Deirdre Clune MEP hosts first in-person Alzheimer Europe lunch debate for two years

Pierre Meulien reflects on his leading public private research in Europe

Iva Holmerová reflects on her time as Chairperson of Alzheimer Europe

Sirpa Pietikäinen MEP and Milan Brglez MEP make progress on European care policy
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**Welcome**

It is with great pleasure that I introduce the 40th edition of our Dementia in Europe magazine, filled with interesting updates on European and national policy developments in the dementia field, as well as European research projects and other research news. We also include interviews with people at the forefront of care, research, policy and advocacy, and articles about some of the issues currently faced by people living with dementia in Europe.

The first section looks at some of the key work our organisation has been involved in. The opening article recounts the European Parliament lunch debate held in June 2022, with delegates able to attend in person for the first time since the start of the pandemic. This hybrid session in our series of debates looked at neurological conditions and mental health in EU and WHO Europe programmes, and was hosted by Deirdre Clune MEP (Ireland). Many thanks to Ms Clune and her colleagues who were able to participate.

After many wonderful years working with Alzheimer Europe, I have decided to step down from my position as Chairperson. The second article in this magazine is an interview in which I discuss my time in the role. It will be sad for me to say goodbye to everyone, but I wish you all the very best in the years to come and look forward to hearing about all the great work being done. I will miss Alzheimer Europe enormously, but I am sure we will meet again, as I am not leaving the community and will continue to be a member of the Czech Alzheimer Society.

In recent decades, a lot of research has been dedicated to gaining a better understanding of brain health and about how to reduce the risk of dementia. Up next, we look at two examples of EU-funded projects working in this area. We also speak to the leaders of another EU-funded project in which Alzheimer Europe is partner, AMYPAD, as it draws to a close.

A recent session of our popular Alzheimer’s Association Academy series, which focused on dementia as a disability, is the topic of our next article and the final article in this section looks at another important European initiative in which we are involved: Data Saves Lives, led by the European Patients’ Forum, which aims to inform people about the benefits of responsible health data sharing and to improve health data literacy among patient communities.

In the Policy Watch section, we hear first about plans for a European Care Strategy, which have recently taken an important step forward. In June, the European Parliament passed a report setting out its priorities for this strategy. Co-rapporteurs, Sirpa Pietikäinen MEP and Milan Brglez MEP tell us more.

The topic of our next article is the “Healthier Together” non-communicable diseases initiative launched by the European Commission, aiming to address the challenges posed by the rising numbers of people living with non-communicable diseases in the EU, including neurological conditions.

Pierre Meulien, outgoing Director of the Innovative Health Initiative, then reflects on how research partnerships have transformed neurodegenerative research and the future of research in the field. It has been a pleasure to work with Mr Meulien over the years and Alzheimer Europe wishes him all the best.

The European Group of Governmental Experts on Dementia, convened by Alzheimer Europe, held a meeting in June, which is the subject of our next article. At the meeting, a range of dementia policy developments were discussed, including how Ukrainians with dementia are being affected by the war, a German paper on the neurological implications of COVID-19 and some updates from the World Health Organization (WHO).

Following this, we look at France’s recent ban on driving with dementia, which was met with an outcry. France Alzheimer tells us more, and members of the European Working Group of People with Dementia (EWGPWD) share their views.

We also take a look at the phenomenon of “dementia dogs”. Dogs can be a great companion and can also be tremendously helpful to people with disabilities, including people with dementia. Alzheimer Bulgaria and Alzheimer Scotland share two such initiatives from their countries.

Our three remaining articles focus on aspects of research. One highlights the impact COVID-19 has had on people living with, and caring for someone with dementia. Another stresses that it has now been 20 years with no new Alzheimer’s medications in Europe while the third examines the role of nutrition in dementia.

If you are reading this at our Bucharest conference, I wish you an excellent and informative time here. I will truly miss my formal role in this wonderful European dementia community and wish you all the very best.
Alzheimer Europe hosts lunch debate examining “Neurological conditions and mental health in EU and WHO Europe programmes”

For the first time since February 2020, Alzheimer Europe welcomed attendees to an in-person lunch debate in Brussels (Belgium) on 14 June 2022. During the session, stakeholders heard about the latest developments in European and international health and research programmes related to mental health and neurological conditions.

The Alzheimer Europe lunch debate was attended by around 70 people, including national member organisations, civil society representatives, industry partners and policy makers and was hosted by Deidre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer’s Alliance (EAA).

Ms Clune opened the session, welcoming people to the meeting, highlighting its timeliness in light of key programmes at an EU level, across the fields of health and research, as well as activities of the World Health Organization (WHO) and WHO Europe.

Ms Clune noted that these developments have the potential to fundamentally change our understanding of, and approach to, neurological conditions.

EAA member, Tilly Metz, MEP (Luxembourg), spoke about the work of the European Parliament’s Health Committee, including its call for a European Action Plan on Mental Health. In addition, she spoke of the importance of Brain Health across the life course, especially in the domain of prevention.

The first presentation was delivered remotely by Ledia Lazeri, Regional Advisor, WHO Europe, who provided an overview of the work underway on the European Framework for Action on Mental Health (EFAMH) 2021-2025, across its three areas: universal health coverage, protection against health emergencies and mental health across the life course. Explaining the multi-stakeholder approach taken in the programme, she also introduced the Pan-European Mental Health Coalition, which operationalises the EFAMH through six work packages, and involves a broad range of stakeholders, including non-governmental organisations (NGOs), Member States, people with lived experience and others. Of specific relevance for the subject of dementia, work package three “Mental Health and Wellbeing of Older Adults”, will examine issues including the implementation of the WHO Global Action Plan on Dementia.

Attendees then heard from Marianne Takki, Team Leader, European Commission, who remotely introduced the EU’s forthcoming “Healthier Together” initiative, which will focus on five Non-Communicable Diseases (NCDs) areas: cardiovascular disease, diabetes, respiratory diseases, mental health and neurological conditions and health determinants. The scope of action will cover aspects such as: knowledge and data, promotion and prevention, screening and early detection, diagnosis and treatment, and quality of life. It was also noted that the European Commission had run an open call to collect good practice examples and
would be working with Member States to implement these, based on the priorities and interest expressed by the Member States. Example of priority areas included: ensuring high quality care, awareness raising and promoting mental wellbeing. The initiative will launch on 22 June 2022. More can be read on the Healthier Together initiative in this edition of the magazine on pages 23 & 24.

Catherine Berens, Deputy Head of Unit, European Commission, focused on the place of brain research at a European level and the actions of the European Commission in supporting this work. She explained that within the Horizon Europe programme, Pillar One would address the need for more basic research and improved research infrastructures, whilst Pillar Two has a dedicated health cluster, which will support improved collaboration.

Pillar Three will boost innovation, improving technologies and systems, such as data infrastructures. Finally, a potential future Brain Health partnership was explored, which aims to bring together brain research initiatives under a single umbrella – this is expected to launch in 2025. Related to this subject, an interview with outgoing Innovative Health Initiative (IHI) Executive Director, Pierre Meulien, can be read on pages 25 & 26.

Joke Jaarsma, President of the European Federation of Neurology (EFNA), introduced the patient perspective on brain health, highlighting the importance of involving patients in the process of developing brain health policies. She highlighted the challenges and barriers which currently exist, noting that patient participation or engagement often limits the ability of patients to set the agenda for programmes related to brain health, only involving them at later stages or as research participants. As such, a Call to Action was drafted by Alzheimer Europe, the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe. The call demands that national and EU governing bodies develop and implement policies to ensure early and meaningful engagement to support involvement of patients across all sectors, including research, public health etc. Crucially, this should include well-defined, transparent processes that are systematically embedded and ingrained in workstreams.

Alzheimer Europe Chairperson, Iva Holmerová, closed the session by thanking the speakers for their contributions to the lunch debate, noting that attendees would have learned much from the presentations on the day.

The videos of the presentations from the lunch debate can be found at: https://www.youtube.com/playlist?list=PLO-PgQHlIWOQ8YtSlogzhi0_AJYTXGWM9
Snapshots from the lunch debate
Alzheimer Europe Chairperson Iva Holmerová steps down

Our Chairperson of six years, Iva Holmerová, has decided to step down from her position and to leave the Board of Alzheimer Europe. In this interview, she tells us about her time with Alzheimer Europe.

How did you first come into contact with Alzheimer Europe?

Well, that’s an invitation for a little excursion into history. That first meeting was actually at the very beginning of Alzheimer Europe, and also of the Czech Alzheimer Society, which was starting its activities at that time. It was introducing a telephone line, self-help groups, putting together information for family members and preparing it in printed form, etc. and we had a very difficult task right away to make the then-new drugs, cognitives, available to people with Alzheimer’s. That’s when we actually started to communicate and collaborate with Alzheimer Europe. We used the available information materials. Jean Georges and Jeannot Krecké came to Prague for an important negotiation on the reimbursement of the drugs, which we managed to push through quite swiftly. And we continued to meet on various occasions. I was honoured to be invited and subsequently elected to the Alzheimer Europe Board. After Martina Mátlová took over the executive function in the Czech Alzheimer Society, I was able to devote myself more to the work of Alzheimer Europe, and for a long time I was Vice-Chairperson, and then I was really honoured to be elected as Chairperson of the organisation. This role was important, relevant, useful and I liked it very much.

You have been Chairperson of Alzheimer Europe since 2016. What were your reasons for taking the position and why have you decided to step down now?

Yes, at the Alzheimer Europe conference in Copenhagen I was elected as Chairperson. I am very proud to have been able to actually build on and continue, for three two-year terms, the work of my predecessors Maurice O’Connell and Heike von Lützau-Hohlbein. I knew that Alzheimer Europe was a professionally run organisation because I had really followed Jean Georges’ initiative and work from the very beginning of our organisations and worked with him, and gradually also with Dianne Gove and other colleagues, members of the Alzheimer Europe staff. I find their work extremely effective, with a great level of commitment to the Alzheimer’s movement. This background has been reassuring (which has been reinforced over the years) that Alzheimer Europe will continue to be well managed and led. I also greatly value the cooperation with the other members of the Alzheimer Europe Board and I must confess that I have always looked forward to and enjoyed our meetings. But this will of course continue even if I am not a Board member or Office-Bearer.

I have also been delighted to work with other Alzheimer societies, their members and leadership, their professional staff. I almost don’t know how to express it, but for me it
has been and I believe will continue to be a privilege and joy to meet wise people who listen to each other and who respect each other, whose values are close to mine. In that context, I must also mention the European Working Group of People with Dementia (EWGPWD) and their representatives on our Board, both Helga Rohra under Heike’s chairpersonship and Helen Rochford-Brennan and Chris Roberts, who under my chairpersonship were members of the Alzheimer Europe Board representing the EWGPWD.

Their perspective on certain issues and problems has always been a tremendous asset. It lent a different angle on the issues that was noticeably absent in other societies (and here I can speak particularly of purely medical or scientific ones). It is this diversity and inclusiveness, in the best sense of the word, that for me is what I love about Alzheimer Europe.

And now, to the reason for my departure. I think that’s an easy answer. I have spent a wonderful quarter of a century working with Alzheimer Europe (which I hope will continue) and I have been on the Board for many years, as Vice-Chairperson and for three terms as Chairperson. So, in my view, that time has come to fruition, making way for others who are great, have great ideas and are wise. I wish them well and will enjoy the continued success of Alzheimer Europe.

Can you share some highlights from your six years as Chair? What do you think have been the biggest achievements of Alzheimer Europe during that period?

I think that there was a lot that was achieved by our predecessors, the management, the team, the Board and Alzheimer Europe as a whole. Here are some examples:

- Alzheimer Europe’s participation in major European projects. I consider this to be another very significant achievement, particularly in recent years. Becoming a trusted partner in dementia research projects alongside the academic and industry partners.
- Creating a truly inclusive European Alzheimer’s community/family and supporting less developed associations through the Alzheimer’s Association Academy.
- Responding to the COVID pandemic and supporting national associations by creating an inventory of resources and highlighting the problem of triage impacting people with dementia in intensive care at the outset of the pandemic.
- Setting up the European Dementia Ethics Network and publishing much respected publications on ethical issues in dementia care and research.
- Turning the Alzheimer Europe Conferences into unique networking opportunities bringing together people with dementia, carers and Alzheimer’s association on the one side and academics, researchers, policy makers and industry representatives on the other.
- The Alzheimer Europe Foundation has been established, which not only provides a certain guarantee of funding stability and the possibility to bridge some of the more difficult periods, but also provides a backdrop for other activities that the Foundation supports.
- Stable funding, initially from the EU Health and now from the Disability programme, is, I think, another important prerequisite for sustainability and for developing further activities.
- I am also extremely appreciative of the work of the INTERDEM scientific initiative, its founder Esme Moniz-Cook, long-time successor and leader Myrra Vernooij Dassen, who has recently handed over the (imaginary) sceptre to her successor Marjolein de Vugt. But I should also mention others, especially Rabih Chattat, who has been the main organiser of seminars, workshops, and the INTERDEM sections of our conferences. I am very much looking forward to the INTERDEM committee meeting that Rabih is organising in Bologna soon. And I should also note Martin Orrell and Frans Verhey, leaders of the European INDUCt and DISTINCT projects, in which Alzheimer Europe is involved, and many others, whom I would also like to thank for their wonderful cooperation and support.

What are your hopes for the future of Alzheimer Europe and what do see as the future priorities of the organisation?

I wish Alzheimer Europe all the best for the future. I think it has all the prerequisites I have already mentioned. An active membership organisation, a hard-working and enthusiastic team, wise and supportive Board members who all work together to make life better for people with dementia and their loved ones in Europe (and not only in Europe), to bring us closer to the time when we will have effective cures, to make the world more welcoming and inclusive for people with dementia.

I am very pleased that other interesting initiatives are being taken at the end of my mandate, such as the Anti-Stigma Award and the European Carers’ Working Group, which will soon be set up and which will also be represented on the Alzheimer Europe Board.

Do you have a few words of wisdom for your successor?

No, I wouldn’t want to do that. I hope that the next Chairperson will be one of my colleagues who already has experience of working on the Alzheimer Europe Board.

So far, that has always been the case, and I think it has been useful. In that case, I would really not presume to impart any wisdom to my successor, because I know that each of them is a wise and kind person who has experience that can be put to excellent use for the benefit of Alzheimer Europe. However, if it were someone without that experience, I would probably advise them to support and trust the management and the whole Alzheimer Europe team, which is truly our treasure.

They are extremely dedicated and knowledgeable people and I think we should continue to cherish them. I would really like to express my thanks to them, as well as to the Board and all my other colleagues.
Brain health: Motivating people to reduce risks for cognitive decline

In recent decades, a lot of research has been dedicated to gaining a better understanding of brain health and how to promote it, as well as what can be done to reduce the risk of developing dementia. In this article, we discuss EU-FINGERS and LETHE, two examples of EU-funded projects working in this important area and in which Alzheimer Europe is a partner.

It is estimated that approximately 8 million people are living with dementia in Europe. Dementia is the leading cause of disability and dependency among older people and one of the most feared age-related conditions. Over the last decade, a large amount of research has been dedicated to better understand how brain health can be promoted and what can be done to reduce the risk of developing dementia.

We now understand a lot more about risk and protective factors (including modifiable and non-modifiable factors), what impacts our brain health and the potential prevention of cognitive decline and dementia. We have good evidence, for example, of how factors people are exposed in early life (education), midlife (hypertension, obesity, hearing loss, traumatic brain injury, and alcohol misuse) and later life (smoking, depression, physical inactivity, social isolation, diabetes, and air pollution) can all contribute to increased dementia risk.

There is also a lot of research looking at how people can manage and reduce such risk. Some interventions, such as the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), have suggested that it is possible to reduce the risk to develop dementia. FINGER is a multidomain intervention which encourages and supports changes in lifestyle factors which are known to increase the risk to develop dementia (e.g. nutrition, exercise, cognitive training, social activity and management of vascular risk factors). The FINGER approach also showed that the benefits of the multidomain intervention go beyond cognition, for instance by reducing the risk to develop cardiovascular disease, functional decline, and also by improving quality of life.

These are very promising and positive messages. However, they also involve several challenges. For example, risk is a complex concept which can be very difficult for a person to fully comprehend. Being at risk or at higher risk of a disease does not mean that the person will certainly develop the disease or, perhaps, not in his/her lifetime. The interventions to manage risk, can be demanding and it is important, for example, that the person implements and continues with these changes during and after the intervention has finished.

EU-funded research in the area of brain health

EU-FINGERS and LETHE are two examples of European-funded projects working in this important area.

The EU-FINGERS project kicked off in 2020. The project is supported by the EU Joint Programme – Neurodegenerative Disease Research (JPND). The aim of the project is to develop tools and methods for researchers working in the area of brain health and prevention of Alzheimer’s dementia in Europe. Examples include methods to accurately measure the level of risk as well as the prevention potential of older adults. This will help to identify individuals with different risk profiles who are more likely to benefit from specific preventative interventions.

The LETHE project has received funding from the European Union’s Horizon 2020 Research and Innovation Programme. It started in 2021 and addresses the topics of prevention and technology. The project includes both technical and clinical partners, and will help to understand how artificial intelligence (AI) and technology could be used in multidomain interventions (such as FINGER) to prevent cognitive decline and dementia.

What are Advisory Boards and why are they important for research?

Alzheimer Europe is a partner in both projects and is supporting the communication and Public Involvement activities. Alzheimer
Europe has set up two Advisory Boards for these projects which are working closely with the researchers and also have some joint activities. The Advisory Boards are composed of members of the public, including older adults with an interest in brain health, people who have participated in prevention studies, people who are at a higher risk of dementia, people with dementia and informal carers. Members of these Advisory Boards have provided feedback and recommendations to several of the activities conducted by the projects. This helps to ensure that the voices of different people (affected or with an interest in this topic) are heard and taken into account. It can also help to better address some of the challenges linked to this new area of work.

The EU-FINGERS Advisory Board has 15 members from 7 European countries. They regularly meet online and have been involved in discussions around the need of this type of work, terminology used, but also a protocol for prevention interventions as well as online registries.

The LETHE Advisory Board has 7 members from 4 European countries. The methodology for working with this Advisory Board combines online meetings as well as individual feedback in writing. Examples of issues addressed so far include the use of technology by older adults, the protocol of the LETHE study, ethical and social implications of the project etc.

A few words from Dr Francesca Mangialasche, Geriatrician and Assistant Professor in Clinical Geriatric Epidemiology at the Center for Alzheimer Research, Karolinska Institute, Stockholm, Sweden.

How important is brain health for older adults?

Preserving good brain health while aging is crucial to most people, as it has a key role in determining individuals’, capabilities and wellbeing.

People wish to maintain their ability to make decisions, cope with their needs, build and maintain relationships, and contribute to society. All of this is largely affected by brain health, which thus becomes a priority.

What we can do, as clinicians and researchers, is to facilitate people awareness and understanding, possibly already at younger age, of factors affecting brain health, focusing on those that can be leveraged on to support brain health across the whole life.

What advice would you give someone who is interested in or worried about their brain health?

I would say that it is never too early and never too late to do something about it. Several factors related to lifestyle, such as engagement in physical activity, cognitive stimulating activities and staying socially engaged, can help across the whole life to boost brain health. The sooner we start the better it is, but benefits are evident even when people engage in these activities later in life. Other key factors we can control include a healthy diet, proper management of vascular conditions and hearing impairment. And the list is getting longer, as research advances and identifies new factors. For instance, quality of sleep and emotional health (e.g., feeling of loneliness, stress) are emerging as factors which can affect brain health, and have been impacted by the COVID-19 pandemic.

Several studies are ongoing globally to test interventions aiming to ameliorate the risk profile of people, and thus improve brain health. EU-FINGERS is a main chapter of the global World-Wide-FINGERS network (wwfingers.com) on multidomain trials for dementia risk reduction. We know that each person is unique, hence we work towards precision
A few words from Advisory Board members

Nick, member of the EU-FINGERS Advisory Board

“I am Nick Montague, 67 years old and I am living in Luxembourg. I have direct family experience of dementia and I am very interested by the topic of brain health.

The use of the words “Brain Health” is important as it does not carry any stigma with the use of those words and it’s not threatening in any way. I think in lots of cases with neurological issues, the terms “brain problems”, “Alzheimer’s disease”, “dementia” can be a bit threatening for a lot of people. A position on the Advisory Board is very important to me and I am learning a lot. I think the most important issue to realise is that, it is not just an intellectual exercise for researchers or for people with the disease. I feel by tuning in to the people who have first-hand experience of mental health issues, that it is by putting everybody’s contributions together that creates a solution.”

Mercedes, member of the EU-FINGERS Advisory Board

“I am Mercedes Fernández, 70 years old, living in Barcelona, Spain. I am experiencing some failures in memory and other cognitive functions and this justifies my interest in the brain health topic. Brain health is key for individual and social well-being. Research in this field is hard and the professionals who choose it need and deserve all our support. As a part of the society, it is my duty to respond to questions or requirements that researchers, scientists, can make to us. Researchers are the base of all this work. Thank you for what you are doing and thank you for continuing investigating because our future and well-being depends on you.”

Jouko, member of the LETHE Advisory Board

“My name is Jouko Riihinen. I am 67 years old and retired four years ago from working full time. I live mainly in Helsinki but spend also quite a lot of time at our summer cottage on the West Coast of Finland. I am interested in brain health because I would like to have as many active years as possible with my grandchildren, travelling and enjoying life. With my father, I could see how much dementia changed his and also my mother’s life, during his final years. With that experience, I would like to do my best to avoid developing dementia in my later years.

When I got the opportunity to be a member of the LETHE Advisory Board, I didn’t have to think twice. I hope that, as a member, I can contribute something useful to the study, which I think is very important for so many people. I have already noticed that the advice we have got during these first months has given me a lot of motivation: it really is possible to reduce the risk of cognitive decline and you can already do a lot just by changing your diet and by being physically and mentally active. I’m convinced that the use of suitable technology could support people in making these changes in everyday life. I’m looking forward to testing some of these new technologies, which could help to improve brain health – both my own and that of others!”

Acknowledgement

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AMYPAD – A European collaboration with a global impact to advance research in Alzheimer’s disease

As the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project draws to a close, Alzheimer Europe looks back at the project and speaks to its co-leads, Frederik Barkhof and Gill Farrar, about their reflections.

The scientific landscape

β-amyloid deposition in the brain is one of the core neuropathological hallmarks of Alzheimer’s disease (AD). It can be assessed in vivo using positron emission tomography (PET) imaging. It is already recognised that β-amyloid PET can improve early diagnosis and today amyloid PET imaging is more frequently used in a clinical setting.

However, reimbursement of the technique is lagging despite mounting evidence on the impact on patient management and diagnosis as there are still gaps in evidence supporting its clinical utility in the routine clinical setting and cost-effectiveness in the diagnostic workup.

An innovative and ambitious project

The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) consortium is a collaborative research initiative aiming to improve the understanding, diagnosis and management of AD through the utilisation of β-amyloid PET imaging.

To this end, two trials were set up: the Diagnostic and Patient Management study (DPMS) including a memory clinic population and the Prognostic and Natural History Study (PNHS), which focused on a pre-dementia and mainly pre-clinical population. AMYPAD was funded by the Innovative Medicines Institute (now known as the Innovative Health Initiative) in conjunction with 15 partner organisations for a period of 6 years, until 30 September 2022.

The AMYPAD Diagnostic and Patient Management study (DPMS)

In this clinical study, participants with cognitive decline where AD was a possible underlying cause were included to determine the usefulness of β-amyloid imaging as a diagnostic marker to determine aetiology of the cognitive problems and to assess the cost-effectiveness of amyloid PET in Europe.

The study recruitment was finalised in October 2020 and a total of 840 participants with variable cognitive stages (244 with subjective cognitive decline plus [SCD+], 341 with mild cognitive impairment [MCI], and 255 with dementia) were enrolled from 8 memory clinics, resulting in the largest European study implementing amyloid PET in clinical practice.

The AMYPAD Prognostic and Natural History Study (PNHS)

The study is an open-label, prospective and multi-centre cohort study aiming to investigate the added value of the amyloid PET imaging technique in assessing a participant’s risk to develop cognitive decline due to AD.

The study has been established to collect amyloid PET scans in a large-scale population in the early stages of AD. The recruitment was ended in June 2022 and the study succeeded in recruiting 1,321 participants. To date, 17 centres have contributed to the study across 11 Parent Cohorts, with two additional Parent Cohorts, expressing interest in joining forces after the IMI-funding period.

The number of prospective scans collected within AMYPAD PNHS is 1,419 (1,192 baseline and 227 follow-up). An additional 1,300 PET scans were acquired through collaborations, bringing the final total available scans for PNHS analysis to over 2,700 PET images.

Pan-European scientific collaborations

The AMYPAD work and the input of each AMYPAD work package throughout the project have resulted in significant outcomes and contributions to the AD field. In addition to scientific data generated from both the DPMS and PNHS, AMYPAD researchers have significantly expanded the knowledge in both the utility and measurement of amyloid PET.

Several key papers have been published using either project’s data, open-access sources or datasets from collaborations established under the AMYPAD umbrella.

The way forward

A legacy of over 3,500 amyloid PET scans covering the entire AD continuum has...
been collected and is curated for sharing with the research community. The Alzheimer’s Disease Data Initiative (ADDI) aims to move Alzheimer’s disease innovation further and faster by connecting researchers with the data they need to generate insights to inform development of new, better treatments and diagnostic tools for AD and related dementias. ADDI has launched in 2021 its Alzheimer’s disease Workbench, a cloud-based platform for scientists to accelerate discoveries and innovations for AD and related dementias. With the funding formally ending at the end of September 2022, AMYPAD has formed new collaborations with ARIDHIA and ADDI to maintain, curate, and provide access to the large data collected from the project.

Thanks to a 5-year partnership between the AMYPAD consortium and ADDI, the PNHS dataset is hosted in the AD Workbench, with the first private data release made in November 2021. The PNHS dataset will become available to the research community beyond the project duration, with the first public release planned by the end of the first quarter of 2023. Bringing the AMYPAD data and the AMYPAD researcher community together through ADDI will ensure the longevity and the value of the AMYPAD project.

A few words from the project leaders

Alzheimer Europe, a partner in the AMYPAD project, asked representatives of the two organisations co-leading the project, Frederik Barkhof (VUmc) and Gill Farrar (GE Healthcare) to share their thoughts regarding various aspects of the project.

How well do you think the key aims of the AMYPAD project were met?

The overall aims of AMYPAD were very broad, to improve the understanding, diagnosis and management of Alzheimer’s disease through the utilisation of β-amyloid PET imaging. The project definitely contributed to each of those elements. But meanwhile, of course, other people have been working on this topic as well; it’s the collective evidence in the end which helps.

Thinking about the diagnosis, we did the AMYPAD Diagnostic and Patient management study. This study was quite conclusive in showing the added value of amyloid-PET but meanwhile also the IDEAS study was performed and found roughly similar findings. Collectively, this contributes to the understanding of what is the diagnostic value of it and more generally to understand Alzheimer’s disease. AMYPAD contributed to that. Although other people have been working in the field alongside, most of the findings are relatively well aligned, showing when amyloid starts. We have shown in AMYPAD that we see really early changes in certain brain regions, which roughly around the same time was confirmed by other people, and linking how that leads to network disruption, cognitive dysfunction, etc.

And then there is the patient management, the most difficult part; who’s willing to pay for an amyloid scan? when is it reasonable to do so? A lot will depend on the outcome of the ongoing treatment trials. If there will be more approved therapies, then obviously the management impact will be much more evident.

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

From the diagnostic study we have clearly seen that there is value in using amyloid-PET to make a firmer diagnosis, especially for people with subjective cognitive decline. From the prognostic study, the very early stages where you see the amyloid developing throughout the brain and the early involvement of the posterior cingulate, for example, and its link with network changes. This is really a novelty of the project. On the other hand, there are also more practical tangible outcomes like our work on the centiloid scaling and the software that we have been producing, which is also very useful in terms of homogenising the analysis of amyloid PET scans with different tracers as well as across multiple centres too.

What were the main obstacles encountered in this collaborative work?

Although we had a very aligned and compact consortium, we were plagued by legal structures and formalities. The multicentric nature of AMYPAD brought challenges with regard to harmonisation and regulatory requirements which are complex and handled differently between countries.

Another obstacle was of course the COVID-19 pandemic and the premature closure of the EPAD Longitudinal Cohort Study. However, we then moved to include non-EPAD cohorts as feeder cohorts for the Prognostic Study, which was beneficial and allowed us to widen the scope of our research across Europe.

How do you think the outcomes of the AMYPAD project can contribute to the future of Alzheimer’s disease research?

We would hope that the direct results of the project are useful about our thinking of when amyloid deposition starts and when it’s clinically relevant. But what is even more important is that the consortium that we formed, started collaborating on things that go well beyond the initial goals of AMYPAD. And actually, we should further integrate AMYPAD, EPAD and all the European cohorts that are now collaborating and join forces in analysis of PET/MRI scans, imaging, biomarker but also genetic data. It is something of great value and will contribute to the future of all samples, definitely in Europe and hopefully also globally.

Finally, could you share one or two personal highlights from the past years?

Frederik: The main highlight was having the privilege of being part of such a good consortium. It was a small but effective consortium...
with committed people making really an active contribution. Centres were really dedicated and as we had such a nice small consortium, we were very effective in collaborating with other cohorts across Europe.

Another personal highlight was the collaboration of a very diverse group of experts. The IMI collaboration between academia and industry was very effective and I certainly enjoyed co-leading the project with Gill a lot. It was very collaborative and a good mutual relationship.

Gill: It was an absolute honour to be working so closely with such talented and committed scientists across Europe. It took some time to get our clinical studies going, but once we were recruiting, there was a huge amount of momentum in all the centres we worked with. For me, a personal highlight over the last six years of AMYPAD has been to witness the incredible impact of biomarker research in the AD field. It is my sincere hope that our AMYPAD consortium has made a positive and significant contribution to further our understanding of the disease, but more importantly, in the future, to possibly managing treatment options too.

Acknowledgement
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Alzheimer Europe hosts Alzheimer’s Association Academy session focusing on dementia as a disability

On 17 May 2022, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series on “Dementia as a disability”. These sessions bring together its member organisations, members of the European Working Group of People with Dementia and representatives from pharmaceutical companies, in the spirit of learning and mutual support.

On 17 May 2022, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series, bringing together representatives of its member organisations, European Working Group of People with Dementia (EWGPWD) and pharmaceutical companies. The topic for this session, which was moderated by Iva Holmenerová, Chairperson of Alzheimer Europe, was “Dementia as a disability”.

Helen Rochford-Brennan, who is a member of the EWGPWD, as well as the Irish Dementia Working Group, began the session with some introductory remarks about the importance of taking a human rights-based approach to dementia. She noted that talking about dementia as a disability can be controversial and that some people do not want dementia to be recognised as a disability. It is therefore important, she stressed, that when we talk about dementia as a disability, it is about ensuring that the human rights of all people with dementia are respected - and recognising dementia as a disability can help with this. Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) dementia counts as a disability because it can cause long-term physical and sensory impairments, she noted. Framing dementia in terms of a disability is quite a new approach, she stated, insisting that it is a positive step and has helped lead to a great shift in public awareness, thanks to advocacy groups. “Our voices are powerful”, she said, “and if we are recognised as having a disability, we have more hope.” People with disabilities, including people with dementia, have the same legal rights as everybody else, but unfortunately, she said, many people with dementia are not aware of their rights or cannot access them. It is our duty, as advocates, to help them become aware of their rights and to understand their implications, she concluded.

Following these opening words, Dianne Gove, Director for Projects, Alzheimer Europe, gave a presentation on the implications of recognising dementia as a disability, for the fields of ethics, policy and practice. She began by stating that Alzheimer Europe has long recognised that impairments linked to dementia can lead to disabilities and that the work the organisation is doing in this area is building on work previously carried out by its ethics working group and the EWGPWD, the result of which was a 2017 discussion paper on the possible implications for ethics, policy and practice of recognising dementia as a disability:


“ Our voices are powerful and if we are recognised as having a disability, we have more hope. People with disabilities, including people with dementia, have the same legal rights as everybody else but, unfortunately, many people with dementia are not aware of their rights or cannot access them. It is our duty as advocates, to help them become aware of their rights and understand their implications”

Helen Rochford-Brennan

Speakers from top left to bottom right, Dianne Gove, Iva Holmerová, Helen Rochford-Brennan and Marine Uldry
Her presentation explored what it means to recognise dementia as a disability, noting various models of disability, including the moral/spiritual model, the medical model, and the social model. The World Health Organization (WHO) describes disability as neither purely medical nor purely social and Dianne Gove also highlighted that there has now been more of a move towards taking a human rights-based approach to dementia. She also reminded delegates that it is not the fact of having dementia that means one has a disability, it is the experience of having certain impairments that lead to society disabling the person, through its actions, through language and stigma.

“Recognising dementia as a disability requires us to reflect on and find the right balance between ethical principles, values, related concepts and approaches. If/ when people with dementia experience disability, they should have the same rights as those afforded to other people with disabilities and this includes the right to expect reasonable accommodations to be made”

Dianne Gove

There are different opportunities to engage and information can either be in written format (called an “alternative report”, submitted together as a disability coalition and/or as individual organisations), or it can also be delivered orally, during the Committee’s two annual sessions in Geneva (including via video conference). EDF’s alternative reports give information to the CRPD Committee about how the EU implements the Convention.

“Civil society and especially disability organisations representing people with any type of disabilities can, and should, take part in the UN CRPD reporting process, because a country’s report may not reflect the situation in that country in the same way that people with disabilities see it. It may be inaccurate and may lack information, for example concerning dementia. It is hugely important, therefore, to engage with the Committee and ensure they have the right information, and that they see it from the angle of the person with the disability”

Marine Uldry

All States that have ratified the UNCRPD are reviewed by the UN Committee on the Rights of Persons with Disabilities. Civil society, she said, and especially disability organisations representing people with any type of disabilities can (and should, she stressed) take part in the process, because a country’s report may not reflect the situation in that country in the same way that people with disabilities see it. It may be inaccurate and may lack information, for example concerning dementia. It is hugely important, therefore, to engage with the Committee and ensure they have the right information, and that they see it from the angle of the person with the disability.

The final talk was given by Marine Uldry, Human Rights Officer at the European Disability Forum (EDF) and focused on UNCRPD reports as opportunities to improve the lives of people with disabilities and dementia. In March 2022, the United Nations (UN) Committee on the Rights of Persons with Disabilities started its second evaluation of the protection of disability rights by the European Union (EU) – an important moment for the disability movement in Europe. The presentation walked delegates through this process, as well as EDF’s response.

Marine Uldry shared what organisations can do to ensure the voices of those they represent are listened to, with regards applying the UNCRPD in countries across Europe. She explained what CRPD reporting is and to whom the reporting is done.
Its first alternative report was prepared for the first review of the EU in 2015. In February 2022, working closely with its members, including Alzheimer Europe, EDF submitted its alternative report for the second evaluation of the EU, with a suggested list of questions. This second alternative report identified 17 main concerns, three of which are specific to people with dementia.

Regarding next steps, the EU will have 12 months to respond and once the Committee receives a reply, it will schedule the “constructive dialogue” and adoption of Concluding Observations (probably in 2024). The EDF will engage in the second part of the process by preparing an updated report and participating in meetings with the Committee.

Delegates were strongly encouraged to check the UN website to see if their own country had sent its report. Marine Uldry also referred to an EDF guide on engagement in the work of the CRPD Committee:

https://www.edf-eph.org/publications/crpd-guide/

There was ample time for lively discussion and questions to the speakers, after which Iva Holmerová closed the session.

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Building public trust in responsible health data sharing by showing how Data Saves Lives

The European Patients’ Forum’s Data Saves Lives initiative aims to inform people about the benefits of responsible health data sharing and to improve health data literacy among patient communities. Alzheimer Europe has been involved in this initiative, especially in helping create its new toolkit. In this article, the team working on Data Saves Lives tells us more about their work.

The power of health data sharing

Health data sharing is a complex area and one that is evolving at an extraordinary pace. The process has been transformed by the introduction of new digital ways of storing, exchanging and analysing data. Incredibly, more scientific data has been generated in the past five years than in the entire history of mankind.

It is no exaggeration to say that this wealth of data has the potential to transform public health. It could be used to help prevent illness, improve treatments and reduce deaths, and indeed there are already numerous examples of situations in which this has happened.

Looking at Alzheimer’s disease (AD) as an example, one of the main obstacles to finding an effective treatment is difficulty detecting the condition in the very earliest phases, before symptoms start. There is no reliable test that can be used to indicate that a person is just starting to develop this form of dementia.

However, research was undertaken to find a new test or biomarker (indicator of the presence of AD) for use in future clinical research. This research required a blood sample from a large number of people that could be tested and from whom the AD process had been measured in spinal fluid or using brain imaging.

Setting up a research study to collect new data would have taken many years and been enormously expensive. The research used pre-existing samples and data from over 1,000 patients, all of whom had previously given informed consent to be part of several studies, similar to this one, taking place in different countries across Europe. In this way, the research was able to be performed very quickly and at a very low cost.

The research discovered a test that is likely to be very useful at predicting which patients are at high-risk of developing AD. More broadly, the work also showed how valuable research can be conducted using existing data and blood samples, and reducing the time to get results. You can read more about this case study here: https://www.datasaveslives.eu/case-study-alzheimer

This is just the start, and the possibilities are infinite. To truly harness the power of health data, it needs to be shared and used effectively. It is the mission of the European Patients’ Forum (EPF) Data Saves Lives initiative to make this a reality.

The role of patient groups and health advocates

The aim of Data Saves Lives is to spread the word about the benefits of responsible health data sharing and to improve health data literacy among patient communities. Patient groups and advocates play a vital role in communicating messages about health data, but levels of knowledge and engagement vary.

The role of patient groups and health advocates

Some advocates are already well-informed about the subject and feel confident discussing it with their communities. Others may be less familiar with the topic of health data and could have concerns around data privacy and security.
The Data Saves Lives website [https://www.datasaveslives.eu](https://www.datasaveslives.eu) shares relevant information and best practice examples about the use of health data, such as the AD example at the start of this article. It offers guidance on how to generate easy-to-use materials about the basic concepts of data sharing, the data journey and the safeguards in place. The resources and additional online events can support patient groups and advocates to start a positive dialogue with their network, on the topic of health data sharing – what it is, its benefits, how to address concerns around security and privacy, and ways of making health data more accessible and engaging.

**Introducing the Data Saves Lives toolkit**

The Data Saves Lives toolkit aims to equip patient groups and health influencers with the information and materials they need to have a positive dialogue with their communities about health data, and to potentially launch their own health data initiatives.

In June 2022, at the EPF Congress in Brussels, Alzheimer Europe Project Officer, Angela Bradshaw co-led a working session on the use of the toolkit. Throughout the session, the group discussed the importance of trust and due diligence between groups and companies; core elements that need to be considered when making decisions on how to collaborate on health data projects.

For anyone looking to become more confident in talking about health data and assessing opportunities to take part in health data initiatives, check out the toolkit here: [https://www.datasaveslives.eu/toolkit](https://www.datasaveslives.eu/toolkit)
Plans for European Care Strategy take important step forward

Following the Green Paper on Ageing, European Commission President, Ursula von der Leyen, announced plans for a European Care Strategy in her State of the Union speech in September 2021. In June 2022, European Parliament passed a report setting out its priorities for the strategy. Here, the co-rapporteurs, Sirpa Pietikäinen, MEP, and Milan Brglez, MEP, tell us more.

Two European Parliament committees were responsible for the drafting of the report on a future European Care Strategy, Women’s Rights and Gender Equality committee (FEMM) and the Employment and Social Affairs committee (EMPL). Sirpa Pietikäinen, MEP, is a member of the FEMM committee, as well as being the Chairperson of the European Alzheimer’s Alliance. Milan Brglez, MEP, is a member of the EMPL committee and is a member of the European Alzheimer’s Alliance.

What are the key points of the own-initiative report passed by the European Parliament?

Sirpa Pietikäinen (SP): For me, one of the most important points is the starting point of the report, which is universal, affordable and accessible quality care belongs to all EU citizens equally, no matter their nationality, age, gender or place of residence. It is a crucial principle in organising care.

Another key point is the Parliament’s ambitious and strong call for the deinstitutionalisation of care. Our care systems are outdated and not responsive enough to our current problems, which became painfully obvious during the COVID-19 pandemic. We should already be transitioning towards community-based and personalised care based on the care recipients’ personal needs and wishes, instead of still basing our systems on care institutions. I am very happy that the report highlights personalised budgeting and personalised solutions for people in need of care. To me it is also extremely important that the report underlines the right to self-determination of the people in need of care. These are core principles that our care systems should build upon.

I am also very proud about how determined the report is on informal care. It is really the first time that the Parliament has taken such a firm stance on supporting informal carers. Our care systems rely greatly on the
contribution of informal carers, and they deserve more acknowledgement and better support systems throughout Europe than what we have in place right now. We propose to develop a common European minimum definition for informal care and to create common European guidelines, status of, and support to informal carers, and urge the Commission to present a European Informal Carers programme.

As the co-rapporteur coming from the FEMM committee, it was very important to me to include the gender aspect of care into this report. If care is not a gender issue, I do not know what is. It is also at the core of informal care: the vast majority of informal carers are women, often caring for other women. The report includes many proposals on how to alleviate the gender bias in care and fix the non-remuneration of women’s care responsibilities.

In addition, the report addresses the need to understand and develop care better on EU level. It calls for improved data collection and ambitious and diverse indicators to measure the quality of care. It also insists on a higher ambition level when it comes to investment and resources - without money, none of these good ideas will actually come true. It was important to me that the report underlines important to me that the report underlines the need to channel EU funding to developing care systems and making caregivers’ working conditions significantly better than how they are now. We cannot have quality care services without motivated and healthy staff.

Milan Brglez (MB): The report towards a common European action on care offers an extensive, in-depth and comprehensive life cycle and human rights-based approach to care. It emphasises the need for effective access to quality integrated public care, accessible to everyone from early childhood, through working and older age, as well as persons in need of palliative care. Moreover, it stresses the need for creating conditions for a genuinely free decisions regarding the realisation and provision of the right to care and the necessity to speed up the transition from predominantly institutional care to community-based care. Finally, yet importantly, it sets a higher level of ambition, preparing the ground for gender transformative care economy in the EU.

What are your hopes for the impact of the future European Care Strategy?

SP: I am hoping that the Parliament’s ambitious stance on how to improve European care systems pushes the Commission towards a more ambitious European Care Strategy than what it had initially planned. I am certainly hoping that the Commission takes on board the Parliament’s proposals on quality indicators and support systems for informal carers, as well as its suggestions on what sort of legislative measures could help in creating better functioning care systems. I also expect the Commission to present measures to tackle the gender bias of care.

MB: I sincerely hope that the report on care will help the Commission in preparation of the European Care Strategy and necessary measures following it. The COVID-19 pandemic revealed the deficiencies in our care systems and opened the eyes of the public and politicians to the fact that care is a right and a public good that requires public support and investment.

The European Care Strategy must offer a broad and effective response to these deficiencies as well as common challenges, such as demographic changes and the aging of our European societies. It must lay the foundation for a joint action at the European level that will be based on the human rights of care recipients as well as the care givers, improve working conditions and, as already mentioned, ensure accessible care to everyone throughout the lifecycle.

The strategy must address women’s over-representation in care and outline the solutions for attracting a larger number of male and younger workers in the care sector, ensuring the recognition, reduction and redistribution of care work, all of which inevitably involves the measures for combating gender discrimination, but also ageism, ableism and other intersecting forms of discrimination.

More specifically, what will be the implications for people living with dementia, their families and carers?

SP: Personally, I see that the two strong principles argued for in the report are very important for people living with memory disabling diseases, their close ones and their carers: the right to self-determination of people in need of care and the personalisation of care. We need to underline and emphasise that this right also belongs to people living with memory disabling diseases. Our care systems must address the needs of people living with memory disabling diseases because they are becoming more and more prominent in the EU.
I do also believe that the firm support the report demands for informal carers is a positive sign for people with memory disabling diseases. In general, informal carers do about 70% of care in Europe, with many of them caring for their close one with a memory disabling disease. Finally, the COVID-19 pandemic revealed that people with memory disabling diseases are an especially vulnerable group when it comes to care emergencies and challenges, so the call for a universal access to good-quality care is of special importance to people with memory disabling diseases.

MB: People living with dementia, among other recipients of care, should have effective access to accessible and quality (preventive and curative) care services, whereas their families and carers will get a better support and an opportunity to decide for themselves, if they want to continue to care for others. As noble as it is to care for others, it must be driven by a completely free choice and not a result of financial or any other form of structural coercion, particularly the lack and inaccessibility of professional care services, which are evident in the case of persons living with dementia, their families and other informal carers.

The report calls on the Commission and the Member States to recognise the benefits of integrated care approaches in prevention of physical and cognitive decline and prolongation of autonomy of the care recipients, including people living with dementia.

The report calls on the Commission and the Member States to recognise the benefits of integrated care approaches in prevention of physical and cognitive decline and prolongation of autonomy of the care recipients, including people living with dementia.

MB: In its report, European Parliament has called on the Commission to present a European Care Strategy that builds on everyone’s right to affordable, accessible and high-quality care, as well as on other principles set out in the European Pillar of Social Rights and other EU strategic documents, such as Gender Equality Strategy 2020-2025, the EU Strategy on the Rights of the Child and the European Child Guarantee and Strategy for the Rights of Persons with Disabilities 2021-2030.

The report very clearly highlights the need for a more coherent approach between health and social systems and coordination between local, regional and national care policies within the EU Member States, alongside horizontal and sectoral integration.

What are the timescales for the publication and implementation of the strategy?

SP: The Commission launched its proposal on the care strategy and on two Council Recommendations on 7 September 2022. After that, the Parliament and the Council will examine the proposal and draw its own conclusions. It is very important to see quickly after how these actions, recommendations, principles and targets are actually going to be implemented.

MB: The Commission published the Strategy in the beginning of September 2022. After the publication of the Strategy, the Member States will have to adopt the necessary policies and measures for its implementation. The European Care Strategy and the aforementioned policies and measures are, in my view, just the first step towards a Care Deal that guarantees the right to quality care.

The Commission has a strong ally in the Parliament for further legislative action and investment into gender-transformative care economy that recognises care as the backbone of our society.

European Commission launches “Healthier Together” non-communicable diseases initiative

In June 2022, the European Commission launched a new initiative, Healthier Together, which aims to address the challenges posed by the rising numbers of people living with non-communicable diseases in the EU, including neurological conditions. Artur Furtado, Deputy Head of Unit for Health promotion, disease prevention, financial instruments, explains how the new initiative works.

Can you tell us about the background to the development of the European Commission’s Healthier Together Non-Communicable Diseases (NCDs) initiative?

The EU NCD Initiative is helping EU countries reduce the human suffering and the financial burden associated with the major non-communicable diseases. It has identified concrete evidence-based actions, countries have shared their specific priorities, work packages were prepared - and financial means to support implementation have been increased by a factor of 10 already in 2022. This is quite a step ahead!

Its aim is to help EU countries reduce the burden of NCDs and improve the citizens’ health and well-being by reinforcing the support for action of the Member States and relevant stakeholders in this area. For the first time, it targets the main sources of mortality and morbidity (other than cancer) in an ambitious and comprehensive manner. It includes a list of actions for countries to implement according to their priorities, as well as a map of EU legal and financial tools that can help realise those priorities.

The content is ambitious and the process is also innovative: the initiative was co-created with the Member States, with input from stakeholders, Commission services, the World Health Organization (WHO), the Organisation for Economic Cooperation and Development (OECD) and the European Investment Bank (EIB). This joint drafting began in December 2021 and the document was published in June 2022.

Healthier Together includes the following five strands: cardiovascular diseases, diabetes, chronic respiratory diseases, mental health and neurological disorders and health determinants. All strands include a health equity dimension, thus supporting the reduction of health inequalities. While they address particular challenges of each disease group, the initiative as a whole promotes a non-disease specific, integrated and coordinated approach to prevention and care. Moreover, the initiative promotes patient-centred pathways accounting for co-morbidities.

To achieve its purpose, the EU NCD initiative:

- Identifies priorities, targets and evidence-based and/or promising practices preferred by the Member States and relevant stakeholders (health professionals, civil society organisations, patients organisations etc.) in the area of NCDs
- Maps, organises and focuses the Commission’s actions and tools on the topic, helping the Member States with knowledge, governance, identification of best practices, collaboration and financing.

The initiative supports Member States in reaching target 3.4 of the Sustainable Development Goals (to reduce by one-third premature mortality from NCDs by 2030) and complements the Europe’s Beating Cancer Plan.

The initiative was launched by Commissioner Stella Kyriakides on 22 June with a comprehensive report published – what are the key areas of focus?

The initiative includes the following five strands: cardiovascular diseases, diabetes, chronic respiratory diseases, mental health and neurological disorders, and a horizontal strand for health determinants (including tobacco, nutrition, physical activity and alcohol, in coordination with the Europe’s Beating Cancer Plan). Some topics, such as health inequalities, integrated and patient-centred care, will be addressed in all strands.

With a strong focus on prevention, the initiative can support:

- Improving knowledge and sharing of best practices
- Health promotion and disease prevention, including screening and early detection
- Optimising tools for diagnostics, treatment and disease management.

What will this initiative mean for policies relating to Alzheimer’s disease and other dementia? How will it benefit people living with the condition?

The EU NCD initiative is supporting and adding value and coordination to national efforts to decrease the human and financial burden of NCDs, as well as the reduction of related health inequalities. It contributes in this way to the resilience of the EU society and the sustainability of health care and social protection systems.
This can be done primarily via implementation of health promotion and prevention actions: for Member States to replicate best practices, develop guidelines, roll out innovative approaches etc. Stakeholders will be supported in actions that can contribute to the same objectives.

Such a list may include replication of validated best practices, revision of guidelines, protocols, screening guidelines and methodologies or accreditation schemes, preparation of NCDs national action plans, re-organisation of prevention and care models, technical and legal preparation for innovative policies, pilot testing of approaches, preparation of training materials, twinning and sharing actions. Possible areas for such actions might include public health, healthcare organisation and cross-sectorial action to promote health in all policies to improve health literacy and reduction of health inequalities.

The initiative lists possible priority areas for mental health, from supporting favourable conditions for mental health and increasing resilience; implementing mental health in all policies; promoting mental well-being and preventing mental disorders; improving timely and equitable access to high quality services; protecting rights, enhancing social inclusion and tackling stigma associated with mental health problems.

For neurological disorders, countries considered prioritising actions in several areas, including: changing attitudes towards dementia, and tackling stigma associated with dementia; prevention and early detection of neurological diseases, in particular Alzheimer’s disease and dementia; implementing person-centred integrated care models, to better manage neurological disorders and support the quality of life of patients and their families.

How does the initiative integrate with other Commission areas of work, including the European Care Strategy and the Horizon Europe research programme?

This initiative collects the list of actions that make the most sense, and that EU countries have prioritised, alongside a mapping of tools, legal and financial, that should be used to implement them. It also promotes legal and financial tools led by all departments of the Commission, as part of the ‘health in all policy’ approach, whilst acknowledging the role of other policies in fighting non-communicable diseases and providing multiple EU tools, including funding.

The process should ultimately result in the implementation of actions on the ground and selecting actions that could benefit from EU funding to achieve faster or wider deployment. To facilitate this process, an overview of available financial and legal support instruments for the years 2022-2027 is provided by the initiative support document.

Commission services have participated – and are still participating – in the discussions on the EU NCD initiative, and may in this way be better informed of countries’ and stakeholders’ needs and priorities, when conducting their programming. This may open additional doors for EU support to priorities identified.

What are the timescales for the initiative and how will patient organisations and civil society be able to contribute to the implementation of the initiative?

The new EU4Health programme, with a EUR 5.3 billion budget over seven years, is a key tool for improving EU citizens’ health. The programme is already proving to be a game changer, at least 20% of its budget should be targeted on health promotion and disease prevention. It is a real financial injection for the strong European Health Union we are working now to build.

A substantial funding from the budget of the EU4Health programme is available for implementing the EU non-communicable diseases Initiative, starting in 2022. To help pace national efforts, the cardiovascular diseases and diabetes strands will be launched first, alongside the lifestyle determinants strand (given its synergy with cancer prevention and other NCDs).

Chronic respiratory diseases, mental health and neurological disorders would follow, in order to take stock and complement ongoing actions. Patient organisations and civil society are warmly invited to continue and deepen their engagement in the EU NCD initiative by now following its priorities and using the opened financial opportunities to help implement change on the ground. Start already by consulting the 2022 work program of EU4Health!


While focusing on promotion and prevention, this initiative may also support better knowledge and data, screening and early detection, diagnosis and treatment management, and quality of life of patients.

Non-communicable diseases represent 80% of the disease burden in the EU. Our NCD initiative is a crucial step to continue tackling them in a systematic and comprehensive way.

Stella Kyriakides European Commissioner for Health and Food Safety #HealthierTogether #HealthUnion

Health Commissioner, Stella Kyriakides, spoke at an online event launching the new initiative on non-communicable diseases
**Outgoing Director Pierre Meulien reflects on European public private partnerships in neurodegenerative research**

As he prepares to step down from the role of Executive Director of the Innovative Health Initiative (the successor to the Innovative Medicines Initiatives), Pierre Meulien shares his thoughts on how the research partnerships have transformed neurodegenerative research and the future of research in the field.

After leading the Innovative Medicines Initiative (IMI) since 2015 and preparing its transition into the Innovative Health Initiative, what are you most proud of?

In IMI, we spent a lot of time reflecting on what kind of projects would benefit most from the Public Private Partnership (PPP) model. I have always maintained that IMI was not for everyone or everything but that some topics lend themselves to the collaborative PPP model. Different categories of topics can be defined, for example, true market failures like Anti-Microbial Resistance, platforms for tool development that can be shared, and of course those topics that are just very tough scientifically—this category being typified by dementia.

There have been so many false starts, false hopes for patients, that it became obvious that both public and private players had vested interests in collaborating and sharing data in this very complex area of research.

In 2015, IMI had already some important projects on the go from IMI1 and it was important to build on this initial investment but go much further in all aspects, whether they be generating new scientific knowledge that could drive the identification of new targets or biomarkers for the disease, developing new paradigms for clinical development, being able to envisage early intervention and, de facto, involving patients and regulators right from the beginning of project conception.

The one thing that IMI can be proud of is how the stakeholder culture has changed over a decade where many misconceptions have disappeared due to IMI projects having all voices at the same table. Each party has its own take on what is important for them and being able to communicate this in real time for everyone thus accelerating all aspects of research and development, avoiding dead ends and blind alleys and above all saving time. This end-to-end integration model also creates trust among the actors, critical for long lasting and sustainable productive collaboration.

Looking at the field of dementia research, what have been the most significant developments in the field?

The list is long due to so many transformations we have seen. The European Prevention of Alzheimer’s Dementia (EPAD) project was a flagship project because it was one of the first attempts in the world to create a clinical research platform for performing clinical assessments of new potential drugs that could be tested in people susceptible to Alzheimer’s disease (due to genetic or environmental factors) but did not yet exhibit symptoms of the disease. The cohort data that has been assembled has recently been added to the global Alzheimer’s Disease Data Initiative (ADDI) platform which will enable researchers, clinicians, and patients to access this very valuable data set to help in designing future clinical trials. This global connectivity of IMI projects has been very important for me personally.

There are over a dozen IMI projects in the dementia portfolio and span a variety of areas from research into the underlying molecular mechanisms of disease, clinical trial design, brain imaging in different phases of dementia, building valuable research tools like stem cell lines, data sets, animal models and much more. All these areas have seen significant developments and the IMI projects have provided important contributions as learnings, development of expert networks and robust data to support further development.

Very importantly, all of these projects are now coordinated by the Neuronet project and they have created long lasting links with other global initiatives (e.g. the Davos Alzheimer’s Collaborative). I have always maintained that

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After leading the Innovative Medicines Initiative (IMI) since 2015 and preparing its transition into the Innovative Health Initiative, what are you most proud of?

In IMI, we spent a lot of time reflecting on what kind of projects would benefit most from the Public Private Partnership (PPP) model. I have always maintained that IMI was not for everyone or everything but that some topics lend themselves to the collaborative PPP model. Different categories of topics can be defined, for example, true market failures like Anti-Microbial Resistance, platforms for tool development that can be shared, and of course those topics that are just very tough scientifically—this category being typified by dementia.

There have been so many false starts, false hopes for patients, that it became obvious that both public and private players had vested interests in collaborating and sharing data in this very complex area of research.

In 2015, IMI had already some important projects on the go from IMI1 and it was important to build on this initial investment but go much further in all aspects, whether they be generating new scientific knowledge that could drive the identification of new targets or biomarkers for the disease, developing new paradigms for clinical development, being able to envisage early intervention and, de facto, involving patients and regulators right from the beginning of project conception.

The one thing that IMI can be proud of is how the stakeholder culture has changed over a decade where many misconceptions have disappeared due to IMI projects having all voices at the same table. Each party has its own take on what is important for them and being able to communicate this in real time for everyone thus accelerating all aspects of research and development, avoiding dead ends and blind alleys and above all saving time. This end-to-end integration model also creates trust among the actors, critical for long lasting and sustainable productive collaboration.

Looking at the field of dementia research, what have been the most significant developments in the field?

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Very importantly, all of these projects are now coordinated by the Neuronet project and they have created long lasting links with other global initiatives (e.g. the Davos Alzheimer’s Collaborative). I have always maintained that
Irrespective of which research area is under study, the role of the patient has been, and will remain critical going forward. The implementation of the IMI patient involvement strategy has been an amazing journey and new developments and innovations in this space will continue with the Innovative Health Initiative (IHI). The last two years have seen the creation of the IMI pool of patient experts which has been a very significant evolution – enabling patients to have the same weight of voice as scientific, clinical, industry, ethical or regulatory experts that IMI has used in evaluations, project reviews, close out meetings, expert workshops and so on. Over 150 patients, family members and carers are currently part of the pool (covering a wide range of conditions, including neurological conditions and from 26 countries in Europe) and we are already planning the next phase of development under IHI.

What do you think have been the greatest contributions of the IMI to making this progress in dementia research?

I have always considered IMI funding to be 100% strategic in nature and so everything that has been built (project outputs) has had strategic impact on the field of dementia research. Just to mention three I would like to highlight:

1. The sustainable solutions provided by the European Quality in Preclinical Data (EQIPD) project facilitating improvements in data quality in preclinical research, for everybody but particularly tailor-made to help innovators in the small companies where most of innovation happens.

2. The fantastic networks for clinical research and trials developed by EPAD and (Amyloid) imaging to prevent Alzheimer’s disease (AMYPAD) projects have already been leveraged by other initiatives worldwide, fostering the spirit of collaboration and working together for the common good of people with dementia, in a field that still suffers from too much unproductive competition and continues to witness one clinical trial failure after the other.

3. Finally, and critically, the open sharing of large resources of high-quality data and samples [e.g. EPAD on the AD Workbench and the ongoing work of the European Platform for Neurodegenerative Diseases (EPND) project] to support rapid progress of dementia research.

What are your hopes for the future IHI programme? What do you consider the key points it must address?

It has been obvious from the beginning of IMI that we would not have a credible neurodegeneration research and development programme without including actors from the medical imaging and data management industries. These actors were brought in on a project by project basis in IMI. Under IHI, these industry actors are part of the founding members of the new programme and as such have a key strategic role to play. Already we are seeing integrated thinking taking advantage of the technology convergence at play in many disease areas. Neurodegeneration will without any doubt take a prominent place in those topics that lend themselves well to this type of PPP. From the recently launched call of IHI, we can see that neurodegeneration is already among the chosen topics.

What does the future hold for you? Will you continue to be involved in the European research field?

I still have energy and would like to remain active in non-operational roles and hope that my experience may be useful to certain organisations in the EU medical research ecosystem (and beyond). I will however not be based in Brussels and will move to calmer environments in Portugal.

I would like to take this opportunity to thank all of those in Alzheimer Europe and well beyond our borders who have been involved in the neurodegeneration research activities funded through IMI. Your support, hard work and energy has transformed the playing field in the area which will continue to bring challenges to patients, their families, carers, and society as a whole.

“ The implementation of the IMI patient involvement strategy has been an amazing journey and new developments and innovations in this space will continue with the Innovative Health Initiative (IHI).”
European Group of Governmental Experts on Dementia meets online

In its first meeting of 2022, the Group met online to discuss a range of dementia policy developments matters, including hearing how Ukrainians with dementia were affected by the war, a German paper on the neurological implications of COVID-19 and updates from the World Health Organization (WHO).

On 17 June, the European Group of Governmental Experts on Dementia held its first meeting of 2022, exchanging information and knowledge on the latest national, European and international developments related to dementia policy and practice. The meeting was attended by representatives of 13 countries: Austria, Bulgaria, Czech Republic, Cyprus, Finland, France, Germany, Italy, Luxembourg, Norway, Poland, Slovenia, Sweden. In addition, representatives from the European Commission (DG SANTÉ), the World Health Organization (WHO) were present during the meeting.

The first presentation was given by Irina Shevchenko, Founder and Director of the Nezabutni charitable foundation in Ukraine, who explained the ongoing situation in Ukraine in relation to persons with dementia. Following Russia’s invasion of the country, she noted that the organisation had to change its way of working to be able to continue to support people living with the condition. It was noted that many older people and people with dementia remained in Ukraine, including in residential settings, with many of these facilities overcrowded. Work has been undertaken in collaboration with other organisations, to provide generators or wells, where electricity and water supplies are disrupted to these settings.

Nezabutni is aiming to set up online services and supports for people with dementia, their families and carers. Additionally, it is working to provide information and resources for people who have been displaced and are in European countries, as many Ukrainian persons with dementia and their family members have experienced challenges in accessing services whilst in these countries.

Katrin Seeher, from the World Health Organization (WHO), recapped some of the key activities of the WHO during 2021, noting that the global status report on dementia had been included in the WHO’s top 10 public health moments of 2021. She explained that during 2021, 42 Member States actively participated in the WHO’s work on dementia, including attendance at online and virtual meetings. The WHO also held a capacity building workshop, launched a dementia-friendly toolkit, published six peer review articles, continued development of the dementia research blueprint and recorded the implementation of the iSupport resource for carers in 36 countries.

She also explained some of the WHO priorities for 2022, including the publication of a research blueprint for dementia in December, as well as a new round of data collection for the Global Data Observatory. In addition, the MhGAP on dementia diagnosis and clinical care will be updated.

It was noted that early studies had demonstrated that a risk of persistent cognitive symptoms was linked to the severity of the disease, with patients admitted to ICUs more likely to have prolonged cognitive deficits. The potential causes of this include hypoxia, vascular damage and systemic inflammation in the central nervous system (CNS). This is consistent with other infectious diseases which are generally associated with an increased risk of dementia. In addition, PET scanning has shown that some cognitive deficits are reversible, CNS ischemia and/or neuronal cell death may cause irreversible damage.

The group also heard a presentation from Małgorzata Michalska of the Polish Government who outlined a three-year pilot project in Poland which aims to improve diagnostic services in the country. The scheme will trial a diagnostic pathway which begins at a primary care level and creates a clear process for the referral of patients suspected of having dementia to secondary healthcare services, to ensure a timely and accurate diagnosis.

Albert Kern from the German Government presented an issue paper which had been published by the Federal Health Ministry, reviewing the state of research regarding cognitive deficits and SARS-CoV-2 and discussed whether the COVID-19 disease poses an increased risk of dementia. It reviewed several international studies, distinguishing long-COVID as symptoms occurring 4-12 weeks after onset of illness, with post-COVID being anything after 12 weeks.

Attendees at meeting of 17 June 2022
Nicoline Tamsma, Policy Officer, DG SANTÉ, introduced the European Commission’s forthcoming “Healthier Together” non-communicable diseases (NCD) initiative, which aims to increase EU support in this area, with a focus on implementation of policies, guidelines and good practices. The initiative will have five thematic strands: cardiovascular diseases; diabetes; respiratory diseases; mental health and neurological conditions and, health determinants (aligned with the European Beating Cancer Plan). It will identify actions (e.g. best practices, best buys etc.), with an emphasis on prevention and health promotion. In addition, the initiative will support the identification of relevant legal and financial tools, promoting a full plan for the budget and legal framework to underpin the work.

Healthier Together will run between 2022 and 2027, with an “adjust, choose, engage” approach, which will allow for refinement of the initiative, responding to the views of Member States and the health policy platform.

The guidance document for the initiative was published on 22 June and sets out a number of potential priority areas in relation to dementia, including:

- Changing attitudes towards dementia and tackling stigma.
- Prevention and early detection of dementia
- Implementing person-centred integrated care models, better managing neurological disorders and support the quality of life.

The next meeting of the group is expected to take place online in December 2022.

Iryna Scevchenko of Nezabtuni presented on the impact of the war in Ukraine on people with dementia.
New World Health Organization (WHO) research blueprint to coordinate the global research response to dementia

As the WHO prepares to launch a dementia research blueprint to improve the coordination of research efforts in the field of dementia, Rodrigo Cataldi from the WHO provides an insight into how it has been developed, as well as its some of key areas of focus.

The World Health Organization’s (WHO’s) Global Status Report on the Public Health Response to Dementia has underscored the impact of dementia globally and the need to urgently act in order to meet the global targets set by the Global Action Plan on the Public Health Response to Dementia 2017-25. Notably, the report highlighted that dementia research and innovation is a key area that requires concerted efforts and has been heavily impacted by the dire consequences of the COVID-19 pandemic.

Dementia research is highly fragmented globally, with wide variability and inconsistency in investment and quality of research efforts. Research on dementia is also inequitable, as the vast majority of studies are conducted in high-income countries, even though most people with dementia live in low- and middle-income countries. Despite growing international attention on healthy ageing and increasing investments in neurological disorders, research funding is still not proportional to the impact and societal cost of neurological diseases, especially those that cause dementia. Research needs to be at the core of the public health response to dementia and needs to be conducted within an enabling environment, where collaborations are fostered and equitable, and sustained investment is realised. The COVID-19 pandemic taught us how fast we can advance research and development if we act in a coordinated manner. It is now to apply these learnings to address dementia.

To this end, the WHO developed a blueprint for the global research response to dementia. The blueprint supports global research prioritisation efforts to identify knowledge gaps, define actions and milestones, build consensus, and offer guidance to the research community. The blueprint will also promote better research coordination to increase collaboration among research sectors, encourage data-sharing to ensure better use of data and avoid redundancy. Throughout its development process, the WHO has engaged with over one hundred dementia experts, across all six WHO regions, representing several stakeholder levels, including researchers, people with lived experience, representatives of civil society, public health agencies and funding bodies. Experts have contributed through a survey, a virtual consultation, and the systematic revision of drafts of the blueprint, where invaluable contributions were received.

The blueprint builds on and applies key lessons learned from previous WHO efforts to prioritise research and coordinate research activities for infectious diseases, and considers the entire dementia research spectrum, incorporating diagnostics and therapeutics, as well as emerging scientific and technological advances such as artificial intelligence, multiomics and biomarkers. It also encompasses epidemiology, health economics, care and carer research, risk reduction, and brain health across the life course. These topics are covered across six research themes (as can be seen in the figure).

The blueprint also provides insights on different drivers of research, emphasising that advances in these areas will only be fully accomplished if appropriate and sustainable funding is allocated, diversity and equity become the norm, and people with lived experience are included throughout the entire research development process, from its conceptualisation to implementation.

As key component to support the implementation of the Global action plan on the public health response to dementia 2017-25, the blueprint is designed to provide guidance to policy makers, funders, and the research community on future activities in dementia research, making it more efficient, equitable and impactful.

WHO will work with stakeholders across all relevant sectors to ensure that the actions outlined in the blueprint are implemented, milestones achieved, and strategic goals realised, with the ultimate goal of improving the quality of life and support for people with dementia, their carers and families.

For more information about the blueprint, visit: https://www.who.int/health-topics/dementia

Rodrigo Cataldi

WHO research blueprint priority areas (reproduced from “A blueprint for the worldwide research response to dementia” Cataldi, Rodrigo et al. The Lancet Neurology, Volume 21, Issue 8, 690 – 691)
Putting a face to commitment – New leadership for the national Alzheimer associations of Iceland and Ireland

Ragnheiður Ríkharsðsdóttir started her new position as Chairperson of Alzheimer Iceland in May 2021. Meanwhile, Andy Heffernan took up his position as the new Chief Executive Officer (CEO) of The Alzheimer Society of Ireland, in May 2022. Each of them reflects on new beginnings, on taking the helm roles during a global pandemic and on plotting a course for the future of their organisations.

Ragnheiður Ríkharsðsdóttir, Chairperson, Alzheimer Iceland

What made you decide to take this position as Chairperson of Alzheimer Iceland?

I had been on the Board since 2019 and when previous chairperson Árni Sverrisson stepped down I decided to run for the office and was elected in May 2021. The reason I joined the organisation was simply that my father was diagnosed with Alzheimer’s disease and it was hard for our family to watch how it progressed. That’s why I was prepared to be a part of the work done by Alzheimer Iceland for those living with Alzheimer’s and other dementias, as well as their families.

How has your experience in the role been, so far? Is it what you expected?

I believe we are doing well even though COVID-19 has had a big impact on us as well as the whole of society. From the beginning, the Alzheimer Iceland manager and I decided to meet to prepare before every Board meeting. After each one we met again and went through the agenda and notes from the meeting. This arrangement has worked well for us. Additionally, I decided to be at the office one day a week in order to meet and get to know key staff members and that has proven to be valuable.

What has surprised me the most is that our clients/patients more often than not are caught between the social care system and the health care system. What I mean by that is that when someone is diagnosed with Alzheimer’s disease or another type of dementia, neither system steps forward and takes care of the individual. This doesn’t change until the condition gets worse, then the health care system takes charge and pays for specialised day-care and additional support. Outside of that time, the families and relatives are the sole carers. This must change.

Alzheimer Iceland decided to establish a unit for recently-diagnosed people and their families. This unit has definitely proven to be a good idea, because social activity as well as physical and mental activity is likely to slow the progression of Alzheimer’s disease and dementia. However, we must do more. Our organisation has funds for one year for this unit. The future is uncertain. In my opinion, the Government and municipalities in Iceland must jointly provide sufficient funds for the unit to remain operational in the future.

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

My wish and my hope is that we continue the good work of Alzheimer Iceland and that we will be able to improve the service for individuals with Alzheimer’s disease or dementia and their families. It is extremely important that the dialogue with the Minister of Health Affairs and the Minister of Social Affairs will continue and that we can build bridges/links between those two systems. That will ensure services are provided by both ministries to our clients/patients and their families. Our motto in that work will be “nothing about us without us”.

We must also start a conversation with representatives from Icelandic municipalities in order to introduce our organisation to them, discuss the need for specialised care and support on a daily basis, also such daily care and support for people just diagnosed with Alzheimer’s or dementia. We must find out how the municipalities see their involvement in those tasks.

Conversations and cooperation with public representatives are vital for Alzheimer Iceland so we can continue to develop and intensify services for individuals with Alzheimer’s disease or dementia.

You have started in this new role during an ongoing global pandemic and public health crisis. How has it been for you to take over the reins at such a difficult time, with uncertainty and anxiety that COVID-19 has created, as well as the impact it is having economically, politically and socially?

It has been a challenge for everyone within the organisation to cope with the unprecedented
COVID-19 situation and we have been forced to react in several ways. Monthly Board meetings have been held both face-to-face and online. This has turned out to be quite successful and we will continue that way.

The work within the organisation in general has of course been affected by COVID-19 in society and we have had to change focus. Educational sessions have been broadcasted (streamed) through the internet. Those sessions have been quite successful and through the situation in society we have learned to use technology better than before and thus been able to connect successfully with our clients/patients and their families. The employees of the centres have done a great job that can never be fully appreciated. During the pandemic, most consultations have been carried out by phone but now that COVID-19 is receding those consultations are being carried out in the offices of our specialist staff members, such as our education manager, psychologist and project manager.

It has surprised me to find out how little assistance the government and municipalities provide for those who are diagnosed with dementia. In the early stages of dementia, people do not get much help or assistance from those authorities. If they go to a specialised day-care centre, or if the condition has progressed so far that the individual has moved to a nursing home, only then do those authorities step in. The family members who may still be working or getting older have to become unpaid carers. This has to change. If not, those family members will themselves become another group of clients/patients. The whole of society must admit and realise that Alzheimer’s disease and dementia affect the whole family.

Andy Heffernan, CEO, The Alzheimer Society of Ireland

What made you decide to take the position as CEO of The Alzheimer Society of Ireland?

Following a career in the Irish Defence Forces, I worked in the non-profit area for nearly 20 years and had been in my previous role as National Secretary of the Society of St. Vincent de Paul for over seven years. I had always intended to remain in that role for six to seven years and then reappraise and determine if I was still adding value to the organisation. Obviously, the onset of the pandemic dictated the need for continuity of organisational leadership and as we began the gradual exit from the restrictions associated with COVID-19 in early 2022, my mind returned to that personal commitment.

Whilst I wasn’t proactively looking to move, the role of CEO at The Alzheimer Society of Ireland (ASI) became available with my predecessor Pat McLoughlin retiring, and following contact from the recruiters I became interested in the possibility of a move. What particularly piqued my interest was the area the organisation worked in, dementia. I need to be completely committed to and believe in the work of an organisation if I am to work there and, in this case, that alignment was just right.

I had my own personal experience with dementia, with my mother having lived with the condition for some ten years before her passing five years ago. A number of her siblings also had diagnoses and as such, it was an area that I had a distinct interest in. This, coupled with my own professional experience in leading national non-profits, led to an opportunity that was attractive to me.

I was also very aware of the reputation of the organisation having worked in the Irish non-profit sector and was impressed with the experience and skillsets within the Board, together with the financial, structural and operational fundamentals of the organisation. Following the recruitment process, I was privileged to be offered the role and commenced with ASI in early May of this year.

How has your experience in the role been, so far? Is it what you expected?

I received a very warm welcome from everybody and my experience to date has been very positive. Everyone I have met has been professional and committed, and initial indications would suggest a very positive person-centred culture. I am very lucky to have an extremely experienced and professional Senior Management Team who have been valuable and supportive in my initial weeks.
The dementia ecosystem in Ireland is quite complex and I have been navigating the various groups, organisations and stakeholders, statutory and otherwise, who make up the area and trying to establish the place of The ASI within the sector. The European and global aspects of ASI are other areas I am learning about quickly.

The ASI itself is a large complex organisation dispersed across Ireland, involved in a range of activities including service delivery (both centre and home based), cafes and social clubs helpline and specialised dementia advice, together with strong advocacy and research components which require significant coordination.

As well as meeting as many people as possible (both internally and externally), I also set aside one day a week to visit our centres and activities across the country. This is extremely beneficial as I gain a full understanding of our services and get to meet staff and volunteers at all levels. It also gives me the opportunity to meet those who we support which is a privilege and hugely informative.

High standards of non-profit governance and adherence to various governance codes is required under statutory law and by the public in Ireland and in that regard, I have been very reassured by the systems and processes in place at ASI. This provides the required level of transparency and reassurance for our funders and donors, but most importantly for the people who use our services and their families.

In Ireland, we are fortunate that there is considerable cross-party-political support for dementia, following on from ASI support for the establishment of a non-partisan parliamentary committee some years back. Consequently, the organisation’s access to politicians, policymakers and Government is excellent.

In my initial weeks as CEO, I have met the relevant Minister on three occasions which is indicative of the influence of The ASI through the good work of my predecessors. Making this access work is important in terms of our advocacy and funding priorities.

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

Having been with the organisation now for several months, I’m beginning to formulate my own views and perspectives on dementia in Ireland. Whilst my experience with my mother has given me some insights into the lives of those with dementia and their families/supporters, the environment in Ireland has significantly moved on in the last 10 years. The ASI has been very much at the forefront of these changes and are seen as leaders in the field and as such, I believe it is important that we continue to play a leading role, ensuring that our insights borne out of the lived experience of our advocates, together with the experience as a service delivery organisation, inform future direction. This, coupled with our political access, ensures we are well placed to influence direction in the future.

In this regard, it is important that the organisation is well positioned to continue in this central role for the future. The ASI’s current strategy concluded in 2020 and due to COVID-19, a strategic process for the coming years has not yet commenced. The development of a strategic plan for the next four to five years is my primary objective in 2022. This will enable the organisation to decide on future direction following on from a comprehensive consultation within ASI, and with external stakeholders.

You have started in this new role during an ongoing global pandemic and public health crisis. How has it been for you to take over the reins at such a difficult time, with the uncertainty and anxiety COVID-19 has created, as well as the impact it is having economically, politically and socially?

When I commenced with ASI, we were ostensibly emerging out of the worst of the pandemic, however COVID-19 continues to be a cloud which impacts on many aspects of what we do and how we do it. The priority in the last six months has been to reopen our services in a safe manner and this is an area that I have also focused on. I strongly believe that we have an obligation to ensure we are in a position to provide an appropriate level of service for those we support; those living with dementia and their families were, in my opinion, disproportionately affected by the pandemic and the associated restrictions. We must ensure this does not continue as time is not always on the side of those living with dementia, and we have no certainty in what the future holds in terms of the pandemic. We must balance the optimisation of services with the inherent risk of COVID-19 and that is always a challenge, however it is a challenge we must and will overcome.

Prior to my commencement, due to the pandemic, The ASI were very innovative in providing alternative options to centre-based and collective activities. I believe these will become embedded in our service offering to provide real choice as opposed to ‘one size fits all’. In July, we launched a “Virtual Dementia Hub” which was the culmination of a collaboration with Fujitsu Ireland in applying their digital capacity and expertise to empower people living with Dementia through technology.

Hybrid working is an area that organisations and their employees are still struggling with, and I believe it will be a number of years before the optimum arrangements for employers, employees and clients will become obvious. I particularly worry that younger and first-time staff will be negatively impacted through the absence of face-to-face interaction with their peers and managers, and that innovation borne out of spontaneous collaboration will decline.

Certainly, my initial months with The ASI have been incredibly positive and I am privileged to work with so many committed and professional staff and wonderful advocates and volunteers all trying to make a difference. If I can contribute in a meaningful way in making that difference, then I will feel very gratified.
In the driving seat? France’s ban on driving with dementia provokes an outcry

A recent French decree to revoke drivers’ licenses at the time of, and even prior to, a dementia diagnosis has been met with shock and anger. We asked France Alzheimer to explain the situation further and to share its response. We also invited members of the European Working Group of People with Dementia (EWGPWD) to give their views on driving with dementia.

The situation in France

France Alzheimer denounced a recent French decree which bans people with neuro-evolutionary pathologies such as Alzheimer’s disease (AD) from driving, as soon as they are diagnosed.

The ban can even occur as soon as any signs of cognitive impairments appear. The decree in question updates a list of medical conditions that it states are incompatible with driving a vehicle, with new conditions for cognitive disorders such as AD and related disorders.

To sum up, there are several categories of driving licence in France. For the categories including cars (the most common use):

- the incompatibility with driving is declared for as long as doubt about the nature of the disorder remains. A specialist opinion is requested without delay from a multiprofessional team, which includes one or more specialist doctors (neurologist, geriatrician, psychiatrist or doctor, etc.)
- the incompatibility is definitive: from the beginning of stage three of the Reisberg scale (Global Deterioration Scale for Assessment of Primary Degenerative Dementia).

For categories of so-called “heavy vehicles”, the definitive incompatibility applies as soon as the disease is diagnosed.

On the ground, when we take into account the reality of this legal procedure, the experts in charge of the decision rarely ask for a specialist opinion (which specialist? the one who already follows the family? someone who doesn’t know the background of the family, of the patient?). Moreover, the Reisberg scale is largely denounced by the French Society of Geriatrics and Gerontology (SFGG) and the Federation of Memory Centres (FCM).

In an SFGG press release of 7 April 2022, Professor Nathalie Salles, geriatrician at Bordeaux University Hospital and President of the SFGG stated:

“You cannot reduce such an important decision to a score and even less when this score, in this case the Reisberg scale, has not been used in geriatrics for 20 years to measure anything!”

While the position of the Ministry of the Interior, via the “Road Safety Authority”, appears draconian and aggressive:

“People with cognitive disorders linked to these pathologies must no longer drive as soon as cognitive decline appears”, the Road Safety Authority said in a press release.

To put it plainly, since the publication of the decree, the diagnosis of the disease automatically leads to immediate withdrawal of car keys.

The “experts” are delivering “certificates of incapacity to drive”, sometimes during a consultation lasting less than five minutes, when the diagnosis has been made. For France Alzheimer, this part of the decree is arbitrary, discriminatory and stigmatising.

Since 3 April 2022, the association has been receiving hundreds of testimonials from families who are shocked, angry and desperate.
This order even came as a surprise to France Alzheimer and raises many questions such as:

- Who takes a decision based on a scale that is no longer in use?
- What measures will be taken to support people with disabilities and their carers?
- What solutions can be proposed to them in the face of mobility problems?

The association also felt incomprehension and anger, because it is involved in a study on mobility, driving and Alzheimer’s disease, together with the Fondation Médéric Alzheimer, as well as “Prévention Routière” under the umbrella of the State. The conclusions should be unveiled in a few months.

“Taking car keys away from a person with a cognitive disorder is ultimately inevitable”, notes France Alzheimer, “but people with dementia are all different and should be assessed individually.”

Moreover, we need to support people with dementia and their carers during this stage of their life and offer them solutions in terms of mobility, not put up more barriers.”

France Alzheimer was not the only organisation to express indignation. This was also the case for the SFGG, the FCM, the Old’Up association and the Fondation Médéric Alzheimer. Faced with such an outcry of disbelief and anger, the Road Safety Authority seemed to take a step backwards quite quickly:

“It is not a question of banning people who have just been diagnosed with Alzheimer’s from driving,” said the organisation, which depends on the Ministry of the Interior, to French newspaper “Le Parisien”, thus contradicting the order and its own press release.

“This decree, in fact, contains several scales: firstly, the person’s doctor provides their analysis but they can ask for the opinion of an approved doctor who can themselves ask for cognitive tests.”

In a joint press release, the SFGG, the FCM, France Alzheimer and Old’Up called for a collective discussion with the Road Safety Authority, which has already expressed its agreement to work together to amend the decree.

France Alzheimer, France Parkinson and APF France handicap have decided to address the Council of State, a process which they initiated some weeks ago.

“What matters, surely, is that we support people through what is a difficult phase of their illness, and which we know is ultimately inevitable: that of stopping driving,” concludes France Alzheimer.

A few words from people living with dementia

Helen Rochford-Brennan, member of the EWGPWD

I am driving, while I still can. When I was diagnosed with early onset Alzheimer’s, it never occurred to me that I might not be able to drive. I was not told so at my diagnosis.

However, at a follow up with my consultant, he informed me that I must tell the road safety authority and my insurer, and that I must take an assessment. I was in a state of shock, as the thought of not driving would depress me.

Of course, I quickly did what was necessary. I think doing a road assessment is a particularly good idea. I am responsible citizen and I would not drive without doing the assessment, though I often feel many of those I encounter driving should perhaps resit their tests!

Driving is a lifeline for me as I live in a rural area with extremely limited public transport, but I always tell myself, “either you can drive safely, or you cannot and when in doubt STOP!” When I am driving places I don’t know well, the GPS can be a big help and, when that fails, for example when it doesn’t know about road closures, Google maps finds the way.

Over the years, I have been told driving is about long term memory, that it requires multiple cognitive functions such as attention, spatial awareness, and memory. It is also about where we are on our own dementia journey, as we are all different.

It is upsetting to me that people still assume that we cannot drive, though from my many years of advocacy I do understand some of the reasons. Something I have heard over and over is “my partner told me not to”, or that side effects of medication prevents people from driving.

As people with dementia, when taking trips, we should give ourselves lots of time, and on exceptionally long journeys take along someone for support if needed. We should also have an assessment annually and, if ever in doubt, reassess the situation, as safety of oneself and others is vital.

Personally, I look forward to many more happy years of driving.

Helene Rochford-Brennan
Carmel Geoghegan, friend and supporter of Helen Rochford-Brennan

For those of us who are not living with a dementia diagnosis, it is impossible to understand what it must mean to even consider never driving again. Driving is a lifeline, in particular in rural areas of any country where public transport is unreliable or non-existent and where neighbours may be some distance away.

On a recent road trip with my friend and inspiration, Helen Rochford-Brennan, she had added me to her car insurance so I could share the driving. As it turned out, she was in full control and I got very little time behind the wheel. Just because someone gets a diagnosis this does not mean they can no longer live a full, independent life.

Let us be non-judgemental and open-minded. I was reminded of the importance of this during our road trip, when we were meeting for coffee with someone who is a distinguished voice for rural ageing, who assumed that I would be driving, not Helen!

Angela Potschnigg, member of the EWGPWD

I myself stopped driving when I got my dementia diagnosis. This is because I was afraid that I might overlook someone or misjudge a situation on the road, because I know that my attention and concentration are not what they used to be.

When I decided to stop driving, I lived in the countryside, in a small community, and a car was almost indispensable and necessary even for everyday shopping. I admit it was difficult. But now I live in Vienna, in a big city, with a well-developed public transport network. I can reach almost any place very easily and quickly with public transport.

On the other hand, apart from the practical side of a car, as a means of transport, every now and then I think somewhat wistfully about how much fun I used to have driving a car.

Many people with dementia tell me that they can drive very well. If the ability is still there, why not?

Here in Austria, it is not forbidden to drive a car with a dementia diagnosis, but the insurance companies make things difficult in case of an accident. The thought that a person could come to harm through my fault is also difficult for me to bear, so I prefer not to take the risk.

My opinion is that the ability to drive should be checked regularly by a driving instructor. This brings clarity and shows self-responsibility. The result of the check can then be helpful for a person deciding whether or not to continue driving.

Petri Lampinen, member of the EWGPWD

I voluntarily gave up the right to drive, as I found myself a danger to others in traffic. I was having trouble with short-term memory, so while I may have thought I was paying attention to where I was going, sometimes I was not. I am happy with the information I have about my symptoms; it helps me to understand things that I can still do safely. Driving a car is no longer going well for me and I understand this perfectly. It is for my protection and for the protection of my fellow human beings!

A bicycle is good enough for me and since my diagnosis with a memory disorder, I have at least started wearing a bike helmet. Better late than never. Brain health should be nurtured in memory disorders.
This is a topic that can vary from country to country and from person to person. Here in Ireland, a lot of people who are newly diagnosed with dementia are told to stop driving immediately. While in some cases it may very well be necessary, in a lot of other cases it can be “going over the top”. When a doctor tells a person with young onset dementia to stop work, stop driving and get their affairs in order, it may not be necessary, in every case to have to do it that fast. Here in Ireland, when you are diagnosed with dementia, you have to tell the driving authority about your diagnosis and they then decide whether or not you are able to drive, by means of a test done every six months.

I am no longer able to drive, but I gave up driving anyway, the day that I got my diagnosis of Lewy body dementia. I suppose I am a bit like a person who is going to go through chemotherapy for cancer and they know they are going to lose their hair: some decide to let it fall out naturally and some decide to shave it off. For me, it was the latter: I decided when it was time to stop driving and not when my disease told me, but that is everyone’s personal decision. People have a right to decide and again, here in Ireland, because dementia is not classed as a disability, people are not entitled to what we call the “blue badge”, which is a permit to allow you to park in the spaces provided for people with disabilities. That, for me, is totally wrong and will stop so many people from being as independent as they could be, for example by going shopping, because finding a parking space and remembering where your car is can, for some people, be a nightmare. Once again, it shows the complete lack of respect that I feel our Government has for people with dementia.

There are also cases where the family knows that their loved one is no longer safe to drive, but it should not be up to the family to tell the person with dementia, as this can cause friction. It should be up to the medical team to tell the person with dementia, if they feel that the reasons given by the family are justified.

Kevin Quaid, Vice-Chairperson of the EWGPWD
COVID-19’s continued impact on people living, or caring for someone, with dementia across the globe

Dr Clarissa Giebel, Senior Research Fellow, University of Liverpool & NIHR Applied Research Collaboration North West Coast, shares details of a new study exploring the effects of the pandemic on dementia carers’ wellbeing, mental health, and access to care.

As we are moving out of the pandemic, the effects of the restrictions can still be felt, and have changed all of our lives in the long-term. That seems to be particularly the case for people living with, and caring for someone with dementia. Very early on in the pandemic, we noticed severe impacts of face-to-face restrictions on accessing and using social care and social support services after a diagnosis, including day care, paid home care, social support groups, and respite care (see https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1822292). In a UK-wide survey, we showed how these social support service closures were linked to poorer mental well-being in those living with dementia and their unpaid carers (see https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5434).

Whilst often forgotten, unpaid carers have been affected negatively as well and need to be considered as individuals requiring support in their own right. Due to the lack of social support services, and the early reductions of receiving external paid home carers to support someone with dementia with daily living activities, many carers took on additional caring duties (see https://link.springer.com/article/10.1186/s12877-020-01719-0). Some carers could not cope without that paid support, however, regardless of their fears of contracting the virus from the care staff, so they decided to continue with paid home care, if available. What’s worse, though, is that some carers wanted to discontinue paid home care during the pandemic, but were too afraid of not getting financial support from their local councils again for that care package, if they decided to discontinue the care for now. These findings have been UK-specific and, since then, much more research has emerged. In order to get a proper overview of the evidence base and how people with dementia and their carers have been affected by the pandemic, I brought together an international team of COVID-19 dementia researchers, all having conducted research in their own countries, from the UK to Germany to Australia. So, let’s talk about what’s been happening on an international scale.

Global impact of the pandemic on people with dementia and carers

We’ve recently conducted a two-part systematic review into the early impacts of the pandemic on people with the condition (see https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2084509) and unpaid carers (see https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2084510?src=recsys). We searched the evidence base for literature on how COVID-19 restrictions and the pandemic more broadly had affected people with dementia and unpaid carers, looking for literature up until July 2021. That is when we conducted our searches.

We were overwhelmed with evidence in the field and still more literature is emerging every week. For that reason, we decided to solely focus on the early impacts of the pandemic, and not the general impacts (such as are now still happening).

Given the large amount of studies we found (46 in total), we decided to split the systematic review into two, to ensure we could dissect the evidence better for each population (people with dementia, carers). Focusing on unpaid carers in part two, we found a whole range of impacts, some noted as early as April 2020, shortly after UK restrictions were imposed. Impacts were noted on accessing care and support, carer burden and well-being. The 36 studies found that carers had limited access to care and support services, increased workload, enhanced feelings of social isolation and reduced well-being. Specifically, reductions in access to care and support increased carers’ unpaid caring tasks, removing any opportunities for temporary respite, and thus further increasing carer burden and reducing mental well-being in many.

What has it been like across different countries?

In this review, we reported on evidence from 18 different countries, including lower- and middle-income countries such as Brazil and India. Across all countries, unpaid carers were severely impacted by the pandemic in terms of increased levels of carer burden, poorer levels of mental well-being, and for those studies looking at care access, reductions in access to support services.

Since this systematic review, our international team from the UK, Australia, Italy, India, and Poland has published a five-country comparison (the first of its kind based on evidence...
Dementia in Europe

from our systematic review) on how people with dementia and unpaid carers have been affected (see https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-022-02821-1). Whilst carers in all five countries have been negatively impacted by the pandemic, this was less severe in India and Poland.

This is because culturally people with dementia are cared for by their family, and generally do not engage, or very little, with external support services. What did affect carers was that the person with dementia was restricted to the home environment, without family members from outside being able to provide support and respite.

Implications for policy and practice

What can we learn from the pandemic and its various impacts on unpaid carers, and the people they care for? In short, a lot. But I fear this is quickly forgotten, so now is the time to put policy recommendations and legislations, and changes to clinical and social care practice, in place to avoid the repeat and continued impact on carers.

For one, access to support was already full of barriers before the pandemic, which has only exacerbated these further. Carers and people with dementia need to have easy access to post-diagnostic support. In the context of face-to-face restrictions, this means that face-to-face support should be enabled for those with dementia and their carers wherever possible, and they need to be upskilled and supported to access remote support. Because what the pandemic has shown is that only accessing remote support, if at all, is a life-line but is not the real thing. Support can be a mixture of both remote and face-to-face, and everyone needs to be enabled to access this. If people fail to, we now know very clearly that this can lead to reduced cognitive, social, physical, and mental health and, in the case of people with dementia, appears to lead to faster deteriorations and possible care home entry.

Secondly, mental health care and support need to be easily accessible for carers from the point of diagnosis. The pandemic has only increased the mental health needs of carers (see https://journals.sagepub.com/doi/full/10.1177/0891988721996816), meaning that many of them will need ongoing access to mental health support. This is not just important for the UK, as our systematic review has highlighted, but also on an EU and global scale. Carers are vital to enable people with dementia to live well and as independently as possible, so it is not right to ignore their needs!

What are the next steps?

Building on this research, I am currently leading a study to explore how paid and unpaid carers for older adults and people with dementia are accessing mental health care, and what their needs are. Paid carers are just as important as unpaid carers, albeit again often forgotten and lacking the right support and recognition.

This study will then underpin interventions to support equitable access to mental health support for both carer groups, trying to tackle some of the many inequalities that carers are facing in getting the care they are entitled to themselves.


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NIHR - Applied Research Collaboration North West Coast

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Tails of success - Dementia dogs are helping people with dementia in Bulgaria and Scotland

Dogs can be a great companions and can also be tremendously helpful to people with disabilities, including people with dementia. A number of initiatives have sprung up, looking at how best to bring dogs and people with dementia together in a successful and mutually-beneficial partnership. Alzheimer Bulgaria and Alzheimer Scotland share two such initiatives from their countries.

Dementia Dog Friends, Bulgaria

Alzheimer Bulgaria has been involved in the project “Dementia Dog Friends”, funded by Solidarity Projects, which is part of the European Solidarity Corps programme. The project started at the end of summer 2021 and ran for one year. The funding for it was EUR 6,740 and one of the objectives of the programme was engaging young people with social problems and improving their project management skills. The project was therefore carried out by five young volunteers who were supported and guided by a mentor from Alzheimer Bulgaria.

The main aim of the project was raising awareness of the problems around communication with people with dementia and the need to improve this. It also focused on the need to improve society’s attitude towards stray animals, of which there are many in Bulgaria. Ultimately, the results of the Dementia Dog Friends project aimed at providing a new social service involving rescued animals, to help improve the emotional state of people with dementia.

Project activities included meetings between people with dementia from the Alexandrovska nursing home for older people, and dogs from the “Every Dog Matters EU” sanctuary. Two training sessions for volunteers have also been held, so far, as part of the project activities. “Every Dog Matters EU” supports the idea of inclusion of animals in social and health services in order to improve the emotional state of patients, as well as to include animals in society.

Project results

The project “Dementia Dog Friends” finished at the end of August 2022, with many positive results. The project started with a study on the good practices and the scientific examinations on the effects of dog therapy for people with dementia. After this, there were two trainings for the young volunteers participating in the project that taught them how to communicate with a person with dementia and with dogs. Topics covered included: “What is dementia?”, “How to communicate with people with dementia in nursing homes”, and “How to manage projects and create reports”. They were given educational cases such as recognising a person with dementia on a photo or sharing how they would react in certain cases (for example, if the person with dementia is angry, sad, nervous, etc.).

The second training aimed at improving the knowledge of the volunteers about stray dogs and the appropriate approach towards them. They were instructed on how to keep the dogs in a friendly and calm mood as well as on how to choose an appropriate dog for a person with dementia. After the two trainings, the volunteers together with their mentors chose different dogs from the “Every Dog Matters EU” sanctuary.

The volunteers had meetings with the people with dementia before they brought the dogs to them. In this way, they had the opportunity to learn more about the people with dementia and to communicate with them. They asked them about stories from their own lives related to dogs, which gave the people with dementia an opportunity to reminisce. Moreover, the volunteers improved their empathy towards people with dementia and their knowledge about the problems they have and the conditions in which they have to live, in Bulgaria.
After these preparatory activities, the team brought the dogs to the nursing home. It turned out to be a positive meeting. The people with dementia opened up to the dogs and started petting and hugging them straightaway. They began talking to the volunteers about their preferences concerning the dogs and sharing more of their own stories (most elderly people in Bulgaria used to live in villages, with dogs in their houses). One woman even said that this was the best day of her life! All of them wanted to have these meetings more frequently. Moreover, besides the positivity that the dogs brought, the people with dementia also had the opportunity to spend some time outside and to talk to younger people. The project even caught the attention of the media in Bulgaria and was praised on TV for helping to raise awareness about the need for a more dementia-friendly, inclusive society.

The Dementia Dog Friends project closed with a final meeting with stakeholders in September and Alzheimer Bulgaria is preparing a final report on the need for such a service, highlighting the positive effect of interaction between the different sections of society. The report will be uploaded on the association’s website. Alzheimer Bulgaria will also try to develop the project further by including organisations with different expertise from Europe.

“Dog Friends of Dementia” is a multi-layered and much needed project. It connects two very vulnerable groups, people living with dementia on the one hand and stray dogs on the other. Both groups are somehow left in the deepest shadows of the society we live in. Our country has no plan whatsoever on how to deal and help people with dementia and how to control the population of stray dogs in a humane way and thus eliminate animal cruelty. Connecting these two groups definitely helps bring awareness to this problem. Meanwhile the regular meetings between the elderly people and the dogs show how beneficial they can be for each other - a better social life, more love and much needed attention for all. With this project we show how stray dogs are much more than unwanted animals - they are a great companion that brings benefits to human physical and mental health.
Innovation forms a common thread through Alzheimer Scotland’s approach, and strongly weaves into Dementia Dog’s work to pioneer different ways of working with specially trained dogs to help people who are living and caring with dementia. This charitable collaboration between Alzheimer Scotland and Dogs for Good, which began in 2012 represented the first project of its type in the world to blend dementia specialist services with the provision of fully trained assistance dogs.

An initial pilot based in east Scotland successfully trained and placed three dementia assistance dogs with couples. The dogs were trained to help maintain a structured routine, act as a social connector out and about in the community and provide an emotional anchor and 24/7 companionship for both the person with dementia, and their carer. The dogs learn a variety of tasks such as responding to an alarm to fetch medication, regulate sleeping patterns, help someone dress, increase physical activity and boost confidence. Together with the added social stimulation a dog can bring by bridging interaction in the community, this can enable a person with dementia to live a better quality of life for longer at home with their family.

Since that time, a further eight assistance dogs were trained and placed with families living in Scotland, each contributing to an independent evaluation study to capture the learning and outcomes of this novel approach to dementia care. This has built evidence to demonstrate the life changing benefits assistance dog programmes can have for families affected by dementia – instilling motivation, joy and independence for the person with a diagnosis, while also providing resilience, respite and hope of positive times ahead for their carer.

In response to the growing number of families being supported it fast became apparent that, while life changing, due to the specific nature of training and matching dogs to families, this approach could only ever benefit a small proportion of the estimated 90,000 people living with a diagnosis in Scotland.

When COVID-19 arrived at UK’s shores heralding an overnight lockdown, we had to think fast on how we could adapt our services to provide the support that continued to be so sorely needed by families throughout Scotland. This was a major challenge for a project where much of the magic is around physical interaction with dogs.

Dementia Dog Scotland

The dogs learn a variety of tasks such as responding to an alarm to fetch medication, regulate sleeping patterns, help someone dress, increase physical activity and boost confidence.”
We started to train the dogs to respond to simple commands given through a mobile or laptop such as ‘sit, stay,’ and built on this to set up regular online sessions with families in their homes, with our Community Dogs (who live with their handlers) interacting on screen and responding to their voice.

Sessions of online ‘doggy bingo’ quickly became a firm favourite in a largely empty calendar, with our team of trained volunteers and pet dogs delivering group sessions with the dog acting as a canine caller, selecting numbered balls out of a box.

This led to much hilarity (and competitiveness) with reports of increased mood and helping reduce loneliness and social isolation which have had such devastating impacts on people over the past few years.

Shaping services around changing needs of families living with dementia

During lockdown and the parallel ‘puppy purchase’ pandemic, the team established a new Family Dog service – providing a one-stop shop of reliable information and advice for families living with dementia who were considering getting a dog.

These workshops enable the team, which consists of expert dog handlers and a dementia specialist, to share their blend of learning and knowledge to help inform families of the various considerations to take on board before “making the leap”.

Underpinning all of this work is the fundamental ethos of shaping our services around the ever-changing needs of families living with dementia, while ensuring our high standards of dog welfare is never compromised.

A truly person-centred approach requires continual reflection, improvement and being fleet of foot, whether that be two or four legged! You can read more about Dementia Dog’s innovations here: [https://www.dementiadog.org](https://www.dementiadog.org)
20 years with no new Alzheimer’s medications in Europe

With the last approval of an Alzheimer’s medicine by the European Medicines’ Agency (EMA) dating back to 2002, people living in Europe affected by Alzheimer’s disease have been waiting to gain access to better treatments for 20 years. We share our thoughts on this and ask two people with dementia to comment on their experience of the “rollercoaster” of hope, expectation and disappointment.

The last approval of an Alzheimer’s medicine by the European Medicines’ Agency (EMA) was in 2002, meaning it has been 20 years that people living in Europe affected by Alzheimer’s disease have been waiting to gain access to new and better treatments. Biogen recently announced that it had notified the EMA about the withdrawal of its marketing authorisation application for aducanumab for the treatment of early Alzheimer’s disease, following discussions with the Agency’s Committee for Medicinal Products for Human Use (CHMP) during which the CHMP had indicated that there was insufficient scientific evidence to support the authorisation of aducanumab, and so the wait for innovative, disease modifying treatments continues in Europe.

Alzheimer Europe continues to monitor clinical trial developments with great interest and notes the welcome announcement by Biogen about the upcoming launch of a phase IV trial of aducanumab. The organisation hopes that this trial and ongoing trials by other companies will lead to positive results and to the approval by the EMA a new treatment against Alzheimer’s disease, after two decades of disappointments.

Alzheimer Europe also calls for continued research into much-needed and anticipated treatment options, including symptomatic treatments for people in more advanced stages of the disease. In addition, the organisation remains committed to a holistic approach to Alzheimer’s disease and dementia where treatment needs to be provided alongside counselling, support and adequate care of people with dementia and their carers throughout the disease process.

A few words from people living with dementia

Angela Pototschnigg, member of the European Working Group of People with Dementia (EWGPWD)

It would be a dream, of course, if a drug were really found that could stop, prevent or even cure dementia. But the developments of the last few years do not give us hope for such a breakthrough. With the last new Alzheimer’s disease drug that was put forward for approval in Europe, I kept reading about warnings because of bad side effects.

It was approved in the USA, but it is controversial, incredibly expensive and the approval in the USA is conditional and may be withdrawn if the company cannot verify that the drug provides the expected clinical benefit. Since I got my dementia diagnosis, I have also been taking a drug. It too has many side effects and when I take it I often worry about the balance between the benefits and how much harm I am doing to my body. It is important to me that the drug regulatory authorities the US Food and Drug Administration (FDA) and the EMA have strict control, because dementia patients are now desperate for drugs and treatments and it can quickly become a billion-dollar game, exploiting our fear. I don’t want to become a pawn of the pharmaceutical industry.

Kevin Quaid, Vice-Chairperson of EWGPWD

It is almost unimaginable that it has been twenty years since the last approval of a new Alzheimer’s disease medication in Europe.

When you consider the amazing advancements that have been made in most other diseases, especially the likes of cancer, you have to wonder, why not dementia?

We had a COVID pandemic and we had a vaccine for that in just 20 months, yet the people in the world who have this horrible condition, which is progressive and incurable, are left waiting year after year.

Recently, there seemed to be some hope after a new drug for Alzheimer’s disease was approved in America, but the European agency didn’t approve the drug as it said there was not enough scientific evidence showing the drug’s benefits. It was so frustrating and disappointing.

The science has to be there, to be able to come up with new medications that will help slow down, cure and maybe even prevent dementia. It simply is not good enough and the time to start righting the wrong is now!
Nutrition has a role in dementia risk reduction and management: Fact or fiction?

Dr Jill Rasmussen is a Primary Care Specialist in Dementia, Learning Disability and Mental Health. She has a specific interest in a holistic approach to risk reduction for, and management of, dementia. In this article, she examines the role of nutrition in dementia risk reduction and management.

In recent years, clinical trials of potential disease-modifying therapeutics that target amyloid in people at risk of, or with, early Alzheimer’s disease have yielded disappointing results. The continued absence of a ‘cure’ for dementia has contributed to delays in diagnosis and fuelled a belief among many primary and secondary healthcare professionals that nothing can be done for people with, or suspected of having, dementia. However, if one takes a broader view of the pathological processes involved in dementia – such as inflammation, mitochondrial dysfunction, synaptic loss and oxidative stress – there is increasing evidence that available interventions can decrease the risk and/or slow the progression of dementia. Interventions that combine a healthy approach to lifestyle with modifications to the nutritional components of diet have proved effective for optimising heart health and have now been shown to decrease the likelihood of dementia, regardless of genetic risk.

The Life’s Simple 7 (LS7) score, which was originally proposed by the American Heart Association for maintaining cardiovascualr health, has also been recommended for maintaining brain health. It comprises seven modifiable health factors, with higher scores associated with lower risk of dementia or cognitive decline: exercising regularly, eating healthily, not smoking, maintaining a healthy weight, keeping blood pressure in check, having healthy cholesterol levels, and maintaining healthy blood sugar levels. Consequently, there has been increasing focus on the importance of nutrition, alone and in combination with lifestyle changes, as a protective factor for dementia, in terms of both modifying the risk of its development and slowing its progression. For example, the European Society for Clinical Nutrition and Metabolism (ESPEN) has published guidelines for nutritional care and support as an integral part of dementia management in all stages of the disease.

What evidence links dementia and nutrition?

Weight loss and associated nutritional deficits often begin prior to dementia diagnosis and become more common with disease progression. The causes of weight loss in people with dementia are complex and multifactorial, and the underlying mechanisms are not fully understood. It is known that changes in olfactory pathways occur many years before overt cognitive decline and this contributes to poor nutrition and weight loss. Studies have indicated the possible value of olfactory impairment as a potential pre-clinical marker of dementia, especially for ApoE4 carriers. Adequate nutrition is vital for brain integrity and metabolism; certain dietary components are the main source of precursors of neurotransmitters, and processes that contribute to neurodegeneration in dementia (e.g., vascular damage, oxidative stress, inflammation) are modulated by specific nutrients. Marked deficiencies in certain vitamins (such as thiamine, folic acid, vitamin B12) are associated with cognitive impairment, and it is thought that milder deficiencies may exacerbate existing cognitive impairment in those at risk of, or with, dementia. Epidemiological studies provide evidence that specific dietary patterns may lower the risk of dementia, and, conversely, that poor dietary patterns are associated with increased dementia risk. Other potential factors that contribute to poor nutrition as dementia progresses include: difficulties with shopping for, storing and cooking food; forgetting to eat, and increasing inability to appreciate the value of a varied and adequate diet; and, in advanced dementia, difficulty with chewing and swallowing. In addition, non-dementia related factors, such as ageing, and other long-term conditions and associated medications, can have a negative effect on appetite and the ability to eat, and thereby contribute to poor nutrition.

Poor nutrition may initiate a cyclical process of deterioration in cognition that exacerbates cognitive impairment in those at risk of dementia and contributes to acceleration of the disease process in those who already have it. Poor nutrition is also associated with greater caregiver burden, which in turn may exacerbate nutritional issues. Therefore, identifying and addressing nutritional deficiencies has the potential to reduce cognitive impairment in those at risk of dementia, and the rate of decline in those who have the condition.

Are specific diets beneficial?

The Mediterranean and Dietary Approaches to Stop Hypertension (DASH) diets are similar in that they are both rich in fruit and vegetables, whole grains, beans, nuts, seeds and olive oil. Importantly, they also have a low
content of meat and dairy products. The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet combines the Mediterranean and DASH diets in a dietary pattern that focuses specifically on brain health. Studies have shown that the Mediterranean, DASH and MIND diets are associated with a significant 20–50% reduction in the risk of cognitive decline and dementia. Moreover, the Mediterranean and MIND diets have been associated with decreased plasma levels of inflammatory markers, the Mediterranean diet has been associated with improved endothelial function and lower adiposity, and the DASH diet has been associated with a reduced rate of cognitive decline, reduced risk of Alzheimer’s disease, and larger total brain volumes in older adults. These results provide strong evidence that nutrition can have a positive impact on the risk of dementia and the rate of cognitive decline.

Are dietary supplements and vitamins beneficial?

Due to the roles played by vitamins, minerals and omega-3 fatty acids in the central nervous system and in maintaining brain health, nutritional supplementation has been suggested as a means of improving cognitive function and decreasing the risk of dementia. Studies of individual supplements have shown mixed results, and a 2018 Cochrane review concluded that folic acid supplementation affords some protection against Alzheimer’s disease, and that a combination of omega-3 polyunsaturated fatty acids and B vitamins in a multinutrient formula provides significant benefits on global cognition and episodic memory in older adults.

Are specific nutrient combinations beneficial?

A nutritional intervention called Souvern (formulated as a drink) was specifically designed to support synapse formation and reduce cognitive decline. It contains the active component, Fortasyn Connect, a multinutrient combination of specific fatty acids, vitamins and other key nutrients that are known to be decreased in patients with Alzheimer’s disease. Evidence from a short-term study suggested a potential benefit in patients with early disease (mild cognitive impairment or prodromal Alzheimer’s disease), and a long-term (8-year), placebo-controlled study showed trends for its benefit on the primary endpoint (change in a neuropsychological test battery score) at 24 months and significant benefits on secondary endpoints of function (clinical dementia rating-sum of boxes [CDR-SB]) and brain atrophy. A subsequent analysis at 36 months showed greater benefit with longer-term use on all previous endpoints, in comparison with placebo, and a more pronounced effect in people who were relatively early in the course of illness.

Summary

In 2015, the aforementioned ESPEN guidelines on nutrition in dementia reviewed available evidence for the role of nutrition in older people with dementia. The overall conclusion from the initiative was that ‘Nutritional care and support should be an integral part of dementia management’. The guidelines include recommendations on screening for malnutrition, monitoring of weight, and the importance of appropriate nutritional support during all stages of the disease. In those with more advanced dementia, they recommend that the individual’s nutritional status be assessed in a comprehensive way, in order to develop personalised interventions that are nested in a multidisciplinary and integrated model of care. The guidelines do not advocate supplementation with single nutrients, unless there is a sign of deficiency.

Since 2015, considerably more evidence has emerged on the benefits of good nutrition for both people at risk of, and with, dementia. Nutritional components of diet that were known to be effective for optimising heart health have now been shown to have a significant impact on brain health, decreasing the risk of dementia by 20–50%. The benefits of nutrition are not just seen for cognition and risk for dementia. Evidence from studies of specific diets (Mediterranean, DASH, MIND) has demonstrated benefit on broader aspects of neurodegeneration associated with dementia; namely, inflammation, mitochondrial dysfunction and oxidative stress. More recent evidence from the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study has shown the benefit of combining nutritional and lifestyle interventions.

The weight of evidence confirms the value of nutritional interventions alone, or in combination with other lifestyle approaches, in people at risk of, or with, dementia. The inclusion of these approaches in management of dementia should be embraced positively by healthcare professionals. These approaches have proven efficacy, no safety issues, are not costly and do not require adjustment of clinical practice or pathways to initiate. Rather, they need to be promoted for people at risk of, or with, dementia, just as similar approaches have been promoted for cardiovascular health.

FACT: There definitely is a role for nutrition in dementia risk reduction and management.

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To pioneer nutritional solutions that help people live longer, more joyful and healthier lives.

**TauRx** has a mission to discover, develop and commercialise new products for the diagnosis, treatment and cure of neurodegenerative diseases caused through protein aggregation.

Tau pathology is widely recognised as a principal driver of clinical dementia in Alzheimer’s disease and TauRx’s Tau Aggregation Inhibitors (TAIs) target the formation or aggregation of tau ‘tangles’ in the brain.

GT Diagnostics, a joint venture between Genting Bhd and TauRx, aims to transform the diagnostic pathway by launching cost effective and accurate assessment tools for dementia.

Learn more about our research and progress at [www.taurx.com](http://www.taurx.com).
Our members are helping people with dementia and their carers in 32 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