Highlights from the 33rd Alzheimer Europe Conference

The 33rd Alzheimer Europe Conference (#33AEC) "New opportunities in dementia care, policy and research" was formally opened on 16 October 2023. The conference took place as a hybrid event, with delegates and presenters able to join either on site at the Messukeskus Helsinki Expo and Convention Centre or online, with the aim of ensuring the event is as accessible, inclusive and interactive as possible. A record number of over 1,100 participants (1,000 of these in person) from 48 countries attended the conference, which took place from 16 to 18 October 2023.

Day one, 16 October 2023

Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, opened the conference. She extended a special welcome to the 56 people with dementia among the delegates, as well as to the 66 carers/supporters in attendance. "I am delighted to note that we have a record number of participants at this year's conference, with over 1,100 people joining us today, in person and online", she said. She also thanked Alzheimer Europe's sponsors, including Gold sponsors, Lilly and Roche and Bronze sponsors, BioArctic, Eisai, MSD and Prothena.

To make a better world for people with dementia, all our efforts must be focused in three main areas, she stressed. Firstly, we need to focus on finding and implementing better practices when providing care, along the disease pathway. All the while, we need to invest in research into better pharmacological and non-pharmacological treatments. Finally, we must also fight to ensure that dementia is recognised as a public health priority, both at European and national level and that specific policies are put in place, accordingly.

On the morning of 16 October, prior to the start of the conference, the Annual Meeting of Alzheimer Europe adopted the "Helsinki Manifesto", which contains a comprehensive range of measures and actions across the key areas that have the greatest impact on the lives of people with dementia, their families and carers. "It is proof", said Rosário Zincke dos Reis,

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"of our commitment to achieve our goals, always with the involvement of people with dementia, ensuring their voice is listened to in everything we do." In closing, she commented that she felt sure that this Manifesto would be another highly meaningful milestone for the European Dementia Movement.

Following these opening words, delegates were addressed by Jenni Kulmala, Chairperson of Muistiliitto and Associate Professor of Gerontology, Tampere University, Finland, who noted that 26 years had passed since Alzheimer Europe first held an Annual Conference in Helsinki. While dementia still poses one of the biggest health challenges we face in an ageing society, she said, it is important that we should also take note of the steps forward that we have taken together over the last decades:

- Advances in science have provided better understanding of biological origins of dementia, its types, symptoms, diagnosis and care.
- We also know how we can promote brain health during the whole life course and possibly delay the onset of dementia.
- In addition, the voices and views of people living with dementia are better heard.

"The Alzheimer Europe conference is a place where we can take new steps forward. We will have dialogue between dementia researchers, healthcare professionals, policymakers and non-governmental organisations. Ultimately, multi-professional collaboration is the key to a more dementia-friendly world", she said and stated that "Finland is paving the way in dementia prevention research, and we also want to be a country where research meets practice".

Kaisa Juuso, Minister of Social Affairs and Health, Finland, was next up to the lectern, addressing delegates on the topics of early detection of memory problems, research work and respect for people with memory disorders. In order for us to be able to meet the growing demand for services and the rising costs, we need action to promote brain health, prevent memory disorders and detect memory problems as early as possible, she stated, noting that there are currently 200,000 people with memory disorders in Finland.

The Minister also commented that the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) had shown that it is possible to prevent memory disorders by managing the risk factors associated with them, when people follow a multidomain lifestyle programme. This can improve cognitive functions in older people, she insisted, and can also prevent memory decline. The FINGER model will be implemented as a preventive measure throughout Finland.

She stressed that the most important thing is to ensure we treat older people with respect for their right to self-determination, and that we provide them with services that meet their needs, support their inclusion and make their lives as good as possible. “We need to learn how to engage with people with memory disorders and treat them with respect for their human dignity”, she said. She also noted that the Conference would be a great opportunity to engage in extensive networking and that the event was an important step towards showing a stronger respect and appreciation for the views of people with memory disorders. “By working together, we have better opportunities to raise memory disorders as an important societal issue”, she said, before giving the floor to the next speaker.

Marjolein de Vugt, Professor of psychosocial innovations in dementia at the Alzheimer Center Limburg, Maastricht UMC+ addressed delegates in her capacity as Chairperson of INTERDEM (Early detection and timely INTERvention in DEMentia). “Focusing on everyday transformations to improve the lives of people living with dementia has the potential to reshape the landscape of dementia care, influence policy development, and cutting-edge research, emphasising the importance of psychosocial innovations”, she said.

She also noted that, as the search for major breakthroughs continues, it is important to recognise the positive impact of psychosocial research and innovations in dementia:

"In our pursuit of major breakthroughs, let's not underestimate the profound transformative impact of psychosocial research. Alzheimer Europe and the INTERDEM network play a crucial role in fostering shared purpose, offering unique platforms for collaboration, learning, and inspiration to reshape the landscape of dementia care, influence policy development, and cutting-edge research”, she concluded.

Sirpa Pietikäinen, Member of the European Parliament (Finland) and Chairperson of the European Alzheimer's Alliance welcomed everyone warmly to the conference and to Finland. During her speech, she stressed that dementia care needs to be more and more person-centred, integrative and transformative. She also emphasised the need to take technology and its opportunities into account. “These are the new avenues for better care for memory-disabled persons in Europe”, she said.

Petri Lampinen was the final speaker at the Opening Ceremony and spoke on behalf of the European Working Group of People with Dementia (EWGPWD). Petri is from Finland and has been a member of the EWGPWD since 2017. Chris Roberts, Chairperson of the EWGPWD translated Petri's words into English.

In his speech, Petri Lampinen pointed out that we all participate in the conference in many roles, but that what unites us all is our desire to advance dementia issues and the many future solutions related to it. In the coming years, times will be challenging, he said, because of the increasing numbers of people with dementia. It is worthwhile, therefore, to conduct active research and to invest in citizens' brain health and make people aware of its importance.

We also need to educate decision-makers about the importance of these issues in society. "We who are diagnosed with dementia, want to make a difference with our loved ones in these matters. Because we can raise the issues, to the best of our ability. We can speak up for our rights. We have already been genuinely listened to and our opinions have also been valued. This has felt very good!"

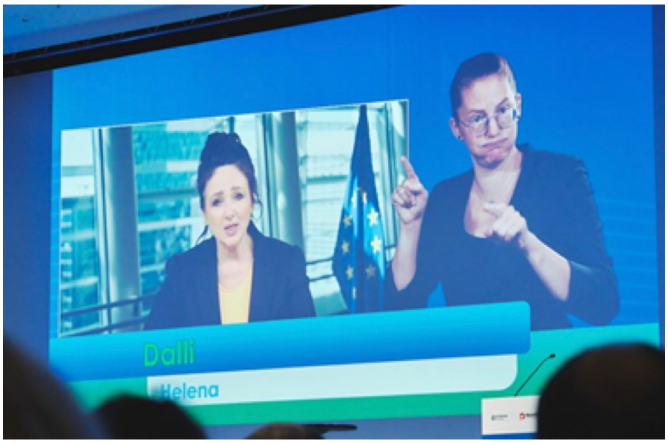
He expressed his gratitude to Alzheimer Europe, its member associations and to dementia organisations the world over, for supporting people living with dementia. "Through them, we get to experience many activities. Without their existence, we wouldn't know where we are going. They pave our way and show us the right direction to go."

He was delighted to share that, together with his colleagues in the EWGPWD, he has been involved in a lot of projects and surveys. "Year after year", he said, "we feel more part of society".

In closing he reminded delegates that together, we can change perceptions of living with dementia and reduce the stigma they cause. He was particularly keen to point out that a dementia diagnosis need not mean the end of life: "My advice is not to give up. It is worth going through the emotions, even the difficult ones."

Welcome words from European Commissioners for Equality and for Health and Food Safety

Alzheimer Europe was delighted to have the support of EU Commissioners Helena Dalli and Stella Kyriakides, who each recorded a welcome video, addressing conference delegates during the Opening Ceremony.



In her address, EU Commissioner for Equality Helena Dalli particularly highlighted the European Commission's Strategy for the rights of persons with disabilities, which aims to ensure full participation of persons with disabilities in society and to prevent any discrimination based on the grounds of disability. She also reminded delegates that in June 2023, the Commission had adopted a Communication on a Comprehensive Approach to Mental Health, an initiative which aims to put mental health on par with physical health and to ensure a new, cross-sectoral approach to mental health issues. You can watch Commissioner Dalli's video, here: https://youtu.be/_bUKC8rvdMnA

EU Commissioner for Health and Food Safety Stella Kyriakides began by thanking Alzheimer Europe and its members, for their dedication in tackling dementia and in supporting people living with dementia, their families and carers. Echoing Helena Dalli, she also highlighted the Commission's Communication on a Comprehensive Approach to Mental Health. Commissioner Kyriakides also mentioned the "Healthier Together" initiative,

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which has one specific strand focused on neurological disorders and emphasises the need to make societies and communities more dementia friendly, and the EU Best Practice Portal which contains some of the best practices on health promotion all of which are publicly available. You can watch Commissioner Kyriakides' video, here: https://youtu.be/_JHiqgcuj7M

Transforming personal experiences into political advocacy and Public Involvement in dementia research

The opening ceremony was followed by the first plenary session of the conference, which showcased the work conducted by the European Working Group of People with Dementia (EWGPWD) in relation to Public Involvement (PI) in dementia research and advocacy. Speakers drew on their personal experiences, both at national and European level.

This session was the first plenary session of its kind, organised, chaired and presented entirely by people living with dementia and Alzheimer Europe was extremely proud to be able to include this special and important plenary in its 2023 conference programme. The work of the EWGPWD and the collective voice of its members are vital to the organisation's work and this long-standing collaboration continues to flourish.

This plenary session was chaired by Chris Roberts (Wales, United Kingdom), Chairperson of the EWGPWD, who presented the group and some of its main achievements over the years. "I'm very honoured to be the current Chairperson of the European Working Group of People with Dementia and am so proud to welcome you to the first Alzheimer Europe Conference plenary session entirely organised and presented by our group", he began.

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012 and the group celebrated its 10-year anniversary last year, he noted. Members of the group work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people living with dementia and as part of this, they do a lot of PI work with researchers across many different projects, sharing their vital insights, as experts by experience.

As well as actively participating in Alzheimer Europe's Annual Conferences, he informed the audience that the group, which is composed entirely of people living with dementia, with different backgrounds, different diagnoses and of various ages, also gives presentations and participates in other events and meetings, both in the members' own countries and internationally.

Members are nominated to the group by their national Alzheimer associations. There are currently 15 members, four of whom are the keynote speakers at this first plenary of the Alzheimer Europe Conference in Helsinki, he said and introduced the first of the four speakers, Kevin Quaid.

Kevin Quaid (Ireland), Vice-Chair of the EWGPWD, focused on his experience of PI in Ireland and the impact of such

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involvement on dementia research and on his personal life. "I am not an expert in too many things, but I am an expert in what it's like to have Lewy Body Dementia. No matter what you are doing in life, you need to listen to the experts and here in the EWGPWD there is a world of expertise on what it's like to live with different types of dementia", he said and insisted that when it comes to PI, the people with the lived experience must be front and centre, in research.

Being an advocate for the past seven years, Kevin Quaid has seen a major change in the way research is done and in how people like him are viewed when it comes to research. Not so long ago, he pointed out that "good PI work meant that a researcher would ask us a question or two and that was considered enough". Involving someone with dementia was nothing more than a 'tick-box' exercise, but he was pleased to say that researchers have now realised how much people with dementia have to offer. He used to think it was "nice" and "kind" for people to involve him and others with dementia in research - "and it is!" he noted - but now he has realised what he brings to the table: Experience, motivation, insight, novel ideas and the willingness to share information.

In conclusion, he implored researchers:

"Invite us into the research space, listen to our insights and we will help you keep your focus on the real-world impact your work can have on someone. It's not to put pressure on you, we are just invested in your work and your research in a different way to you. We have insights that can help. We can help you consider things you maybe hadn't thought of before. And if we don't understand something, we'll let you know. PI improves research and therefore it can improve lives."

Pia Knudsen (Denmark) was up next. She introduced herself and after sharing that she has two children, loved her job as a teacher for many years and is a keen and talented artist she also mentioned, "by the way, I am here today because I was diagnosed with Alzheimer's disease back in 2020."

Something that has been particularly important to her since she was diagnosed is getting involved in a lot of different political, cultural, and informational contexts. As one of the newest members of the EWGPWD, she is delighted to have already been involved in several projects. and believes it is incredibly important to involve people with dementia in everything that has an impact on them.

"It gives me SO much energy and purpose to use my voice and raise awareness", she enthused and highlighted that it was a complete misconception that people with dementia are all living in nursing homes and cannot hold a conversation:

"Here I am, in flesh and blood. I am just a human being struggling with a difficult life situation. Otherwise, I am fully functioning. Almost. After losing my beloved job as a teacher when I was diagnosed, I now have a new job as a spokesperson for people with dementia – but I must emphasise that it has only been possible because of people believing in me and helping me to get involved."

Based on her experience, she noted three important points about involving people with dementia:

- Listen to people with dementia. They are the ones experiencing dementia from within.

- Create the framework and foundation that gives people with dementia the possiblity to get involved. A practical coordinator/facilitator who understands the challenges and is keen on listening is important.

- Take action, move beyond the talking stage. Make the words matter and implement the opinions and experiences shared, so they impact on real lives.

In closing, she said:

"I know that there is a long way to go and that it takes time. We are not even close to making voices of people with dementia matter all over the world. But if we all start to whisper, eventually it will become a loud roar."

The next speaker, Věra Ryšavá (Czech Republic) talked about her experience contributing to the work of the Czech Alzheimer Society to raise awareness and tackle the stigma of dementia in her country, as well as their efforts to ensure that issues of relevance to the lives of people with dementia are taken on board by policymakers. She opened by sharing her personal experience following her diagnosis:

"After my diagnosis, I didn't live, I just survived, crying at night, thinking about the information about Alzheimer's disease that I had known from the press and TV up to that point - unfortunately, it was mostly information about the last stages of the disease. It wasn't until I discovered the Czech Alzheimer Society and then Alzheimer Europe, that I began bounce back. Now I'm kind of internally reconciled with my illness and thanks to a timely diagnosis, I have the opportunity to organise my future."

Through the EWGPWD, she now feels able to understand her diagnosis better, to get answers to her questions but also to contribute, sharing her knowledge and feelings. Through the Czech Alzheimer Society, she also contributes to the National Action Plan for Alzheimer's and Similar Diseases, in the Czech Republic.

She thanked the audience, saying that she greatly respects and appreciates people who are trying to change the current (but in her eyes, still insufficient) situation in care and who provide help for people with dementia so they can live their lives with dignity.

The last speaker was Nigel Hullah (Wales, United Kingdom), who reflected on the relevance of PI for local and national initiatives and how such involvement can give people with dementia a purpose, a sense of belonging and hope. PI, he said, is significant when making decisions that affect a community. It is vital that everyone has their voice heard. An active and well-supported PI approach allows people to engage in meaningful and genuine co-production and allows everyone involved to share responsibility and power in a reciprocal and supportive manner. The outcomes, he stressed, can be hugely empowering for all concerned, helping create a more inclusive and supportive society.

"I always feel better after participating in a PI event because I've been focusing on my sense of worth. It's a complex process, but it's worth it. When I feel good about myself, I'm much more confident and capable of achieving my goals. To be listened to, really listened to, is a transformative experience in a world where the deficit agenda of dementia

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looms large. Dementia can be challenging for anyone to deal with and particularly difficult for individuals who struggle with self-worth. It's essential for people affected by dementia to remember that their dementia does not define their self-worth and that they are still valuable and crucial members of their community."

Addressing the audience and especially the researchers in the room, he said, "please ask us not what you can do for us but how we can work together by engaging with us and recognising us as contributing members of society."

The plenary session ended with a standing ovation for the speakers.

Welcome Reception

To close day one of the conference, a Welcome Reception was held at Helsinki City Hall, hosted by the Mayor of Helsinki.

Day two, 17 October 2023

The second day of the conference had two plenary sessions, one focusing on brain health and prevention and the other on intersectionality in dementia, co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events, as were the fourth and fifth plenary sessions on 18 October.

Brain health and prevention

Professor Miia Kivipelto, University of Eastern Finland and Karolinska Institutet, was the first speaker at this session, discussing "Building the evidence base for multi-modal interventions through European and International collaborations". She said that risk reduction of cognitive impairment and dementia is possible and indeed is already happening. Brain health, she stressed, should be a priority for society. She then urged everyone to ensure that we "fill the implementation gap" and start fully implementing the available evidence.

She reminded the audience:

"It is never too early, never too late. We can and we should offer preventive interventions supporting brain health to people without cognitive symptoms, but also those already experiencing symptoms, to help maintaining brain functions".

With an increasing body of evidence from clinical trials to show that multidomain interventions targeting several risk factors are effective and feasible, the EU-FINGERS and World-Wide FINGERS networks are now working on further developing and adapting these interventions to different target populations and settings.

In closing, she stated that:

"We need to connect and combine prevention, early detection, and interventions, both non-pharmacological and pharmacological. We are moving towards precision

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prevention and combination therapies". She also stressed the importance of global strategies, public engagement, and broad collaborations with all key stakeholders, including academia, industry, advocacy groups, regulatory bodies and citizens.

Nikolaos Scarmeas, Professor of Neurology, National and Kapodistrian University of Athens was next to take the floor, with his presentation "The role of nutrition in the prevention of dementia". He highlighted the associations between healthy dietary patterns and risk reduction for dementia, noting that these have been reported but have not yet been fully confirmed in randomised trials.

Many different aspects of nutrition, including chronobiological aspects (i.e. at which times during the day, or in relation to sleep, or how often we eat certain foods and nutrients, etc.) are still unexplored, he said, also noting that new studies have started utilising precision nutrition approaches in relation to cognitive function. "Chrononutrition and precision nutrition are new avenues of exploration in relation to cognition", he enthused.

The third speaker in this plenary session was Professor Katja Kanninen, A.I. Virtanen Institute for Molecular Sciences, University of Eastern Finland, who spoke about environmental factors and air pollution as risk factors for dementia. She highlighted that there are 12 modifiable risk factors that account for around 40% of worldwide dementias, noting that air pollution had recently been added to the list of modifiable risk factors for dementia.

Epidemiological studies, she said, demonstrate that "life in highly-polluted areas is linked to increased incidence of cognitive impairment and risk of neurodegenerative disease".

The fourth and final speaker in this plenary session on Brain health and prevention was Giovanni Frisoni, Director, Centre de la mémoire, Geneva University Hospital and Professor in Clinical Neurosciences, University of Geneva. His presentation, titled "Dementia prevention in memory clinics: recommendations from the European task force for brain health services", opened with the assertion that dementia prevention is currently done either when it is too early (primary prevention in the general population) or too late (tertiary prevention in those who already have dementia).

A European Task Force, he noted, has summarised available evidence for the much-needed area of secondary prevention, i.e. in persons without dementia but at a higher risk of dementia. Procedures have been drafted for dementia risk assessment, communication and reduction, as well as cognitive enhancement, he said, while emphasising that these would need to be delivered in ad hoc services called "Brain Health Services" for the prevention of dementia.

"Dementia Researchers of the future" - a special symposium highlights the work of ten early stage researchers who won bursaries to attend and present

From 12.00-13.00, a special symposium was held, to present the work of the ten early stage researchers who were selected by our jury in July, to benefit from the bursaries provided by the Alzheimer Europe Foundation to attend and present at the 33rd Alzheimer Europe Conference.

The selection of the ten bursaries was based on the best average scores each received from the jury members. The session, called "Dementia Researchers of the future", was chaired by Iva Holmerová (Czech Republic) and Fania Dassen (Netherlands). The researchers, and their presentations, were:

- Thanos Chatzikostopoulos (Greece): The effects of pomegranate seed oil on mild cognitive impairment

- Carlos Gómez Martínez (Spain): COVID-19 and cognitive impairment in older adults: Longitudinal analysis from the PREDIMED-PLUS Cohort

- Ieva Petkutė (Lithuania): Photovoice practice and carer of people living with dementia involvement for transformative change in Lithuania

- Thais Lorenzo (Spain): Engaging participants in lifestyle interventions to prevent cognitive decline: The role of psychoeducation in the PENSA study

- Aysan Mahmoudi Asl (Spain): Acceptability of the Social Robot Mini and Attitudes of People with Dementia and Mild Cognitive Impairment

- Miren Altuna Azkargorta (Spain): Down Syndrome - Basque Alzheimer Initiative (DS-BAI): Integrative health care plan based on personalized medicine and clinical-biological research cohort

- Rafaela Troulou (Greece): Music-making for older people with and without dementia in residential care facilities: Preliminary findings from a community music intervention

- Naia Ros (Spain): Including the socio-emotional approach in a finger-like multi-domain intervention to prevent cognitive decline. CITA Go-On Study

- Electra Chatzidimitriou (Greece): Premorbid personality traits and their relationship with functional impairment in early-stage behavioural variant frontotemporal dementia

- Marina Makri (Greece): Attitudes, motivations, and barriers to pre-symptomatic Alzheimer's disease screening: a comparison between informal caregivers in five European countries.

This session was organised by the Alzheimer Europe Foundation and the INTERDEM Academy, with thanks to Roche for supporting the meeting space.

Intersectionality in dementia

The third plenary of the conference covered topics related to intersectionality in dementia. A presentation on "Achieving Cultural Inclusivity in Dementia Care" was delivered by Karan Jutlla, Head of Health Research Centre & Dementia Lead for the University of Wolverhampton.

Dr Jutlla discussed ways for improving cultural inclusion to reduce inequalities in dementia and ensure widespread accessibility to care becomes a reality. As evidenced in her latest report, co-production is integral to achieving equitable access to support services for people with dementia and their family members and carers. She also highlighted the importance of co-production and invited the audience to consider how culturally-inclusive care can be achieved, via a person-centred approach:

"In order to achieve cultural inclusivity in dementia care, we must recognise the importance of intersectionality and practice person centred dementia care", she said.

Dr Alain Dekker from Alliade Care Group and University of Groningen/UMCG (Netherlands) was the second speaker to take the stand. He discussed "Dementia in people with intellectual disabilities: introduction to both Down syndrome and severely disabled populations". He began by stating that a diagnosis of dementia in people with intellectual disabilities is important for understanding changes and making informed choices about support, treatment and organisation of care. People with Down syndrome, he noted, are at extremely high genetic risk to develop dementia due to Alzheimer's disease.

In people with severe/profound intellectual disabilities, whom he said are until now a largely neglected group when it concerns dementia, the observability of dementia symptoms is different and diagnosing dementia therefore requires closer observation of small changes, in specific daily contexts. He said this depends on acquired skills at baseline and requires a newly-developed diagnostic aid.

The next speaker was Linn Sandberg, whose presentation was called "Are they here, are they queer? LGBTQ People with Dementia and the limits of person-centred care". Dr Sandberg, Associate Professor Gender Studies, Södertörn University, Sweden, reminded delegates of the importance of challenging heteronormativity in dementia care. Dementia care staff in her current research often stated that they 'treated everyone the same' and that sexual and gender identities were very rarely discussed. But, she said that this results in a continuous invisibility and lack of recognition of lesbian, gay, bisexual, trans and queer (LGBTQ) people living with dementia.

"Having to repeatedly 'come out', to navigate heteronormative care, and to advocate for one's rights puts undue stress on LGBTQ people living with dementia and on their partners", she said, stressing that dementia illnesses, as well as the organisation of dementia care, poses particular challenges for LGBTQ people to communicate their life histories, maintain relationships and connections to communities that have been significant to them:

"Dementia care needs to be organised in ways that enable people to express their gendered and sexual selves, to communicate queer life histories and have their relationships in the past and present recognised", she finished.

The fourth and final speaker was Päivi Topo, Ombudsman for Older People in Finland, who discussed "How to better support people living with dementia from socio-economically disadvantaged groups". The Ombudsman for Older People in Finland is an autonomous and independent authority that promotes the realisation of the rights and best interests of older people.

The Ombudsman highlighted several virtual health promotion activities, including web-based activities that require no digital skills which she said are very important. Digital skills are rarer among older adults in lower socioeconomic groups than other older adults, she said, also sharing that provision of digital tools with no cost and availability of personal support in the use of the digital tools was a priority. Most important, however, from her perspective is that older adults find the activities on offer to be both interesting and beneficial. Group activities are particularly helpful in this respect as they help create social contacts.

Explaining the service model of online exercise for older adults, she noted its development project which took place from 2017-2020 and which was then implemented in pilot programmes with municipalities and NGOs. The study on implementation began in 2019 and ran until 2023, with structural and cultural factors affecting implementation in municipalities.

Two national programmes promoting health and exercise for older adults exist in Finland, with emphasis being put on better access to care of older adults in socially disadvantaged groups, but improvements are needed in several areas, as there is a lack of knowledge about memory disorders and possibilities for treatment, the cost of getting a diagnosis is high and there are difficulties in accessing diagnostic services. Medicines, care and assistance are also expensive and the care system is highly complex, meaning difficulties in access to care. Finally, she noted that there is a lack of information about care services and social security system and how to apply social security benefits.

“People with dementia living alone with no social network are at high risk of not receiving support, services and care they need across all socioeconomic groups”, she concluded.

Black and Minority Ethnic Dementia Service wins Alzheimer Europe’s Anti-Stigma Award

In the evening of 17 October, at a special award ceremony during the Networking Dinner, Touchstone’s BME (Black and Minority Ethnic) Dementia Service was announced as the winner of Alzheimer Europe’s 2023 Anti-Stigma-Award. Touchstone provides health and wellbeing services to thousands of people across Yorkshire, in the United Kingdom.

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Lilly and Roche launched a call for applications in April 2023, with the aim of giving recognition to an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. This year’s call focused on initiatives and campaigns addressing the stigma experienced by people with dementia and their carers from minority ethnic groups, the LGBTQ+ community, people with intellectual disability and/or Down syndrome and from socio-economically disadvantaged groups. Applications were open to individuals and organisations established in a member country of Alzheimer Europe for initiatives and projects which were developed and/or implemented in the past three years (2020-2023).

The first place award, together with a cash prize of EUR 5,000 was presented by Iva Holmerová, the Treasurer of the Alzheimer Europe Foundation.

The second place award, with a cash prize of EUR 3,000, was presented by Helen Rochford-Brennan from the Alzheimer Europe Foundation. It was awarded to Brighton and Hove LGBT Switchboard’s initiative “Rainbow Neighbours”. Switchboard is a charity for LGBTQ people looking for a sense of community, support or information.

The third place, with a cash prize of EUR 1,500, was scooped up by Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for its campaign “Assess your assumptions”. The award was given by Heike von Lützau-Hohlbein, Chairperson of the Alzheimer Europe Foundation.

During the Networking Dinner, held at The Old Student House in Helsinki and moderated by Kim Coppes from Live Online Events, the three finalists were invited to present their initiatives, before the winner and runners-up were announced.

The winning initiative was presented by Ripaljeet Kaur from Touchstone for its project BME Dementia Service. BME Dementia Service provides specialist support to people living with memory problems or a diagnosis of dementia and their carers/family members from Black and Minority Ethnic communities predominantly South Asian community living in and around Leeds.

Accepting the 1st place Anti-Stigma Award, Riplajeet Kaur said:

“I am deeply humbled to be selected for the Anti-Stigma Award 2023. I share this award with a dedicated team and the courageous individuals who have shared their dementia journey stories.

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Let this award be a symbol of hope, encouraging others from diverse communities to speak up and seek help so they too may be able to live well with dementia without the multi layers of stigma attached.

Thank you to everyone who has contributed to and networked with our service. Let's continue this journey towards a more inclusive and empathetic world.

Our work continues, but today, we celebrate progress. Thank you for this incredible recognition.

We feel seen, we feel heard."

"Rainbow Neighbours", the initiative winning second prize was presented by John Hammond from Brighton and Hove LGBT Switchboard, which takes a creative approach to addressing the stigma, loneliness and isolation that can be experienced by LGBTQ+ people living with dementia, particularly those who are living in residential care settings. Rainbow Neighbours provides transport for LGBTQ+ people living with dementia at residential care settings to join Switchboard's fun and engaging peer support activities and broader wellbeing events. The project also gives those living at residential care settings access to ongoing multi-generational support from other LGBTQ+ people - a "Rainbow Neighbour".

Accepting the Award for second place, John Hammond said:

"Brighton and Hove LGBT Switchboard's dementia support service tackles the stigmas and stereotypes that LGBTQ+ people living with or affected by dementia experience. We are delighted to have this work recognised by Alzheimer Europe and we share the organisation's passion for changing perceptions of dementia and prioritising inclusive dementia care for all."

Third place was awarded to Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for "Assess your assumptions". The campaign was presented by Gili Yaron. Studies by the Hogeschool Windesheim research group "Living Well with Dementia" found that health and social care professionals hold stereotypical beliefs about people with dementia especially those from minority ethnic communities. Addressing these beliefs is vital to ensure this group receives good care and support. Based on input from professionals and informal carers, the Hogeschool developed a pocket-sized card deck featuring 16 common misconceptions about culturally sensitive dementia care, to be used as conversation starters or 'serious games' (e.g. stereotype bingo) in practice and education.

Accepting the third place prize, Gili Yaron said:

"We're so proud to win this award, which helps us further our goal of enabling people with dementia to live well—regardless of their background. We know that professionals are eager to provide culturally sensitive dementia care and support. By raising awareness about inclusivity, our card deck helps them do so!"

More information about the Anti-Stigma Award can be found at: https://www.alzheimer-europe.org/our-work/anti-stigma-award

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe anti-stigma award: Alzheimer Europe Foundation, Lilly and Roche.

Day three, 18 October 2023

The third and final day of the conference had two plenary sessions, one on "New opportunities" and a policy round table on "Dementia as a European public health and policy priority".

New opportunities

Plenary four opened the conference programme on this final day, and comprised four presentations revolving around the theme "New opportunities".

Nicolas Villain, Associate Professor of Neurology at Sorbonne University, Paris, France and at the Institute of Memory and Alzheimer's Disease, Department of Neurology, Pitié-Salpêtrière Hospital, Assistance Publique – Hôpitaux de Paris, opened the plenary with a presentation looking at "How to evaluate the efficacy and safety of anti-amyloid treatments as a researcher, a clinician or patient". Anti-amyloid therapies have shown efficacy in the early stages of Alzheimer's disease. However, serious side effects are a potential concern that cannot be overlooked, he stressed, also noting that the complexity of their implementation in the healthcare system can affect their accessibility as a treatment option.

Dr Villain stated that, when assessing drug efficacy, "it is essential to consider the perspectives of various stakeholders". This is because while minimal benefits may be meaningful for some individuals, a quantitative evaluation of drug efficacy that takes into account the complete disease course is necessary "to provide a global perspective and balance the risks". He also stressed the importance, in the future, of clinical trials aiming to better capture the potential efficacy and risks according to the overall disease course. Additionally, he emphasised that such trials should take into account the complexity of implementing the treatment within the healthcare system, to help ensure it can be an accessible treatment option.

Summing up, he said:

"Anti-amyloid therapies hold promise for Alzheimer's treatment, but they are not a cure-all. A fair and quantitative evaluation of their risks and benefits, not just statistical significance, is crucial to assess their value."

Ukrika Granér, Silvia Nurse, MSc Specialist Nursing – Elderly Care and Cognitive Impairment Care, Stiftelsen Silviahemmet, shared her presentation with the audience next, focusing on "Vision zero: A Swedish model for dementia care without restraint". Despite current legislation and declaration of human rights, restraint in dementia care is still common, she said, which both violates self-determination and causes reduced quality of life for people living with dementia:

"Reflection on the use of restraint in dementia care and working with person-centred methods are basic prerequisites for safeguarding the human rights of people living with dementia", she commented.

Her presentation demonstrated that working with a person-centred approach, to prevent the use of restraint, is possible, as long as the care team in question has the knowledge, structured tools and clear leadership that is absolutely vital for success. She particularly emphasised the importance of strong leadership in this area.

The third speaker up to the podium was neurologist Eino Solje, Adjunct Professor and research director at the University of Eastern Finland and at the Brain Research Unit and Kuopio University Hospital Neuro Center. He made the point that accurate diagnosis of both dementia with lewy bodies (DLB) and frontotemporal dementia (FTD) is essential, to ensure the correct disease management is attributed to the right patient, stressing the important differences that exist in the management of common neurodegenerative diseases. "The role of the correct diagnosis will become even more pronounced in the future, when disease modifying, biology-specific medications become available", he finished.

Professor Martin Orrell, Director of the Institute of Mental

Health at the University of Nottingham United Kingdom, was the fourth and final speaker in Plenary 4. His talk revolved around ways to improve the lives of people with dementia through the use of technology. Technology can help people living with dementia to maintain their independence and autonomy, he noted, but said that it was not always clear what technology was needed or what works well. This is due to a poor understanding of how people with dementia use technology in everyday life, he said, and new applications are designed without an in-depth appreciation of people's needs, preferences, and difficulties.

In closing, he highlighted that international consensus good practice guidelines could enable researchers and developers to design better technology to help improve lives for people with dementia: "Designing better technology based on the needs and preferences of people with dementia can help them feel more confident managing at home and maintain their independence for longer".

Dementia as a European public health and policy priority

The fifth and final plenary session at the conference, took the form of a roundtable discussion. To open the session, Dr Natasha Azzopardi Muscat, Director of the Division of Country Health Polices and Systems at the WHO Regional Office for Europe, addressed delegates on behalf of Hans Kluge, WHO Regional Director for Europe, in a video message. She welcomed everyone to the policy round table on "Dementia as a European public health and policy priority" and noted the growing numbers of people with dementia in the European region, with approximately 10 million people in European region and numbers set to almost double by 2050, to around 18 million.

The WHO is working with partners around world, implementing the Global action plan on the public health response to dementia 2017-2025 and has a number of tools and resources to support countries in achieving the 2025 targets therein. But, Dr Azzopardi Muscat noted, "we are in danger of falling short of the targets if we don't step up our work together and push for change across some key areas". She mentioned five key areas in which more needs to be done:

1. Ensuring that all countries have dementia policies with plans, with appropriate resources and investment, so that they reach the people who need them most.

1. We need to set up strong health and long-term care systems to provide universal access to diagnosis, treatment and care.

1. Expanding age-friendly environments to be dementia inclusive, will be key to make sure that people can connect with the communities and thrive.

1. We need to improve countries' capacity to maintain health information systems.

1. Finally and crucially, we really need to increase investment in dementia prevention.

Despite these areas of improvement, she noted and celebrated recent scientific breakthroughs and commented that technological advances also provide some promising avenues to improve the health and wellbeing of individuals with dementia and their caregivers through early detection, personalised treatment plans, medication reminders, safety monitoring, remote person monitoring and online peer support forums.

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In closing, she reminded delegates:

"We have a collective responsibility to build a society that is inclusive for all, including people living with dementia and their families. As we redouble our efforts to realise the goals set forth in the Global Action Plan on Dementia by 2025, let us draw inspiration from the Finnish concept of 'sisu' or tenacity."

You can watch the video, here: https://youtu.be/ZiOldzo90YA

Roundtable panellists were: Andy Heffernan, Chief Executive, The Alzheimer Society of Ireland; Taru Koivisto, Deputy Director General, Department for Communities and Functional Capacity, Ministry of Social Affairs and Health, Finland; Sonata Mačiulskytė, Chairperson of the European Dementia Carers Working Group (EDCWG) and Board member of Dementia Lithuania; Anne Remes, Vice-Rector and Professor of Neurology at the University of Helsinki, Finland; Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD) and Elina Suzuki, Health Policy Analyst, Organisation for Economic Co-operation and Development (OECD).

Participating in the discussions, Andy Heffernan noted that Ireland is approaching 10 years since the inception of its National Dementia Strategy, with philanthropy being very much the catalyst initially. The strategy included 35 actions and a review on its 10th anniversary in 2024 is timely, he said. He also highlighted that significant Government funding and supports in recent years have been supported by the Department of Health, The Health Service Executive and a very interested and committed Minister. The launch of the Model of Care for Dementia in Ireland, in June of this year, has the potential to be a 'game changer', as it sets out a range of targets and advice on assessment, diagnosis (and communication of diagnosis), treatment, care and supports. Finally, he noted that the Assisted Decision Making capacity Act commenced in April 2023, having being legislated for as far as back as 2015. It moves away from a 'best interest' approach towards that of graduated supports.

Taru Koivisto emphasised that "good brain health should be promoted in all stages of life - prevention of memory disorders can be improved. We need an active and visible debate on the memory disorders, with the voice of older people at the centre. A whole-of-society approach is necessary, as the population's ageing will affect all sectors of society."

Sonata Mačiulskytė stated that people often tend to shift the responsibility for delayed or misdiagnosis of dementia on to the professionals and to blame shortcomings of diagnostic practices, while less consideration is given to the lack of brain health awareness among the general public, which continues to allow stigma to thrive. "The level of dementia awareness varies between countries with and without national dementia plans, but it is still insufficient everywhere", she said. Regarding the situation in timely dementia diagnosis, she pointed out the inequalities in health services access across and within countries, saying "we are used to focus on the development of diagnostic infrastructure, leaving the gatekeeper – primary health – behind our field of vision. We should maintain an equal focus on the preparation of GPs and their teams to play a leading role in timely diagnosis." She also stressed that European governments shift the burden of ageing and long-term care onto the community and onto families, but don't think about the long-term economic consequences for the labour market and the impact on the national GDP. Real support, she said, tends to come from the NGO sector, but it is not sufficiently developed and supported by the state in all countries.

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Anne Remes felt that memory disorders should be included in national health-related strategies, either as separate programmes (memory programmes) or integrated into broader public health promotion efforts. However, she said, "mere strategic discourse is not sufficient; practical measures and adequate financial resources are needed." More investment is also needed in research and in "actions are required to make the field of memory disorders and dementia attractive to researchers, clinicians, and healthcare personnel", she commented.

Panellist, Chris Roberts commented that, from his perspective, "everything is changing but nothing is changing regarding dementia; We need to do more!". With one in three people affected by dementia, he pointed out that nobody is safe and that we need to work together to solve this. On the topic of making dementia a public health priority, he stated "dementia 'IS' a European public health and policy priority!" and reminded those present that "we have a right to quality care and services, don't leave us behind!"

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