networks like the Dementia-Friendly City make it possible to overcome the obstacles and talk about this disease. This is always how things start, and if we can make our voices heard, we will already have won.

The challenges with dementia are both to encourage progress in research that delays its effects and to enable the people affected and their loved ones to talk about it. We are all facing the same problems linked to urbanisation, especially in Europe, as our cities are very similar. The reason we are facing the same problems is that dementia is not just about research, but also about how we approach our families, friendships, housing, patients’ social relationships and so on.

The City of Brussels has two large budgets that make us different from traditional local authorities: education and health. Despite a profoundly egalitarian system in Belgium, we do not confront the disease on an equal footing. This is because many people are in denial about the disease: they do
not get tested and, above all, they do not want to know. However, we know that with dementia, stimulation and ongoing encouragement to use one’s faculties can delay symptoms and preserve people’s abilities. We are setting up Alzheimer Cafés where people can share experiences and encourage each other in a relaxed setting. When you do this in a community centre, you are in a place where people come anyway, where they know others and have social relationships, and where they can talk about it. But sometimes there is a sense of a “shameful disease” and the idea that “if I get dementia, I will be labelled and rejected.” We may also confuse dementia and madness... there may be obstacles, but the most important thing is to talk about what is happening. What do you think the ideal Dementia-Friendly City looks like?

It is a perpetually evolving city that also has a long-term vision because life expectancy is continuing to increase. This is good news, but unfortunately it also means that more and more people will get dementia. And one of the major challenges of our societies is to let people continue living at home for as long as possible. Institutionalising people has a huge budgetary impact and, moreover, takes people out of their social context. Being able to keep someone at home with assistance, safely and in suitable housing, is very important.

Cities also have a genuine role to play in mobility. All the policies put in place for people with mobility challenges are important, whether they are parents with pushchairs, older people with walking sticks or people who are disorientated. How do we help people find their way around their neighbourhood, thinking in terms of inclusion for everyone?

If we can let people stay living at home for as long as possible, this is the best solution structurally and socially, as well as being what many in the community are asking for. It is up to our society to provide a satisfactory response, in terms of both care provision in nursing homes and the arrangements required to enable people to stay in their homes safely for as long as possible.

Are you aware of the needs expressed by the general public? Have they made any more specific requests?

Very little is known about dementia, even now, and it cannot be cured. When someone notices degeneration and does not know how to deal with it, they really start asking questions. What makes dementia different is that the questions do not come from the patient, because they are not aware of what is happening to them, so their relatives are the ones who find themselves asking questions. Something rather special about the Dementia-Friendly City network is that it is aimed at carers as well as people with dementia, because the carers are the ones who need a lot of answers. The person who has dementia does need care, but they are not directly involved in the interactions, whereas their relatives ask a lot of questions.

What is your personal view of dementia?

There are two things that are occurring increasingly often: dementia and strokes. When we consider vascular dementia, we find ourselves confronted with constant doubts about people: what would they have wanted? Are they happy? Does this life suit them? Are they suffering? That’s what’s most difficult for those on the other side, the loved ones. And this is what the networks need to explain and be there for. Besides talking about what is going on, it’s also important in terms of public health when we don’t know something. We want to give an answer to everything. With dementia, we need to have the courage to say that we do not have all the answers, but that we are looking for them. I am someone with a profound belief in science, and I think we will find solutions, as we are doing for cancer.
Dementia in Europe

One of the major challenges of our societies is to let people continue living at home for as long as possible."

Cancer always used to have a fatal outcome, but now, in many cases, it does not. What is important to bear in mind about dementia is that it is a disease that affects everyone and that every person counts.

Is there any other Brussels-led initiative for dementia that you would like to tell us about?

There is the Santkin Prize, initiated in 2005 by the National Alzheimer’s League, which rewards a researcher or a research team for their work on the disease. The City of Brussels has organised the presentation of the Jacques Santkin Prize for many years. It’s interesting as it’s all about funding research, which is what allows us to make progress today. Especially when a disease has no cure, it is very important to keep researching. The state finances many things but the donations and prizes that can be awarded to researchers are very much appreciated. That is why the Jacques Santkin Prize is awarded to a researcher or a research team for their work on the disease. The City of Brussels has organised the presentation of the Jacques Santkin Prize for many years. It’s interesting as it’s all about funding research, which is what allows us to make progress today. Especially when a disease has no cure, it is very important to keep researching. The state finances many things but the donations and prizes that can be awarded to researchers are very much appreciated.

The real challenge is for every inhabitant of Brussels, and every person who comes to the city, to feel like they belong here. For example, 35% of the people in Brussels are not Belgian nationals (82% of these people are European expats). Two-thirds of them stay in Brussels after 20 or 30 years here. European officials for example, but they still don’t feel that it is their country or their city. When you spend three decades in a city, you can consider it your city. It’s the same with dementia: they do not lose their citizenship, but remain someone who matters to society.

Everyone needs to find their place, and tracing people who are not aware that they have dementia is a serious challenge because there is real social inequality. As a public authority, we must be able to find and help you. Only 40% of Brussels residents have a GP. This is a problem because there is no follow-up of the medical file that allows each GP to know their patients’ history. Pharmacies are a very good point of contact. For example, we have started a pilot programme in Molenbeek and Anderlecht to detect diabetes. In practice, especially among French speakers, we often find that people do not have a GP. If they are sick, they go to the hospital or see specialists. On the other hand, they know their pharmacist very well. We noticed this especially during the COVID pandemic: people knew the pharmacist in their neighbourhood, a person of trust for those who did not have a doctor. So, the role of pharmacists is also important in being able to make the disease known, to talk about it and to give advice. Another way to raise awareness of the disease and the various initiatives that exist, such as Alzheimer Cafés, is to publish articles in local newspapers, on social networks or in other media in order to support these efforts.

According to the World Health Organization (WHO), dementia is a top priority. Is dementia on the political agenda?

I think that public health, including dementia, is on the political agenda. Today, we are lucky enough to be living longer and longer. In Brussels, life expectancy has risen from 36 years to 82 years in one century. Unfortunately, this also means that we will be increasingly confronted with the disease, so we must be able to develop our support, research and treatment. Public health is a large area that combines prevention, research, curative treatment and care, as well as the social aspect, because we are not all equal in the face of disease. Dementia is a public health concern. Everyone has the right to treatment and support.

What does the charter mean for people with dementia and their carers?

One in five Europeans will be diagnosed with dementia at some point. This prognosis is inextricably linked to the ageing population. The need for an inclusive society in our cities, where people with dementia and their informal carers are well supported, is therefore rising sharply. Sabine Henry, President of Ligue Alzheimer in Brussels and Walloonia, and Jef Pelgrims, President of the Alzheimer Liga Vlaanderen, welcome Brussels signing the “Dementia-Friendly City” charter:

“As the capital of Europe, Brussels has an exemplary role. That is precisely why it is so important for the city to commit to improving the quality of life of its residents with dementia and their informal carers. After all, 70% of people with dementia live at home. Brussels now needs to work towards an adapted policy that gives informal carers and people with dementia a say. Tailored solutions are required at the neighbourhood and district level. The city will also have to ensure that civil servants and city services are trained to recognise people with dementia and deal with this issue appropriately.

In partnership with the Alzheimer Leagues, Brussels will appoint several people, working in the social field. “They will be essential to ensure that residents are informed, heard and supported, to avoid feelings of loneliness, isolation and discouragement. People talk a lot about dementia, but we know almost nothing about it. This lack of knowledge leads to fear that feeds the taboo. It’s not enough to be a Dementia-Friendly City: it’s necessary to act to improve the daily lives of people with dementia in Brussels.”
Caring for people with dementia during the war in Ukraine: the story of charitable foundation Nezabutni

In Ukraine, there is relatively little awareness about dementia, but its prevalence is high. In this article, Iryna Shevchenko, founder of charity Nezabutni (“Unforgettable”) discusses her organisation’s activities and what changes have been made since the start of the ongoing war.

How it all began

According to the Global Burden of Disease (GBD), as of 2019, there were around 651,000 people with dementia living in Ukraine and by 2050, this figure is projected to reach one million. Despite such a prevalence, it is still little researched in Ukraine. Nezabutni decided to change the situation and support those who are faced with dementia and some of the difficulties it can cause.

For Iryna Shevchenko, founder of Nezabutni, the impetus to deal with this particular problem was not only the statistics, but also personal history and an interest in gerontology. When her husband’s grandmother fell ill, she recognised symptoms that made her suspect it was dementia.

“I realised that this was not just that she was getting older, but rather that there was a serious problem. We called a doctor and he diagnosed her with dementia. I started looking for organisations in Ukraine that could help people with dementia, but there were none.”

She decided to start such an organisation and after studying various courses, assembling a team and conducting research (because there is very little data on dementia in Ukraine and official statistics are 10 times lower than the estimated number of cases), in early 2021, “Nezabutni” was born. There are five people in the team as well as more than 80 volunteers (psychologists, doctors, copywriters and translators).

What does the foundation do?

The foundation is still quite young, but it has already managed to outline its activities and launch several interesting projects, with two main goals:

- The first is to build a dementia-friendly society where people know what dementia is, where they have a high level of awareness, and where families faced with dementia do not “fall out of society”. The foundation is moving towards this goal through information campaigns and the distribution of guides - the team adapts these guides from already existing information in other countries. These contain information about what dementia is and how to explain it to others.

- The second goal is to support people with dementia and their families. The foundation team started a number of groups to provide emotional and psychological support to relatives. They began as face-to-face groups, but were transferred to an online format. A professional psychologist conducts group therapy sessions (once a week or once a month, depending on the group). The team also began to organise informational webinars with doctors and launched consultations. People can apply to join webinars on various issues via social networks or by email.

Before the Russian invasion, Nezabutni also began re-creating an interesting international initiative in Kyiv, a Memory Café or Alzheimer Café. “Café Unforgettable” operated in the local “Urban Space 500” where people with dementia and their relatives came once a month. The team created a safe space where people were accepted.

The programme included entertainment activities, dancing, delicious food, drawing. With the war, however, the project is on hold, but the foundation plans to resume these “cafés,” because it saw great value in them.

Another initiative, in place since September 2021, is the photo project “We are. People with Dementia”, depicting people with dementia who are in contact with the foundation, photographed by Anastasia Nakorneeva. An exhibition of these photos was shown before the play “The Father” at the Drama and Comedy Theatre on the left bank of the Dnipro river in Kyiv. Volunteers distributed information booklets to the visitors at this event.

Finally, the foundation took part in creating an app called “Seven”, together with the IT company ScrumLaunch. The aim of the app is to help identify the first symptoms of dementia, as well as to develop memory and to promote communication within families (games can be played together).

The app is being developed in Kharkiv and, over the last year, Nezabutni has conducted several tests and involved people with dementia. For
ne, the app is undergoing clinical tests in one of the senior living facilities in the USA. It can already be found on Google Play listed as being in development.

The foundation during the war

Iryna Shevchenko left Ukraine during the first days of the full-scale Russian invasion. She settled with her daughter in Geneva, where she had previously done an internship at the United Nations and therefore knows the city quite well. There, she continues to study dementia and to collaborate with various foundations, including Alzheimer Europe. Indeed, Nezabutni was warmly welcomed as a new member association at Alzheimer Europe's Annual Meeting in Bucharest, on 17 October 2022. Iryna Shevchenko was also invited as a keynote speaker to one of the plenary sessions at the 32nd Alzheimer Europe Conference, which took place in Bucharest from 17-19 October 2022. Her presentation touched the audience and was met with a standing ovation. She presented the work of her foundation, and noted that the war has not stopped their efforts for a single day. The activity of Nezabutni has, in fact, only increased, she noted. The team has continued to work and communicate online, but of course the war has affected the foundation, because plans changed and new directions were taken, she said.

During her presentation, she also stated that Nezabutni had conducted an in-depth study, examining how the war was affecting people with dementia, what needs had emerged and what had changed. It consists of semi-structured interviews with relatives or caregivers of people with dementia.

“We already had a database of such contacts, and since the beginning of the full-scale war, we have launched various questionnaires to help, so there were enough people to interview. We made a sample to cover as many regions as possible, as well as stages of dementia development and diagnoses” said Iryna Zborovska, project manager at the foundation. There is also a new focus of work - global. It covers interaction with Ukrainian ministries and international organisations.

“We realised that we, as a small organisation, cannot change everything. The problem is much bigger than us, so we decided to involve the State. We wrote letters to the Ministry of Health and the Ministry of Social Policy and received answers. Many countries have a national plan for dementia but not in Ukraine. So we decided to create one” says Iryna Shevchenko.

During the first six months of the full-scale invasion, the foundation was engaged in emergency assistance which became their main priority. For example, they arranged the supply of medicines. There is a list of free medicines in Ukraine, containing one hundred drugs, but none for people with dementia. So, the volunteers at Nezabutni first searched for medicines in Ukrainian pharmacies and delivered them to people who applied to the foundation. But that was only a temporary solution. “Most people with dementia need to take medication, and once started, it should not be stopped. Some did not take any medications at all because they are expensive. I started writing to different organisations, we created a list of mandatory medications and started searching. The Americares organisation helped us. Now they deliver large batches of medicines to Ukraine, and we distribute them among the regions. We involve the Institute of Gerontology, the Institute of Psychiatry and the National Social Service. Medicines are handed out both to special institutions and individually” says Iryna Shevchenko.

The foundation also takes care of electricity generators for institutions where people with dementia are staying. The destruction of Ukraine’s infrastructure by the invader caused problems with the electricity supply throughout the territory. Usually, institutions for vulnerable people have autonomous water and heat supplies, and therefore depend almost entirely on electricity. Since the beginning of the war, Nezabutni has delivered 27 generators with a capacity of 6.5 to 150 kW to psychoneurologic institutions, nursing homes and other institutions providing services to people with dementia, in 11 oblasts (regions) of Ukraine.

The foundation also helps with evacuation and useful information and has created an online-platform called “Unforgettable united”, in collaboration with the organisation Médecins Sans Frontières (Doctors without Borders). People can leave requests for help and find useful links and articles. On the site you can:

- get help in Ukraine and abroad
- submit an application for medicines
- sign up for a consultation with a professional nurse, psychologist, psychiatrist
- find a map of institutions that accept patients with dementia
- submit a request for evacuation
- view tips on care of, or communication with, a person with dementia.

Nezabutni also has a joint project with Médecins Sans Frontières on evacuation: specialists advise and support the team that evacuates people from institutions in the Dnipropetrovsk and Donetsk regions. There is a big challenge in Ukraine now as there are not enough places for evacuation for vulnerable people, all the nursing homes and psychoneurologic institutions are overcrowded. Together with its partners, the organisation is trying to find a solution. There must be an official permission for evacuation from the guardian. Volunteers should understand what dementia is and that it manifests differently in each person.
Before evacuation, it is necessary to do a medical screening, an assessment of the condition. A person with dementia can find it difficult to tolerate any changes, so you need to be careful, if possible, you should take personal belongings that are important to the person and ensure psychological support. There should be a caregiver nearby” says Iryna Shevchenko.

What is next?

The main focus in 2023 remains on Emergency response. The organisation is constantly searching for partners who can help with providing medications and diesel generators. Mental health support is another priority for this year, as, according to the research done by Nezabutni, the emotional state of people with dementia and their relatives has deteriorated by 50% since the beginning of the war. Nezabutni is planning to continue its advocacy work and the development of the National Dementia Plan together with the Ministries of Health and of Social Policy. “The state of people with dementia and relatives is indeed very difficult. Lots of people lost their jobs and homes, being forced to flee and live in shelters with constant blackouts for long hours or days. The government is doing the maximum it can but we must support these vulnerable people as much as possible. I encourage everybody who would like to help people with dementia in Ukraine to contact Nezabutni and we will discuss the best way to implement your support. I would also like to say a big thank you to Alzheimer Europe and everybody who has been supporting us all these months!” says Iryna Shevchenko.
Behind the headlines: disease-modifying therapies for Alzheimer’s disease

With recent approvals of aducanumab and lecanemab by the US Food and Drug Administration, new treatments may soon be authorised for Alzheimer’s disease in Europe. We interviewed Dr Nicolas Villain, who has published two reviews on anti-amyloid immunotherapies, and was a sub-investigator in several clinical trials evaluating lecanemab, donanemab, aducanumab, gantenerumab and other drugs. We also asked three other experts for their perspectives on lecanemab.

In May 2002, the European Medicines Agency approved a drug called memantine, which treats some of the symptoms of moderate to severe Alzheimer’s disease (AD). Few would have anticipated a 20-year wait for the authorisation of new treatments for AD. Since 2002, however, huge strides have been made in understanding the biological processes which cause AD. As we enter 2023, with recent approvals of aducanumab and lecanemab by the US Food and Drug Administration (FDA), we may now be on the cusp of new treatments being authorised for AD in Europe.

A new class of medicines for Alzheimer’s disease?

Over the last two years, drug development headlines have been dominated by medicines that are classed as “disease-modifying therapies”. This designation is reserved for drugs that have an impact on the fundamental biological processes that drive AD. Of the 21 disease-modifying therapies currently being evaluated in Phase 3 clinical trials, 29% target a protein called beta-amyloid, which builds up in the brains of people with AD. Aducanumab and lecanemab both fall into this category of anti-amyloid immunotherapies, along with drugs such as gantenerumab and donanemab. To learn more about these novel therapies for AD, we spoke with Dr Nicolas Villain, an Associate Professor of Neurology based at the Institute for Memory and AD at the Pitié-Salpêtrière Hospital in Paris. Dr Villain recently published two reviews on anti-amyloid immunotherapies, and was a sub-investigator in several clinical trials evaluating lecanemab, donanemab, aducanumab, gantenerumab and other drugs.

In your reviews, you discuss a number of different drugs classed as high-clearance, anti-amyloid immunotherapies. How do they differ?

Nicolas Villain: Drugs such as aducanumab, donanemab, and lecanemab are all antibodies that target amyloid proteins in the brain. However, they target different sections of the amyloid protein, and may also target different sub-species of aggregated amyloid. Proteins, such as amyloid, are composed of a string of amino acids and the antibodies are designed to target a sub-set of these amino acids. In addition, amyloid proteins can clump together in aggregates, adopting different structures. An aggregate composed of two proteins is called a dimer; amyloid oligomers are composed of 2-5 aggregated proteins, and you can also have amyloid protofibrils and fibrils, which are medium or large, insoluble aggregates.

In AD, plaques of aggregated amyloid proteins build up in the brain. Within these plaques, there are many different forms of amyloid aggregates, and anti-amyloid immunotherapies variably target these forms of amyloid. For example, lecanemab preferentially targets amyloid protofibrils, whereas donanemab only targets mature amyloid fibrils within plaques. While they all have slightly different mechanisms of action, all these anti-amyloid immunotherapies...
demonstrate a similar ability of achieving high clearance of amyloid plaques in the brain.

**Based on the clinical trials, what are the main benefits of these drugs for people with AD?**

**Nicolas Villain:** In our meta-analysis, we reviewed the evidence on efficacy and safety for the lecanemab, aducanumab, donanemab and gantenerumab. As I mentioned earlier, all of these drugs achieved impressive reductions in brain amyloid, which suggests they are indeed disease-modifying therapies. When it comes to memory loss and cognition, the effect of the different drugs on clinical decline was fairly similar. Based on the CDR-SB (Clinical Dementia Rating – Sum of Boxes) scale, the benefit compared to placebo was, between 0.0 and 0.39 points in the aducanumab trials; 0.19 and 0.31 points in the gantenerumab trials; 0.36 points in the donanemab trial and between 0.40 and 0.45 points in the lecanemab trials.

What does this mean? Well, at the MCI and early dementia stages of AD, there is an average clinical decline of 1.5 – 2 points on the CDR-SB scale, over a period of 18 months (the duration of these trials). So, the CDR-SB differences above, which range between 0 to 0.45 points, suggest that the clinical benefit of these drugs is modest – particularly when considering that the CDR-SB is an 18-point scale. To put this into context, we can look at the changes in relation to the “minimal clinically important difference” (MCID), which is defined as the smallest change in a treatment outcome that would be deemed meaningful by a clinician. For patients in the early stages of AD, the MCID is 1 point on the CDR-SB scale.

So, the small improvements observed with the different anti-amyloid immunotherapies may not be very clinically meaningful at this stage. However, the effect size may become larger over time if these drugs will prove to be actual disease-modifying therapies and keep working at later stages of the disease; we are still waiting for long-term follow-up data.

**Are there any safety concerns linked to the use of anti-amyloid immunotherapies?**

**Nicolas Villain:** The major safety concern for anti-amyloid immunotherapies is small bleeds or swelling of the brain. These can be detected on brain MRI scans, and are termed “amyloid-related imaging abnormalities”, or ARIA. Most ARIA are asymptomatic or mild, and resolve after treatment is suspended. However, our meta-analysis showed that in about 1 in 100-150 cases they could cause serious, severe and long-term problems for patients. We also found that the ARIA rate varied between drugs. For example, high-dose aducanumab was associated with an ARIA rate of 41.3% (compared to 10.3% in the placebo group), whereas lecanemab was associated with an ARIA rate of 12.4% (compared to 5.7% in the placebo group). Of note, three deaths under lecanemab have recently been reported by journalists in the US, in the open-label extension of the clinical study. We don’t have many details so far to assess whether lecanemab directly caused these deaths, but we should remain cautious.

Overall, it looks like safety is not perfect for anti-amyloid immunotherapies, with potential for long-term issues. So, we need to take care if and when we prescribe these drugs, and balance out the risk/benefit ratio on an individual patient basis. Regulators will also need to decide whether the treatments deliver clinically meaningful improvements, and whether the safety concerns are manageable in that context.

**Recently-published results from the Phase 3 clinical trial of lecanemab are convincingly positive. What makes you excited about these results, and what tempers your enthusiasm?**

**Nicolas Villain:** Actually, there is a lot to be excited about! The physician in me says that we need to be careful, as the clinical gain isn’t huge and there are safety concerns. However, the scientist in me is excited that we may have a new disease-modifying therapy for AD! Even if lecanemab isn’t a miracle drug, the results are really encouraging and represent new hope for patients. We have to remember that the first drugs in class are often not miracle drugs, but can lead to new drugs or drug combinations. So, perhaps in twenty or thirty years we will make enough incremental gains to eventually win the fight against AD.

On the other hand, safety issues temper my enthusiasm. These drugs could potentially be delivered to millions of patients, so even a low rate of severe ARIA in about 1 per 100 patients is something to worry about; especially since the expected benefits appear to be modest for the moment. As a physician, I think that risk minimisation should be one of our main concerns; we need thorough safety monitoring programmes after regulatory approval. But I think we can find a way to identify individual patients and subgroups who would benefit most from treatment, and get more data using risk minimisation programmes, then keep moving forwards with these innovative new medicines.

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**A few words from experts in the AD field**

On 30 November last year, results from the Phase 3 CLARITY-AD trial of lecanemab were published. Attracting widespread acclaim from the AD community, CLARITY-AD showed that bi-weekly, intravenous infusions of lecanemab could efficiently clear amyloid from the brain in early AD, whilst slowing clinical decline.

Unlike many other clinical trials of anti-amyloid immunotherapies, results from CLARITY-AD were consistently positive across all prespecified endpoints. The 898 trial participants randomised to receive lecanemab experienced between 24-37% slower decline in cognition and executive function over the 18-month trial duration. While these effect sizes are undoubtedly modest, and although safety issues such as ARIA remain, the CLARITY-AD results are widely viewed as a turning point for AD. To find out more, we approached three experts from the AD field, who shared their perspectives on lecanemab.
The consistent and positive results of the lecanemab trial suggest that we may actually approach a future with disease modifying therapies for AD. Although the gantenerumab trials were negative, they were also very informative for the field. As they provide further evidence that removal of amyloid helps to modify the disease process in terms of downstream processes such as tau pathology, and ultimately to slow down clinical progression.

A picture is emerging that enough amyloid must be removed to translate into a clinical effect, and that after treatment, amyloid levels should be back to normal. Side effects of lecanemab were relatively few and seemed manageable.

Yet, my recommendation would be, after the authorities have approved the drug, that we start carefully and gradually with implementation of disease modifying treatment. Taking as a starting point that only a subset over patients is eligible for treatment, and that we need to carefully monitor side effects, particularly ARIA.

Prof. Wiesje van der Flier, Scientific Director of the Amsterdam Alzheimer Center, Amsterdam UMC (Netherlands)

The provider pool skilled in prescribing this drug is limited and truly undefined. Who is an Alzheimer’s expert? I will prescribe the drug to my patients who conform to the kinds of patients who participated in the CLARITY study; that is, persons with cognitive impairment causing either inefficiencies or disabilities in performing life’s instrumental activities such as managing finances, cooking or using transportation (commonly, these are persons with either MCI or mild stage dementia) and who have evidence of elevated amyloid. I’ll prescribe with great attention to educate the patient and a caregiver about the effort to take the drug (the infusions and tests), and the risks of brain bleeding and swelling and how testing for the ApoE gene, frequent MRIs, avoiding blood thinners can mitigate those risks.

I will ask them to pay special attention to the risks and challenges of that genetic test, specifically how the result can ramify into a family: We often say Alzheimer’s disease is a “family disease.” Truly, lecanemab spotlights this. I hope I’ll prescribe this drug as a participant in a mandated clinician and patient registry implemented as part of an FDA Risk Evaluation and Mitigation Strategy, or REMS. These strategies are tailored to address the challenges, risks and uncertainties of a novel therapy whose benefits are modest but valuable and risks notable. Lecanemab is just such a therapy. Brain bleeds and swelling are certainly a risk, so too is the risk of putting such a drug out into my country’s (non)system of care, a consequence of the limited resource of expert providers.

Science is universal, but the practice of medicine is quite local. This practice reflects nuances in how diseases unfold in culture and the resources we bring to their diagnosis and care. Sadly, in the US, for the diagnosis and care of persons with Alzheimer’s disease, we bring limited resources. The likely arrival of lecanemab amplifies this disparity. Knowing what I know about lecanemab, the presentations at CTAD and the publication in the New England Journal of Medicine, the drug is effective. It’s also risky.

Prof. Jason Karlawish, Professor of Medicine at the University of Pennsylvania Perelman School of Medicine (USA)

We don’t currently have a drug available in Europe which slows the progression of AD, and until recently haven’t been able to show this was possible, so the results for lecanemab were very exciting. We hope this could mean people with AD will have more precious time with their families. But this is the start of a long journey, there are many hurdles to jump before lecanemab might be available in Europe or the UK with questions raised about the benefit lecanemab will have in a real-life context. This will of course be a key consideration for all regulatory bodies reviewing the drug alongside its safety and cost effectiveness. We could see a situation where lecanemab has been approved in Europe but our healthcare systems are not prepared to roll it out. In the UK, the system is weighed down by overstretched staff and infrastructure which has been further strained by the COVID-19 pandemic, resulting in a plummeting dementia diagnosis rate.

The UK’s 10-year dementia plan is crucial to help push up this stagnant diagnosis rate and boost system readiness for new dementia treatments. Everyone with dementia must receive a diagnosis which specifies which subtype of dementia they have, as early as possible, so that people with AD can access treatments like lecanemab, which work best when given in the early stages of the disease. Delayed diagnoses for people with Alzheimer’s disease simply stop people accessing the benefits these medications can bring. Many of these issues will be commonplace across European nations so shared learning of best practice and collaboration alongside people affected by dementia will ensure this is a success across the continent.

Dr Richard Oakley, Associate Director for Research at the Alzheimer’s Society (UK)
Alzheimer Europe supports Older Adults Mental Health Awareness Week

In October 2022, Alzheimer Europe became an Endorsing Partner of the International Psychogeriatric Association’s Older Adults Mental Health Awareness Week.

The 2022 edition of the International Psychogeriatric Association’s Older Adults Mental Health Awareness Week began on 1 October, United Nations’ International Day of Older Persons and ended on 10 October, World Mental Health Day. Alzheimer Europe signed an agreement to become an endorsing partner and supported communications activities during this online event.

This was the second annual ten-day initiative, launched by the International Psychogeriatric Association (IPA) and it focused on raising awareness of the importance of better mental health for older people. The IPA also focused on raising awareness around the impact of ageism on health outcomes and to support the protection of human rights of older persons with mental health conditions. Older Adults Mental Health Awareness Week aimed to highlight both older persons’ mental health as well as promoting healthy ageing initiatives around the globe.

IPA President Dr Manabu Ikeda welcomed participants on 1 October, and noted that, of the 1 billion people worldwide who are over the age of 60, around 20% face mental health issues, including dementia, depression and anxiety. He also noted that these are often further complicated by physical and psychosocial comorbidities resulting in disability.

The event programme featured a number of topics related to dementia and Alzheimer’s disease, indeed, day two was entirely dedicated to Alzheimer’s disease. Speakers on this day included Paola Barbarino, President of Alzheimer’s Disease International and Claire Sexton of the Alzheimer’s Association (UK). Alzheimer Europe’s “What Makes You, You?” video campaign for World Alzheimer’s Day was also shared with delegates via the online platform (find out more about this campaign on page 17 of this magazine).

Day six opened with a video presentation on “Perspectives of people with dementia” by IPA Early Career Network Chair Sascha Bolt, while day nine of Older Adult Mental Health Awareness Week focused on protecting the human rights of older persons and opened with a video message from Sirpa Pietikäinen, MEP, a former long-time Board member of Alzheimer Europe and the current Chairperson of the European Alzheimer’s Alliance of MEPs. Ms Pietikäinen stated that she had been pleasantly surprised to hear European Commission President Ursula von der Leyen, announcing a new initiative on mental health, to be presented in 2023, in her “State of the European Union” speech on 14 September 2022.

“This is certainly needed” stressed Ms Pietikäinen. “Many issues are having a negative impact on our mental health, including climate problems, COVID-19 fallout and of course the war in Ukraine” she said. She also emphasised the need to ensure that older people’s human rights are upheld and their mental health needs properly met, as she pointed out that both of these important areas are often ignored. She also reminded everyone of the trauma and mental health difficulties faced by refugees.

“It is our duty and it is in our interest to support all these people, with their varied stories and histories, whether they are male or female, young or old, and to try to help them to find support and to integrate into our societies”, she said. “This we can do and this we must do.”

Closing the event, on 10 October, IPA’s President-Elect, Prof. Anne Margriet Pot highlighted the stigma that still remains around many mental health issues, including depression, dementia, anxiety and loneliness, some of the main mental health areas affecting the older population. She also spoke about the impact of ageism which, she stressed, is a global phenomenon. Older Adults Mental Health Awareness Week aims to raise awareness, increase empathy and understanding and eradicate ageist policies and practices, she said.

Find out more about IPA: https://www.ipa-online.org/
See the programme and resources from Older Adults Mental Health Awareness Week: https://awareness-week.ipa-online.org/
LILLY IN ALZHEIMER’S DISEASE: ADVANCING THE SCIENCE, CARING FOR PEOPLE

At Lilly, patients and loved ones are at the center of everything we do. For over 30 years, we have been committed to the development of both diagnostics and therapeutics in the AD space. Through our continuous investment, we are advancing the field by helping to set high standards for Alzheimer’s disease research.

To pioneer nutritional solutions that help people live longer, more joyful and healthier lives.
Living with dementia and sleep problems

Sleep can be negatively impacted by dementia, particularly certain types of dementia, such as Lewy body dementia. Kevin Quaid, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) shares his personal account of sleep difficulties and disturbances, which he experiences quite intensely with his Lewy body dementia. He also shares some tricks and tips.

Sleep problems, for a lot of people, can be the biggest and most distressing part of Lewy body dementia. The nightmares can start a long time before a person gets a proper diagnosis and indeed can be a red flag as to what type of dementia, possibly indicating Lewy body dementia.

Having a particularly disturbing nightmare, for example about killing someone or about moving dead bodies, can have a profound and traumatic effect. The nightmares can be so real that at times it’s difficult to determine what is real and what is not. Even smells that you might smell in your dreams, quite possibly could stay with you the following day and this can be very upsetting for a person with dementia as well as for their family members, who have to watch them. At times, the nightmares just won’t leave you.

It is a very frightening thing to wake up at night because of a nightmare. You might not know who you are, where you are, or what is actually happening and it may be that only the voice of someone you love can put your mind at rest, giving you some reassurance that you are safe.

One of the hardest things for a partner to cope with is when a person suffers from REM sleep behaviour disorder. Simply put, a person who doesn’t have this problem, when they sleep their muscles paralyse, but when you have REM sleep behaviour disorder, this doesn’t happen and so, all too often, the person with this disorder will physically act out their dreams and may well punch, kick, strike out and hit the person they love the most, sometimes hurting them.

The drug clonazepam can work, to ease the severity of the nightmares, especially for people who have Lewy body dementia and as this brain disease progresses, the medication may have to be increased. However, no medication should be taken or increased or stopped without first discussing it with a medical practitioner!

The problem with severe nightmares is that, all too often, a person is afraid to go to sleep because of the nightmares and can sometimes go for days without getting any proper sleep. This leads to exhaustion, loss of appetite and a general lack of energy which, in turn, affects their mood and their lifestyle.

I have some tips, that might help:

1. Always have a nightlight on when you are asleep, that way when you wake up you are not in a completely dark room, it may then be not as frightening when you wake up and you may recognise your surroundings within a very short period of time.
2. For people who use an iPhone or iPad, it can be very useful to have them by the side of your bed so as you can put on a comedy, or music or meditation or whatever can take your mind off your nightmare.
3. It’s always handy to have earphones as well, so as not to wake the person next to you.
4. If you are afraid, though, wake them up and look for the reassurance that you need. Sometimes that’s all a person is looking for, to be told that they are ok.
5. A drink of water nearby is also very useful, so keep that near you as well.

I hope this gives you an idea of what people with dementia, and especially Lewy body dementia, can and do go through at night, so my hope for you is that you have sweet dreams!
32nd Alzheimer Europe Conference takes place in Bucharest and online

The 32nd Alzheimer Europe Conference, “Building bridges”, was the organisation’s first ever hybrid conference, with delegates and presenters able to join either in person or online. The event took place from 17 to 19 October 2022 and included 544 participants from 42 countries.

Face-to-face at last

Iva Holmerová, outgoing Chairperson of Alzheimer Europe, opened the conference, commenting on what a pleasure it was to be back together and to have so many delegates attending in person. She extended a special welcome to the 22 people with dementia among the delegates, as well as to their supporters. Echoing the theme of the conference, she said, “we hope to ‘build bridges’ across European borders, to ensure that good practices in dementia care and innovations in diagnosis and treatment are made equally available across the whole European continent.”

She highlighted the vital work of the European Working Group of People with Dementia (EWG-PWD), noting the 10th anniversary of the group this year, singled out the fantastic collaboration that Alzheimer Europe has developed with the INTERDEM network, and expressed the organisation’s gratitude to its corporate conference sponsors, Biogen, Lilly, PAVE and Roche.

Working together to improve dementia care delivery

Following these opening words, delegates were also welcomed by Diana-Loreta Păun, Presidential Advisor, Romania, who noted that we are currently in the UN Decade of Healthy Ageing, but that dementia is a leading cause of death as well as of disability. She stressed the importance, therefore, of working together, to improve the delivery of care for people with dementia, stating that “this is the opportune time for us to build bridges, to ensure good international collaboration”. She also said that “It is vital that we ensure the medical community is provided with the most up to date information available”, in order to achieve this goal of better care delivery.

The importance of not making assumptions about people with dementia

Chris Roberts was next up to the lectern, addressing delegates in his capacity as a person living with dementia and as the

In closing, she informed delegates of her decision to step down from the position of Chairperson of Alzheimer Europe. “The organisation has grown a lot in my time here and I am very proud of our achievements, not least of which is our success in truly giving a voice to and integrating people with dementia in all our work”, she stated. She also warmly congratulated her successor, Maria do Rosário Zincke dos Reis from Portugal, who was elected as her successor, during Alzheimer Europe’s Annual Meeting, just prior to the conference. “I am sure that the association will continue to grow and flourish under the new leadership and I wish all of you a very successful and interactive conference”, she concluded, and gave the floor to the next speaker.
Chairperson of the EWGPWD. He urged those present not to make assumptions about him and other people with dementia. “Speak to me, ask me, and understand me! I still have a voice and opinions of my own”, he emphasised. “I am still a person even though I am living with dementia”. He also highlighted the importance of working together and of involving people with dementia in all our work, calling to mind the slogan “Nothing about us without ALL of us!” He continued by giving thanks to everyone present, for the assistance, support, services, information, research and understanding afforded to people living with these “cruel and life changing brain diseases”.

“Speak to me, ask me, and understand me! I still have a voice and opinions of my own. I am still a person, even though I am living with dementia.”  
Chris Roberts

Strengthening connections between research and practice

Marjolein de Vugt spoke on behalf of INTERDEM (Early detection and timely INTERvention in DEMENTia). “Building strong bridges between research and practice is key to sustainable implementation of innovations, and there is much to gain for both researchers and society”, she said. She also stressed that “strengthening intergenerational connections in dementia research and society will help to build a better future for people with dementia”.

“Strengthening intergenerational connections in dementia research and society will help to build a better future for people with dementia.”  
Marjolein de Vugt

Involving people with dementia in the work of Alzheimer Europe

Cătălina Tudose, Chairperson of Societatea Română Alzheimer welcomed everyone warmly to the conference and to Romania. She also thanked Alzheimer Europe for the guidance and support over the years since her association joined, in 1994. “Many things have changed throughout these years”, she said, but one of the things she wanted to draw particular attention to, in terms of evolution, was that she felt Alzheimer Europe has been able to provide a “unique structure” and an example, due to its involvement of people with dementia in all of its work.

“Alzheimer Europe has been able to provide a unique structure and an example, due to its involvement of people with dementia in all of its work.”  
Cătălina Tudose

Building bridges - Promoting good dementia care through pan-European collaboration

The opening ceremony was followed by a keynote presentation delivered by Alexander Kurz, Klinikum rechts der Isar, Technical University of Munich, Germany, who began by pointing out that many national health and social systems in South Eastern Europe are not prepared to meet the challenge of the rapidly rising number of people living with dementia which is predicted over the coming decades. He also noted their limited ability to provide a good standard of care, due to a lack of public awareness of dementia, outward migration of skilled health workers, insufficient knowledge and cooperation among professional groups, and weakening traditional familial support.

He said, however, that European collaboration could make significant contributions to improving dementia care in the region, and listed several examples of EU-supported collaborative projects. “Transnational collaboration can help to overcome gaps and barriers in dementia by sharing a person-centred model of care, promoting comprehensive and proactive forms of management, developing novel tools and services, taking steps to put dementia higher on political agendas, and advocating for national dementia strategies and plans”, he said.
More attention needs to be given to knowledge translation from projects to practice, to dissemination, implementation and sustainability. This requires careful planning, smart delivery and intensive networking.”

Alexander Kurz

He also pointed out, however, that while there is a wealth of excellent ongoing collaborative projects, these projects do not, in themselves, automatically improve dementia care. Indeed, most do not survive the end of funding, he stressed, and insisted that “more attention needs to be given to knowledge translation from projects to practice, to dissemination, implementation and sustainability. This requires careful planning, smart delivery and intensive networking.” Bridges need to be built from projects to peers, policy makers and other stakeholders, he concluded.

To close day one of the conference, a welcome reception was held in the foyer, with musical entertainment provided by Cvartet ANIMA.

Moving beyond the COVID-19 pandemic

The second plenary of the conference, which took place on the morning of 18 October, was on “Moving beyond the COVID-19 pandemic” and was chaired by Alzheimer Europe Vice-Chairperson Charles Scerri.

Bernd Heise, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) shared his lived experience of adapting to the COVID-19 pandemic as a person with dementia. He was keen to emphasise that people with dementia are still individuals and have valuable knowledge to share. Despite the difficulties and hurdles encountered due to the pandemic, he continues to stay as active and as healthy as possible, and intends to do so for as long as possible. “I will not give up!” he concluded.

Clarissa Giebel from the University of Liverpool was next to take the floor, with her presentation “Who cares for the carers? The long-term impacts of the pandemic on dementia carers”. She highlighted the extent to which carers have been neglected, not only during the pandemic but also before it and since. Most are without any respite or support, she pointed out, and insisted that “now, more than ever, we need to put support systems in place that support the carer in their own right, as an individual with their own needs, to live well and support the person they care for to continue to live well.”

The final speaker in this plenary session was Brigitte Juraszovich, Senior Health Expert at the Austrian Public Health Institute, who spoke about implementing the Austrian dementia strategy during the COVID-19 pandemic. She began by saying that, during the pandemic, most of the support and communication with people with dementia took place online, and that participation of people affected by dementia in the implementation of the dementia strategy worked quite well, via online discussions and video conferences. Indeed, she and her colleagues found that “involving people affected by dementia in strategic processes leads to targeted and needs-based planning and implementation of measures” and that “their involvement was especially valuable during the pandemic, where it was crucial to develop solutions tailored to the needs of different target groups in a constantly changing and uncertain environment. It came to light that one of the most important issues for persons with dementia and their carers was, that ‘health’ needed to be viewed and discussed in a comprehensive way (bio-psycho-social-approach), with any impact of measures and interventions on social relationships and connectedness being vital to take into account (e.g. avoiding loneliness and social isolation).

In Memoriam Alexander Kurz, 1950-2023

We were deeply saddened to learn of the passing of our dear friend and colleague Alexander Kurz, on 29 January 2023.

He served on the Board of Alzheimer Europe from 1998 to 2004 and was a member of the Board of Deutsche Alzheimer Gesellschaft, since 1997. He was a vital part of our big European family and will be very much missed.

We will remember Alexander Kurz as a dear friend and a passionate, dedicated researcher in the dementia field and will think back to his excellent keynote speech with gratitude and fondness. His passing has been a big shock to us all and we offer our most sincere condolences to his family, friends and colleagues.

Now, more than ever, we need to put support systems in place that support the carer in their own right, as an individual with their own needs, to live well and support the person they care for to continue to live well.”

Clarissa Giebel

Plenary 2 speaker panel (left to right), Bernd Heise, Brigitte Juraszovich, Clarissa Giebel and Alessia Rossetti

52 Dementia in Europe
The involvement of people with dementia in our work was especially valuable during the pandemic, where it was crucial to develop solutions tailored to the needs of different target groups in a constantly changing and uncertain environment. 

Brigitte Juraszovich

Brain health and prevention

The third plenary of the conference took place on the afternoon of 18 October and covered topics related to brain health and prevention. This session was chaired by Marjolein de Vugt from Alzheimer Center Limburg, Netherlands.

A presentation on “Increasing awareness of dementia prevention through public campaigns” was delivered by Jan Steyaert, Scientific Officer at the Flemish centre of expertise on dementia and Professor in the department of social sciences at the University of Antwerp, Belgium. He explained that research over the past decade has clearly shown that there are modifiable risk factors for dementia and that “We can slow down the future increase of dementia by focusing on these.” He pointed out that this adds a third challenge to the work being done in this area, because, in addition to developing good dementia care and looking for pharmaceutical solutions, it is also clear that it is necessary to work on primary prevention, on promotion of a brain healthy lifestyle.

“As dementia care organisations, we need to outreach and build strategic alliances with public health organisations on a local and (inter)national level”, he said.

Primary prevention of dementia was the focus of the next speaker, Edo Richard from the Radboud University Medical Centre, Nijmegen, Netherlands. In answer to the question “What is the way forward, in primary prevention?” his presentation showed that, where dementia risk factors are concerned, lower may not always be better and that “we need to rethink the design and evaluation of individual dementia risk reduction strategies.”

The final presentation in this plenary was called “From assessing risk to communicating risk” and was given by Wiesje van der Flier, Scientific Director of the Alzheimer Center Amsterdam. She emphasised that “risk and probabilities can be difficult for patients to understand, and equally difficult for clinicians to explain.

“Risk and probabilities can be difficult for patients to understand, and equally difficult for clinicians to explain. Yet, patients increasingly want information and clinicians need tools and training to support them in communicating risk. She also noted the importance of learning from other fields that have experience with communicating risk and the inherent uncertainty that comes with it, such as oncology or cardiology. Best practice examples include use of plain language, precise numerical risks, and graphical representation, she noted.

She also said that the “teach-back” method helps to check understanding. Finally, she stressed that “in the debate about communicating risk based on biomarker information, we often tend to forget that there is particular value in negative biomarkers giving a powerful message that risk of progression is low.”

Building bridges across Europe

Plenary four opened the conference programme on the third and final day, and comprised four presentations revolving around the theme of “Building bridges across Europe”. The session was chaired by Alzheimer Europe Chairperson Iva Holmerová.

Cătălina Tudose, President of Societatea Română Alzheimer (Romanian Alzheimer Society), discussed “Progress of Dementia Care System in Romania as a Consequence of European Integration and Support”. She gave an overview of the history of the Romanian Alzheimer Society, which was set up in 1992, and joined Alzheimer Europe as a full member in 1994. Initially, she said that her organisation’s main goal was to focus on practical things, because there was so much to do. She expressed her gratitude to alzheimer Europe and other European and international organisations for their guidance and support over the years, and especially in the early days, helping to re-focus some of their efforts on policy, as well as practical support, as the latter should be provided and funded by governments.

As dementia care organisations, we need to outreach and build strategic alliances with public health organisations on a local and (inter)national level.”

Jan Steyaert

Yet, patients increasingly want information and clinicians need tools and training to support them in communicating risk. She also noted the importance of learning from other
Their focus has also shifted from supporting older people in general, to people with dementia and towards promoting earlier diagnosis, reducing stigma and ensuring the national dementia strategy is carried out.

Up next, Iryna Shevchenko, Founder and Director of Nezabutni charitable foundation, Ukraine, spoke about the impact that the ongoing war in her country is having on people with dementia and their families. “It is important to minimise the factors that influence the symptoms and psycho-emotional state of people with dementia she stressed, listing three main factors, which were: a person’s understanding about the ongoing war; changes in their usual environment; and changes in their routine.

She gave details about the incredible ongoing efforts that her organisation, other organisations, and individuals are making, to try to ensure that people have access to medicine, to information, and to online care, at a time when face-to-face care is not possible.

Adrianna Senczyszyn from Wroclaw Medical University, Poland, took the floor next, to share her presentation with delegates, which was called “Between frozen dementia care in Ukraine and building bridges in Europe: the experience of Poland”. She began by saying that her organisation is “still at the beginning of the road. A lot has been done but we still have so many things to do.” Despite this statement, the work that she presented, which was being done in international projects, for example, was considerable, until 24 February 2022, when Russia waged war on Ukraine. Since that time, “normal operations” have halted, for the most part, and vast humanitarian aid efforts are being made in Poland, and in other countries in Central and Easter Europe, to support Ukraine and Ukrainian refugees fleeing the conflict. She hopes that this war will end very soon and that their focus can return to supporting people living with dementia.

Cassie Redlich, Technical Officer, Mental Health Flagship, WHO Regional Office for Europe (Denmark) was the final speaker in this plenary, and discussed “Opportunities for improving dementia care and support through the Pan-European Mental Health Coalition”. The WHO pan-European Mental Health Coalition, she explained, “harnesses the collective wisdom and expertise of our diverse members to accelerate implementation of the WHO European Framework for Action on Mental Health 2022-2025.” The Coalition mobilises key stakeholders – including those living with dementia and their carers – to “drive momentum for reducing stigma and ageism, improving care and increasing investment”, she said.

Reprioritising dementia as a care, policy and research priority

The fifth and final plenary session at the conference took the form of a roundtable discussion, chaired by Alzheimer Europe’s Executive Director Jean Georges. The discussion revolved around “Reprioritising dementia as a care, policy and research priority” and panellists were: Charles Scerri, Chairperson of the Malta Dementia Society, Vice-Chairperson of Alzheimer Europe and National Focal Point on Dementia in Malta; Katrin Seehler, Mental Health Specialist (Brain Health), World Health Organization; Cătălina Tudose, President, Societatea Română Alzheimer; Myrra Vernooij-Dassen and Jean Georges
Vernooij-Dassen, professor at the Radboud University Medical Center; and Gunhild Waldemar, professor of clinical neurology at the Faculty of Medicine and Health Sciences, University of Copenhagen and chair of the Danish Dementia Research Centre (DDRC) at Rigshospitalet in Copenhagen, Denmark.

As part of his contributions to the discussions, Charles Scerri stressed that “it is our duty, as policy makers, to ensure that dementia remains at the very top of our health and social care priorities”. He also stated that “the future, and hope for all those living with dementia, lies in our research efforts and the money we’ll put into this.”

Panelist Katrin Seeher noted that only one in four countries have national dementia plans. Governments need to accelerate efforts to develop, fund and implement comprehensive national policies and re-commit to making dementia a public health priority, she said. She also emphasised that dementia policies and services continue to fall short, especially in low- and middle-income countries, and that, in order for our global response to be successful and equitable, “multisectoral actions must be coordinated within and across WHO Member States and Regions.”

Myrra Vernooij-Dassen stressed the importance of implementing psychosocial interventions, based on the needs of people with dementia and their carers. She also highlighted the importance of focusing on new priorities, which, she suggested might include the recognition of social health as a specific area of epidemiological and intervention research. Research into biopsychosocial mechanisms of interventions was another point of focus in her contributions to the discussion, which she felt could help us to learn more about why and how interventions work.

Gunhild Waldemar’s contribution to the roundtable discussion revolved around what has been learned from the COVID-19 pandemic. Infections, she underlined, are associated with a much higher mortality rate in people with dementia, as compared to people without dementia. She also noted that social interaction is of key importance for people with dementia. Finally, she also pointed out that “with delayed diagnosis, many people with dementia and their carers risk unnecessary decline in function and will not get sufficient support”.

Cătălina Tudose spoke about how dementia services in Romania changed during the pandemic and noted that there were some positive changes, such as the development and normalisation of online interactions with clinicians. When asked whether there were things that might be beneficial to keep in place after the pandemic, she said: “For me, the hybrid way of working. It strengthens relations. It’s a bridge. The theme of the conference is ‘Building bridges’, and I think we should keep that one in place”.

Alzheimer Europe is trying to be as socially responsible as possible and is delighted to have worked with a local charity in Bucharest, called “Serve the City”, to ensure no food went to waste. The charity redistributed leftover food from conference coffee breaks and lunches, to those in need, across the city of Bucharest.

La revedere, Bucureşti. Hei, Helsinki!

The closing ceremony of the conference included the announcement of the winners of the Anti-Stigma Award (see page 21) for more information about this award and its winners). The trophy and prizes were awarded by Alzheimer Europe Chairperson, Iva Holmerová. She also announced the winners of the poster competition, which are awarded each year by the Alzheimer Europe Foundation. Closing comments were made by Cătălina Tudose, President, Societatea Română Alzheimer and Maria do Rosário Zincke dos Reis, Chairperson-elect, Alzheimer Europe, who then invited Katarïna Suumu, Executive Director of Muistiliitto, the Alzheimer Society of Finland, who welcomed attendees to the 33rd Alzheimer Europe Conference in Helsinki, from 16 to 18 October 2023.

We are delighted to invite you to submit abstracts for the 33rd Alzheimer Europe Conference (#33AEC), “New opportunities in dementia care, policy and research”. The call for abstracts will close on 30 April 2023. We look forward to welcoming delegates and speakers to our 33rd Annual Conference!

See here for more information: https://www.alzheimer-europe.org/conferences/2023-helsinki/abstract-submission

Serve the City - being more socially responsible

Alzheimer Europe is trying to be as socially responsible as possible and is delighted to have worked with a local charity in Bucharest, called “Serve the City”, to ensure no food went to waste. The charity redistributed leftover food from conference coffee breaks and lunches, to those in need, across the city of Bucharest.
Between 17 and 19 October 2022, during the 32nd Alzheimer Europe Working Group of People with Dementia (EWGPWD), five special symposia were held on a wide range of topics, including one by members of the European Working Group of People with Dementia.

**“Building bridges, our voices, our lives” – a special symposium by the European Working Group of People with Dementia**

One of the highlights of the second day of the Alzheimer Europe Conference was a special symposium organised by the European Working Group of People with Dementia (EWGPWD).

The symposium was chaired and facilitated by the current Chairperson of the EWGPWD, Chris Roberts (United Kingdom – Wales). The four speakers at the session discussed how different aspects of their lives had been affected by dementia and how they are “building new bridges” to try to improve their lives and those of others.

The speakers were:

- **Vice-Chairperson Kevin Quaid (Ireland),** who spoke about the need for a proper and timely diagnosis of dementia. He referred to his own experience of a diagnosis of a less common type of dementia (Lewy body dementia).
- **Erla Jónsdóttir (Iceland),** who shared her experiences related to dementia and employment. In particular, she told the audience how she experienced the transition from being an active person in the working place to suddenly lacking a specific role or purpose in everyday life.
- **Nigel Hullah (United Kingdom),** who discussed the contribution of people with dementia to different aspects of research, policy- and service-development relevant to them. He drew on the concept of “co-production”.
- **Angela Pototschnigg (Austria),** who talked about the importance of having a stable connection, “a bridge”, between people with dementia and their relatives and carers. She feels it is her task to maintain and create connections, by informing others about her everyday life with memory problems. Lieselotte Klotz (EWGPWD member from Germany) supported Angela with the translation from German to English.

Chris Roberts commented: “Our symposium at the Alzheimer Europe Conference was an hour long and was organised and written by ourselves, members of the EWGPWD. Using our collective knowledge and personal experiences to speak about the ‘bridges’ we have built during our diagnosis, whether it be: accepting our diagnosis and learning/adapting to live with it; building bridges with families and professionals to help them understand and work with us for better quality of life for all and to further research/projects that might not help us directly, but might help future generations; or building the bridges needed to alleviate the stigma and assumptions that surround everyone living with life-changing diagnoses which lead to dementia. I’m very proud to be the Chair of a group of amazing individuals who, through adversity, have not only become great friends but inspirational members of the EWGPWD, working closely with Alzheimer Europe.”

**Davos Alzheimer’s Collaborative**

The Davos Alzheimer’s Collaborative for Healthcare System Preparedness, launched in 2021, was created to fund healthcare system operational change to better care for our ageing populations. Using Implementation Science to evaluate pilot programmes focused on seeding health system transformation, it has clear actions and goals aimed at sustainable solutions. At this symposium, organised by the Davos Alzheimer’s Collaborative on 18 October 2022, day two of the conference, panelists discussed some of the first funded programmes on studying the real-world implementation of a timely and accurate diagnosis and informed delegates about how to become involved.

**Rethinking the early detection and diagnosis of Alzheimer’s disease**

A third symposium session, held at the end of the programme on 18 October, was organized by the European Brain Council (EBC) and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

Alzheimer’s disease (AD) is a major unmet medical need that requires innovation to be aligned with public health and health system needs. AD represents between 60% and 70% of dementia cases. It is still diagnosed too late, when the symptoms become more evident as the disease progresses.

AD is now portrayed as a continuum consisting of three stages: an asymptomatic preclinical phase, a mild cognitive impairment (MCI) phase, and dementia. To match this continuum, current research efforts are now focusing on the earlier stages of the disease (MCI stage), when it is believed that a therapeutic intervention could slow or prevent disease progression.

The speakers presented around the subject of “Rethinking Alzheimer’s disease”, which is the name of an EBC-EFPIA-led project. The project aims to identify the roadblocks to early detection and diagnosis of AD and to propose new clinical pathways, building bridges between all stakeholders to improve the current situation and prepare for the future. The speakers at this session were:

- **Kevin Quaid, Vice-Chairperson of the EWGPWD (Ireland)**
- **Lenka Krajcovicova, Masaryk University (Czech Republic)**
- **Wiesje van der Flier, Alzheimer Center Amsterdam (Netherlands)**
- **Lydia Lanman, Roche (Switzerland)**
- **Annette Dumas, EBC (Belgium)**
Community matters: Developing Alzheimer’s clinical trials together

On the third and final day of the conference, Roche held a symposium on “Community matters: Developing Alzheimer’s clinical trials together”, chaired by Wendy Weidner from Health Interactions (United Kingdom), and with a broad panel of speakers, including specialists in dementia and patient representatives. They were:

- Kash James, Health Interactions (United Kingdom)
- Ramin Nilforooshan (United Kingdom)
- Helen Rochford-Brennan, Irish Dementia Working Group and EWGPWD (Ireland)
- Karan Jutlla (United Kingdom).

The panel had an interactive exchange exploring the importance of co-creating clinical trial designs with the broader Alzheimer’s disease (AD) community, with different perspectives and experiences presented by the panel, regarding the benefits of collaboration and how this can help meet the specific needs of people living with AD. Presentations featured examples of successful collaborations, as well as how clinical trial designs need to evolve to ensure more equitable access to trials for all people living with AD. The session finished with an interactive question-and-answer session, to afford the audience the opportunity to ask any burning questions, as well as sharing their thoughts with the other attendees.

Warm Technology in the Expertise Center Dementia & Technology (ECDT)

Dementia is often a complex condition that affects people differently over time and between individuals. In addition to other strategies, technology provides an opportunity for people to live well with dementia with more independence and dignity. However, technology is often focused on the disease itself to “fix deficits” rather than supporting the people behind the disease. With this in mind, Alzheimer Nederland organised a symposium to present a new perspective on “Warm Technology”.

The concept of Warm Technology focuses on contributing to quality-of-life and well-being. For this, it is important to consider people’s abilities, make technology non-stigmatising, and ensure it is user-friendly and congruent within the user’s specific social context, emphasises Alzheimer Nederland.

The session covered examples of Warm Technology and elaborated on current research projects conducted by Alzheimer Nederland as part of the Expertise Center Dementia & Technology (ECDT), powered by Alzheimer Nederland and Eindhoven University of Technology (Netherlands). The projects discussed were:

- the QoLead project, wherein a broad consortium collaborates with people living with dementia, to co-design artificial intelligence (AI) applications based on factors that influence quality-of-life
- the WECARE project, which focuses on designing an interactive companion (like a robot), in line with the principles of Warm Technology
- the Certification-D project, which brings the knowledge of Warm Technology to companies that have products on the market, collaborating with them in Living Labs, to improve their product offering.

The hope is that the ECDT research will lead to a better understanding of Warm Technology and what the requirements are for technology to be a natural part of everyday life for people with dementia and carers.
INTERDEM features prominently at #32AEC

INTERDEM (Early detection and timely INTERvention in DEMentia) is a network of researchers interested in psychosocial interventions. It is made up of 221 researchers and academics with different professional disciplines, spread across 21 countries (19 in Europe). Alzheimer Europe is a key partner of INTERDEM and, as every year, INTERDEM held its Annual Meeting prior to the Alzheimer Europe Conference and featured prominently on the conference programme.

The INTERDEM Academy aims to promote the career development and capacity building of dementia care researchers and supports their pathway to senior academic posts in the field. Chairperson Marjolein de Vugt congratulated the winners, before ending the session. Alzheimer Europe is proud to be a key partner of INTERDEM and was represented at this Annual Meeting by Director for Projects Dianne Gove and Project Officer Ana Diaz.

At the conference opening ceremony, on 17 October, Marjolein de Vugt, spoke on behalf of INTERDEM, from her perspective as the network’s current Chairperson. “Building strong bridges between research and practice is key to sustainable implementation of innovations, and there is much to gain for both researchers and society”, she said.

She also stressed that “strengthening intergenerational connections in dementia research and society will help to build a better future for people with dementia”.

The fifth plenary session at the conference took place on 19 October, in the form of a roundtable discussion chaired by Alzheimer Europe’s Executive Director Jean Georges. The discussion revolved around “Reprioritising dementia as a care, policy and research priority” and panelists included Myrra Vernooij-Dassen, former Chairperson of INTERDEM.

During the panel discussion, she stressed the importance of implementing psychosocial interventions, based on the needs of people with dementia and their carers. She also highlighted the importance of focusing on new priorities, which, she suggested might include the recognition of social health as a specific area of epidemiological and intervention research. Research into biopsychosocial mechanisms of interventions was another point of focus in her contribution to the discussion, which she felt could help us to learn more about why and how interventions work.
INTERDEM parallel sessions

During the three-day Alzheimer Europe Conference, a number of parallel sessions were held.

Including three organised by INTERDEM. The first of these sessions was called “Applying an intersectional lens in dementia care research” and was chaired by Martina Roes (Netherlands). Presentations included:

- “Intersectionality and dementia care research: preliminary results from a scoping review”, delivered by Martina Roes together with other speakers from the INTERDEM Taskforce
- Huerrem Tecan-Guentekin (Germany) spoke about an “Intersectional analysis of racial discrimination experiences of Turkish dementia caregivers in Germany”
- Carolien Smits (Netherlands) presented on “Sharing of family care in family carers with a migration background, applying an intersectionality lens in research and communication tool development”
- Saloua Berdai Chaouni (Belgium) gave a talk titled “Beyond cultural sensitivity: Using intersectionality as a building block to capture the complexity”.

The second parallel session was a seminar hosted by INTERDEM Academy in collaboration with the Alzheimer’s Association International Society to Advance Alzheimer’s Research and Treatment (ISTAART) Professional Interest Area (PIA) to Elevate Early Career Researchers (PEERS). The INTERDEM Academy looks to stimulate career development and capacity building of early career researchers (ECRs) and supports their pathway to senior academic posts in the INTERDEM network. ISTAART PEERS aims to foster, develop, and support ECRs in the dementia field, across the world.

Although ECRs significantly contribute to dementia research, there are concerns about how to best support them throughout their career and what are most prominent challenges. The University College London and ISTAART PEERS recently investigated ECRs’ experiences via a global online survey (Smith et al., 2022, Alzheimer’s & Dementia). Results (n=584) have reassured that most ECRs are enthusiastic, dedicated and a thriving community with 77% being happy in their current role. However, there are also many areas which can be improved, particularly funding (74%), job availability/security (60%), and work-life balance (54%) (Smith et al., 2022, Alzheimer’s & Dementia). In a recent online survey (summer 2022), the authors are building on these insights by questioning ECRs in dementia across Europe, to further investigate the most prominent challenges and type of support needed.

Applying the World Café methodology, participants in this workshop explored solutions for these challenges (rated highest in the surveys). Participants interacted in small groups, sharing experiences and ideas. The output of the seminar will be used to help to focus the work of the organisations involved and to formulate potential approaches for improvements, as well as being disseminated to academia, funders, and policymakers. This seminar also provided a great networking opportunity. It was approved by the Ethics Committee of Universitair Ziekenhuis Brussel - UZ Brussel.

The session was moderated by Fania Das sen (Netherlands), with the participation of:

- Joni Gilissen (Belgium)
- Sara Laureen Bartels (Netherlands)
- Pascale Heins (Netherlands)
- Rita Maldonado Branco (Portugal).

The third and final INTERDEM parallel session was on “Social health: explorations of its potential to prevent cognitive decline and dementia” and was chaired by Myrra Vernooij-Dassen, Radboud University Medical Center (Netherlands) who examined “The interplay between Social Health and Dementia - A System Dynamics Model: is it complicated?” and the second looked at “How to assess Social Health in the Context of Cognitive Decline and Dementia? A Systematic Review on available Instruments”.

The final speaker was Marieke Perry, Radboud University Medical Center (Netherlands) who examined “The influence of the social environment on the functioning and well-being of the person with dementia: a qualitative study”.

The INTERDEM manifesto 2019 encouraged bridging the divide between biomedical and social sciences. The JPND funded “Social Health And Reserve in the Dementia patient journey (SHARED)” project provided the opportunity to make the bridge and to explore the potential of social health in preventing cognitive decline and dementia. In this session, the SHARED effort on concept advancement was presented, as was a conceptual framework and a hypothesis on the relationship between social health and cognitive decline.

The results of this ambitious project provide new insights into the potential to prevent dementia and guidance in studying the relationship between social health and cognitive functioning.

Speakers included:

- Myrra Vernooij-Dassen, who discussed “Conceptual advancement: Social health as a facilitator in the use of cognitive reserve”
- Jane Maddock, J Johnson (United Kingdom), whose presentation focused on “Social relationships, cognitive capability and cognitive decline: Findings from four European longitudinal studies”
- Karin Wolf-Ostermann, University of Bremen (Germany) gave two presentations, the first of which asked: “The interplay between Social Health and Dementia - A System Dynamics Model: is it complicated?” and the second looked at “How to assess Social Health in the Context of Cognitive Decline and Dementia? A Systematic Review on available Instruments”.

INTERDEM parallel sessions
Twitter highlights

Dr Clarissa Giebel @ClarissaGiebel · 18 Oct 2022
#32AEC Group photo! Great to see people finally in person again (over great lunches and cups of tea) #Dementia

Victoria Tischler @victori9ner · 19 Oct 2022
Excellent talk by Dr Karen Jutla about a useful toolkit she & colleagues have developed to improve involvement of Black, Asian & minority ethnic communities in research. Communication in appropriate languages & formats is key #32AEC

Welcome to the 32nd Alzheimer Europe Conference #32AEC Building bridges. Bucharest. 17-19 October

Dr Karen Jutla and University of Wolverhampton

The Alzheimer Society of Ireland @alzheimerireland · 18 Oct 2022
"It’s essential that FDRs should be on an Alzheimer’s journey. There needs to be acknowledgement on both sides that it makes research better" - Research & Policy Manager presenting at session 1 #32AEC

Teresa Tattal @TeresaTattal · 18 Oct 2022
Attending the Alzheimer Europe conference in Bucharest with Danny Moss and Michaela Ahmetaj. Danny is presenting in the session on "Dementia, war and sexuality" #32AEC

Laura O'Flaherty, PhD · 18 Oct 2022

Ioan George @IoanGeorgeEU · 18 Oct 2022
In one of the amazing workshops co-hosted by Ioana Chehraez and Nicolae Atanasiu, the new member of AlzheimerEurope from Romania #32AEC... find out more here: nicoatanasiu.org

Diane O’Doherty @DianaODoherty · 18 Oct 2022
Really looking forward to the next #32AEC session on gender, sexual and sexuality. Focusing on the experience of the LiMiTO community with dementia

Anneli Takki @annelitakki · 15 Oct 2022
#32AEC Environmental Session Primary care with self-organising teams: Bucharest. 17-19 October. #32AEC Environmental Session Primary care with self-organising teams: Bucharest. 17-19 October.
Karen Watchman @karenwatchman · 19 Oct 2022
Finally meeting in person! @WeldnerWendy @AlzDisInt #32AEC

Olivier Constanț ECD Vlaanderen @EcoOlivier · 18 Oct 2022
We must continue to build bridges and move forward, until there is no more stigma, shame, isolation or misdiagnoses. What an honest and inspiring speech by Kevin on behalf of the “European working group of people with dementia”!

Katarina Suomu @katarinasuomu · 19 Oct 2022
Thank you @PetricLampinen for your open, honest and moving speech 😊 You’re a great dementia anti-stigma ambassador! @Muistilitto is priviliged to have people like you in our community. Many thanks to Nina Lampinen too for your support. dementia #FTD #32AEC
## Facts and figures

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**TOTAL** 543

![Bar chart showing distribution of delegates by role.](image)

- **Academics/Researchers** 228
- **Alzheimer association staff and volunteers** 124
- **Health or social care professionals** 74
- **Students** 32
- **Industry representatives** 29
- **Carers** 21
- **People with dementia** 20
- **Civil servants** 6
- **Policy makers** 5

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98% of delegates would recommend future Alzheimer Europe Conferences to their colleagues.

90% of delegates rated the opening ceremony, keynote lectures, plenaries and closing ceremony of the conference to be good/very good.
Our members are helping people with dementia and their carers in 37 countries.
33rd Alzheimer Europe Conference
New opportunities in dementia care, policy and research
Helsinki, Finland
16 - 18 October 2023 #33AEC
www.alzheimer-europe.org/conferences