Vicky McClure
BAFTA award-winning British actress comments on how co-founding “Our Dementia Choir” has changed her life

Frank Golden
Irish Dementia Working Group member discusses publishing his novel after a diagnosis of dementia

Jane Mahakian
Founder and Chair of Alzheimer’s Care Armenia speaks about the country’s new dementia strategy

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Welcome

It is with great pleasure that I introduce the 42nd edition of our Dementia in Europe magazine, filled with important updates on European and national policy developments in the dementia field, including national dementia strategy news, initiatives on better ageing and combating ageism, campaigning for governments to prioritise dementia, recent developments in dementia care, long-term care and in ensuring the voices of dementia carers are heard at the European level. We also include updates on European research projects and other areas of research related to prevention and to continence care, as well as articles related to the inclusion of people with dementia in the arts and in cultural activities.

We open the Alzheimer Europe section with a report on our most recent European Parliament lunch debate, held in February 2023, which focused on dealing with behavioural and psychological symptoms in dementia care. I would like to thank MEPs Sirpa Pietikäinen (Finland) and Deirdre Clune (Ireland), Chairperson and Vice-Chairperson of the European Alzheimer’s Alliance, respectively, for co-hosting this highly interesting and interactive session.

Alzheimer Europe has recently launched the European Dementia Carers Working Group (EDCWG), to give carers and supporters of people with dementia a voice at the European level and to ensure their priorities and views are reflected in the work of our organisation. The EDCWG’s first in-person meeting was held in March 2023 and included elections for the positions of Chairperson and Vice-Chairperson, both of whom are introduced in this article, as are the remaining members of the group.

The other two articles in this section focus on European research projects VirtualBrainCloud and the European Platform for Neurodegenerative Diseases, with the former having just come to a close and the latter having launched a new online Cohort Catalogue featuring more than 60 research studies on Alzheimer’s disease and other neurodegenerative disorders.

In the Policy section we take a look, firstly, at some important national developments, starting with Jane Mahakian, Founder and Chair of Alzheimer’s Care Armenia updating readers on her country’s first ever national dementia plan. We also report on the French National Assembly establishing a dedicated working group on Alzheimer’s disease designed to create a community of parliamentarians aware of the condition and relevant policy issues; the Alzheimer’s Society in the UK leading a high-profile campaign and delivering an open letter signed by over 36,000 people calling on the UK Prime Minister to deliver on previous government commitments; and the Irish Alliance of Age Sector NGOs launching a report on combating ageism.

At the EU level, we include an article about a high-level meeting on active and autonomous ageing organised as part of Sweden’s Presidency of the Council of the EU, in February 2023. We also give readers a round-up of several recent developments concerning the European Disability Card, the future of social protection and the welfare state, Horizon Europe health research proposals, and the Fundamental Rights Agency’s UNCRPD indicators report. Closing off the policy section, we discuss a Global Ageing Network call for action on ageing and long-term care.

Our third and final section, Dementia in Society, starts off with three articles looking at various aspects of dementia in the arts and of inclusive cultural activities.

The first is an interview with Frank Golden, about his new novel “The Irish Job”, which explores the role of intelligence in the Irish War of Independence (1919–1921). The author, who is living with dementia and is a member of the Irish Dementia Working Group, has drawn on the experiences of his father, a close associate of Irish revolutionary, soldier and politician Michael Collins.

The second piece explores how music can help people with dementia, through the lens of “Our Dementia Choir”, which started out as a BBC TV programme five years ago, fronted by BAFTA award-winning British actress Vicky McClure who is also an Ambassador for the UK Alzheimer’s Society, while the third is an article from Alzheimer Portugal, which has joined 11 other institutions to form a new informal network called “Museums for Inclusion in Dementia”.

We end this section and indeed this magazine with a look at two different scientific publications. The first is an interview with two authors of a recent research study examining how continence care impacts on people with dementia in acute hospital settings. The second is an interview with the lead author of a set of guidelines for innovative services to help prevent Alzheimer’s disease, published in the journal Lancet Regional Health – Europe and put together by an international task force, headed by the University of Geneva (UNIGE) and Geneva University Hospitals (HUG) and including Alzheimer Europe Executive Director Jean Georges.

I hope you enjoy this edition of the magazine and wish you all a nice summer ahead!
Alzheimer Europe lunch debate focuses on dealing with behavioural and psychological symptoms (BPSD) in dementia care

Alzheimer Europe held its first European Parliament lunch debate of 2023 on 21 March, in Brussels. The session explored how to deal with behavioural and psychological symptoms (BPSD) in dementia care and was hosted by Sirpa Pietikäinen MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA) and Deirdre Clune MEP (Ireland), Vice-Chairperson of the EAA.

The Alzheimer Europe lunch debate of 21 March 2023, focusing on “Dealing with behavioural and psychological symptoms (BPSD) in dementia care”, was a hybrid event attended by MEPs and other representatives of the European Parliament, the European Commission, Health Ministries and other national policymakers, industry partners, researchers, members of the European Dementia Carers Working Group (EDCWG) and Alzheimer Europe member organisations, Board and staff. There were 111 participants in total, with 78 of these attending in person and the remaining 33 joining online.

Sirpa Pietikäinen MEP opened the session with a warm welcome to all delegates both in Brussels and online. She began by highlighting that over 90% of people with dementia experience BPSD, making this a vast issue and one which can be hugely stressful for carers and others close to the person, as well as for medical professionals and of course for the person experiencing the symptoms.

Sirpa Pietikäinen MEP opened the lunch debate, introducing the topic and the speakers

She asked those present to imagine that they were experiencing a memory lapse themselves, for example having misplaced their phone and that, rather than helping to find it, those around them offered them a coffee and a biscuit and told them to calm down; that perhaps they were mistaken and had never had the phone in the first place. In the case of someone experiencing a situation like this because of their illness, the frustration and the confusion is just as real, she pointed out, even if the loss of the item may not be. “I would get mad as hell if someone didn’t take my needs and problems seriously!” she exclaimed, noting that we should carefully consider the ways in which we interact with people with dementia and how we can better help them to feel less anxious, stressed, or agitated.

Sirpe Banerjee discussed the impact of agitation and aggression on the well-being of people with dementia and their carers

Overall, she drew attention to the importance of first understanding the root cause of a problem, before responding accordingly, “as we would do for a blind person, we should do the same for a person with a brain illness”. She also stated that she was proud and delighted to host this lunch debate and introduced the first speaker, Sube Banerjee, Professor of dementia and Executive Dean of the Faculty of Health: Medicine, Dentistry and Human Sciences, University of Plymouth, United Kingdom.

Sube Banerjee discussed the impact of agitation and aggression on the well-being of people with dementia and their carers

Sube Banerjee discussed the impact of agitation and aggression on the well-being of people with dementia and their carers. His talk aimed to put in context some of the issues of BPSD and of quality-of-life for people with dementia. He suggested that one of the services we need to provide is to identify and help with BPSD. He referred back to what Sirpa Pietikäinen had said about how common BPSD are, with 90% of people with dementia experiencing them at some point during their illness.

Focusing particularly on agitation, which is both very common and very intrusive as well as persistent, he stated that it was important that dementia should not be the first explanation that we attribute this to.
“Dementia should be the last thing we peg agitation on”, he said. First, we should consider: unmet needs (pain, hunger, thirst, constipation, delirium); response to a stimulus in the environment (over/under stimulation, overcrowding, inconsistent routine, provocation by others, noise, light activity); psychosocial needs (stress, loneliness, depression, lack of purpose); responses to the approach of carers, nurses, or other residents; and lastly, dementia. Agitation is absolutely worth looking at, he said, as we can really make a difference.

From Prof. Banerjee’s perspective, pharmacological solutions are not the answer, in most situations. They often don’t help, he said and indeed can make things much worse. He shared results from studies which backed up this assertion and said that we should reduce the use of antipsychotics (which can work to an extent, but lead to increased mortality rates in people with dementia) and of other drugs. He questioned why medical professionals persist in administering these drugs.

There are, however, things that do work and that we can do, he said, noting that in 2014, there had been 33 trials of non-drug treatments. These showed that person-centred care, communication skills training, adapted dementia care mapping and sensory intervention decreased symptomatic and severe agitation immediately, while activities and music therapy decreased overall agitation. These solutions, though proven to be much more effective than drugs, are very seldom provided as part of any response to BPSD.

Careful assessment, imaginative care planning, information, support, problem solving and working with families is the way forward, he stated. Our approach has to change, said Prof. Banerjee. Funding needs to be in place and policymakers and healthcare providers need to be informed and convinced that change is needed. We cannot solve the existing problem overnight, but “there is no rationale for doing nothing”, he concluded.

Sirpa Pietikäinen MEP thanked Prof. Banerjee for his presentation and complimented him highly for his candidness.

She then introduced Jacqueline Hoogendam, Co-ordinator for international affairs on dementia, long-term care and ageing, Ministry of Health, Welfare and Sport, Netherlands.

“Act on Dementia” recommendations to improve crisis and care co-ordination

Jacqueline Hoogendam’s talk revolved around improving crisis and care co-ordination and drew on the recommendations of “Act on Dementia”, the EU Joint Action on Dementia. She agreed with the previous speaker that the situation is not easy to resolve quickly and noted that a multidisciplinary approach is needed. Medication may be needed in some cases, she said, but should not be the first or only choice.

She shared some best practices from the Act on Dementia findings: In France, multidisciplinary mobile teams existed, to help people in more isolated, rural settings; in Italy, there was a system with a more regional approach, with regional hospitals for treatment or assessment of BPSD or causes of crisis; Scotland had post-diagnostic support centres; while in the Netherlands, they trained case managers.

Regarding the latter, she highlighted that it soon became clear that a different approach was needed by the case managers, dependent on the individual, stage and type of dementia.

There are many differences in BPSD and its causes, she said and noted that the main point established by the Dutch training was that every case manager should get to know the person, their habits and their likes and dislikes. She gave the example of a woman who hated the popular Dutch songs that were being played in her care home. She got agitated and frustrated regularly but no-one knew, for quite some time, that this was due to the music that was being piped into the communal areas of the home. Once this was understood, the case manager was able to give the woman a device with headphones, to play classical music (Mozart was her favourite). The agitation all but stopped. Of course, Ms Hoogendam conceded that solutions for BPSD are rarely so simple, but sometimes they can be.

In closing, she listed meaningful activity, feeling respected, informed and listened to, as the main contributing factors to helping prevent these crises.

Sirpa Pietikäinen thanked Jacqueline Hoogendam and complimented her for her respectful presentation. She then introduced Øyvind Kirkevold, Assistant Research Director, Norwegian National Advisory Unit on Ageing and Health, Norway.

Quality in Residential Care – Evidence and Recommendations

Øyvind Kirkevold shared some recommendations about BPSD in residential care, from Act on Dementia Work Package 6, “Quality in Residential Care – Evidence and Recommendations”. Firstly, he discussed non-pharmacological interventions, highlighting the need, first and foremost, for person-centred care. Using a set of activities, including sensory interventions (music therapy, aroma therapy, massage) and structured activities (dance, exercise, gardening and other hobby activities), was the first recommendation. “We recommend that all residential care units implement routines for a systematic approach to challenging behaviour”, he said, noting that these should be based on the principles of the TIME (Targeted Interdisciplinary Model for Evaluation) or DICE (Describe-Investigate-Create-Evaluate) models, or other similar models.
logical interventions have clearly been shown
Kirkevold summarised that non-pharmacological interventions have clearly been shown to be effective and we have to know that the way we approach BPSD, but some of the main challenges that stand in the way lie in how to translate evidence-based frameworks into practical tools and to implement these tools into practice”, he stated. When well implemented, these approaches are feasible and efficient, but the implementation process may be demanding. Resources are not sufficient and we have to know that the way we work will have an effect on the people we want to help and that it will be adopted into the organisation properly. In closing, Øyvind Kirkevold summarised that non-pharmacological interventions have clearly been shown to reduce BPSD (especially agitation) with the approaches they used in this Joint Action.

Sirpa Pietikainen thanked Øyvind Kirkevold for his very interesting and informative presentation and introduced the final speaker, Sara Fascendini, Director, Alzheimer Medical Centre, Fondazione Europea Ricerca Biomedica, Italy and co-lead of the Respectful Caring for Agitated Elderly (RECaGe) project.

Respectful Caring for Agitated Elderly (RECaGe) project
Sara Fascendini drew attention to the fact that the RECaGe project was funded by the European Union Horizon 2020 programme and then began her presentation by telling delegates what approach the project had taken.

In a small town near Bergamo, Italy, a Special Care Unit for BPSD (SCU-B) was set up. SCU-Bs, she explained, are residential medical structures lying outside of a nursing home, in a general hospital or elsewhere, for example in a private hospital. Patients with BPSD are temporarily admitted to such units, when their “behavioural disturbances” are not manageable at home, she explained and “the mission of the SCU-B is to improve patients’ behaviour, so as to allow, where possible, their return home”, she continued.

The therapeutic approach in most of the existing SCU-Bs is a mixture of cautious pharmacological treatments, rehabilitative and non-pharmacological therapies (occupational therapy, physiotherapy, doll therapy, pet therapy...), creating an appropriate environment and ensuring a trained staff of experts (composed of doctors, psychologists, educators, occupational therapists, physiotherapists, nurses and healthcare professionals). “The staff training is the core of our work”, she said. They try to go deeply into the personal history of patients in the SCU-B and try to understand the reasons for their behaviour, so as to manage it accordingly.

There were 150 stakeholders across the seven countries involved in the project (France, Germany, Greece, Italy, Netherlands, Norway, Switzerland). Focus groups and interviews were used and the data from these and from a scoping literature review was analysed and presented at the RECaGe Consensus Conference in Brussels, on 21-22 February 2023.

Despite the fact that, unfortunately, the study did not achieve its primary endpoints, Ms Fascendini stressed that the evidence found in the literature on the acute effectiveness, as well as the shared common experiences from physicians running SCU-Bs across Europe, showed that SCU-Bs can successfully tackle acute challenging clinical situations that are not easily manageable at home. The SCU-B, she said, “can be regarded as socially innovative” insofar as it satisfies a social need that is largely unmet, that the unit provides patients and their families with strong crisis support from a skilled team and that it is a “privileged place” for the training of health workers and caregivers. She also noted that implementation of new SCU-Bs is recommended in countries which lack them completely or have only a few, if only in an experimental manner.

In any case, she particularly highlighted the importance of using SCU-Bs “only as a component of a comprehensive network of dementia care”. The model received positive feedback from experts involved, across the different countries, but there is a lack of resources, which is the main barrier to implementing it. A political commitment to putting SCU-Bs into practice is essential, she insisted.
Questions and discussion

Deirdre Clune MEP, co-host of the event, thanked all the speakers and the attendees and opened the floor for questions.

Jean Georges, Executive Director, Alzheimer Europe echoed Ms Clune’s thanks and drew attention to an oversight in the programme. “I realise that the four excellent speakers here today have covered the experience of managing BPSD by healthcare professionals in great depth, but that the experience of people living and caring at home needed more attention. How can we support and better train carers at home to deal with BPSD, so as to avoid crisis situations requiring emergency care in hospitals or a move to residential care?” he asked.

Sube Banerjee responded that this was absolutely fundamental and that, in fact, everything he had said in his talk was about people in their own homes as much as it was about those in hospitals and care homes. The critical thing, he stressed, is to enable identification at an early stage and to support people to remain living in their own homes. He also noted that much of what he said was about carer intervention as well, which he said was equally important.

“If we can intervene on both sides, help both parties (person with dementia and carer), we can avoid the lose-lose and go for the win-win”.

Jacqueline Hoogendam admitted that carers had not come into the foreground as much as perhaps they could have in her presentation, due mainly to a lack of time, but noted that the Joint Action had produced a number of leaflets for informal carers, to help support them in crisis situations.

Mary Frances Morris, shared that she had been a carer for both her parents over a period of 10 years. She agreed with Prof. Banerjee that neuropsychiatric symptoms were key to quality of life and that quality of care was essential. Both her parents stayed at home. She was there much of the time and so was able to ascertain that it was often poor training that led to difficulties in managing crisis situations. This lack of training occurred, she emphasised, because care agencies “skipped, to cut cost and increase profit”.

She wondered whether others agreed that there was a need to change attitudes at government level, to ensure that care agencies were not employed if they did not use correct and proven methods and did not ensure proper staff training.

She mentioned the Alzheimer’s Society’s Dementia Carers Count, which upskills carers and supports them in their work. She also highlighted the importance of taking a proactive rather than a reactive approach, where possible, so that a crisis can be avoided and underlined the need to upskill health-care workers such as nurses and other staff, not just carers. “Training in dementia is scant among professionals who are supposed to support us”, she said.

Øyvind Kirkevold agreed and mentioned a project in Norway which tries to identify highly trained staff as well as identifying people in the most vulnerable situations and to anticipate, rather than react.

Deirdre Clune closed the lunch debate, thanking everyone for their participation and giving a special thanks to Alzheimer Europe for bringing everyone together. She was pleased to see that there was a great deal of interesting work happening and said that it was vital that these best practices were implemented.

The videos of the presentations from the lunch debate can be watched here: https://www.youtube.com/playlist?list=PLO-PgQHiWQUu-hx-hoF8uBtNSy7syw

Paddy Crosbie, member of the EDCWG, commented on the importance of person-centred care
Snapshots from the lunch debate
Alzheimer Europe is proud to launch the European Dementia Carers Working Group

The European Dementia Carers Working Group (EDCWG) was launched by Alzheimer Europe to help ensure that the voices of carers and supporters of people with dementia are heard at the European level and that their priorities and views are reflected in the work of the organisation. The EDCWG’s first in-person meeting was held in Brussels on 21-22 March 2023 and included elections for the positions of Chair and Vice-Chair, which went to Sonata Mačiulskytė and Trevor Salomon, respectively.

In December 2022, Alzheimer Europe was delighted to announce the launch of the European Dementia Carers Working Group (EDCWG). The group is composed both of current carers, relatives and supporters of people with dementia, and of people with prior experience in a carer’s role, within the five years prior to their nomination to the group. The members of the group are nominated by the member associations of Alzheimer Europe in their countries and the group’s mandate is for two years. In tandem with the European Working Group of People with Dementia (EWGPWD) a group composed entirely of people living with dementia themselves and set up by Alzheimer Europe and its members in 2012 – the new carers group will work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of carers and supporters of people with dementia.

In particular, members of the group will advise the organisation on how to involve carers and will make recommendations for improvements, when necessary. Members of the EDCWG will be involved in the development of policy documents issued by the organisation and take an active part in consultations in the context of EU-funded research projects. The Chairperson of the group, Sonata Mačiulskytė, is an ex-officio member of the Board of Alzheimer Europe, with full voting rights (as is the Chairperson of the EWGPWD, Chris Roberts).

The creation of the EDCWG was proposed in Alzheimer Europe’s Strategic Plan (2021-2025) as part of the objective of “providing a voice to people with dementia and their carers” and was included in the organisation’s 2022 Work Plan. Alzheimer Europe aims for gender balance in the group (each sex represented by at least 40% of the membership).

Jean Georges, Executive Director of Alzheimer Europe, said: “This is truly an exciting step for Alzheimer Europe and will help us to ensure we can continue to give a voice to carers of people with dementia and to improve and extend how we do this, throughout all our activities. For many years, we have championed the importance of listening to and amplifying the voice of people with dementia, through the EWGPWD, which does fantastic and important work.”

“The accompanying carers and supporters are also vital to this work, supporting the attending people with dementia (and not speaking on their behalf). The views and experiences of carers are, however, often quite different from those of the people they are supporting and in some EU projects, separate focus groups were organised, as researchers were looking for feedback from carers, as well as from people with dementia. This led us to the decision to set up the ECDWG and I personally look forward to the same successful partnership with this new group, and warmly welcome its Chairperson Sonata Mačiulskytė to the Board of Alzheimer Europe.”

In December 2022, Alzheimer Europe was delighted to announce the launch of the European Dementia Carers Working Group (EDCWG). The group is composed both of current carers, relatives and supporters of people with dementia, and of people with prior experience in a carer’s role, within the five years prior to their nomination to the group. The members of the group are nominated by the member associations of Alzheimer Europe in their countries and the group’s mandate is for two years. In tandem with the European Working Group of People with Dementia (EWGPWD) a group composed entirely of people living with dementia themselves and set up by Alzheimer Europe and its members in 2012 – the new carers group will work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of carers and supporters of people with dementia.
The Chairperson and Vice-Chairperson discuss their priorities and hopes for the group

Alzheimer Europe spoke to Sonata Mačiulskytė and Trevor Salomon the group’s Chair and Vice-Chair, to ask them why they joined, what their priority is, what they hope the group will achieve and why they feel that working groups like the EDCWG and national dementia carers’ working groups are important.

Sonata Mačiulskytė, Chairperson

The community of dementia carers in the country that nominated me is just under formation, so I find it important to network with similar communities in other countries, in order to communicate, cooperate, support and join forces to raise dementia awareness in a more diverse range of European languages. Every voice and effort matters in making dementia an important part of the political agenda in all countries, equally. I have always been an action person. I’m clearly aware that in order to achieve change, you need to start the change yourself, so it seemed quite natural to me, not only to become a member of the EDCWG, but also its Chairperson.

The EDCWG is freshly established, so we need to create a certain identity for it, which will complement the EWGPWD, but at the same time highlight and address the problems of dementia carers. I dream about bringing together an international community of carers, where every member is heard and has an opportunity to express themselves. I enjoy being among like-minded people and creating a space where everyone feels involved. It is also important that we, as the EDCWG, respond to Alzheimer Europe’s expectations and goals, for which this group was created.

Carers can be of different ages, levels of education, personal and professional experience, gender, etc. Carers are an underestimated group on the dementia agenda. Meanwhile we have our own needs in the care process. Many of us are in the most active professional and career period when we become carers, we have family and professional obligations as well as a deep personal responsibility to take the best possible care of our loved ones with dementia. We experience a huge burden, the highest risk of burnout, social isolation, and we risk developing various self-destructive behaviour modes.

Groups like the EDCWG address the issue of carers as a separate as well as a complex one, within the huge topic of dementia. I believe this group may bring valuable insights in the dementia field.

Trevor Salomon, Vice-Chairperson

I’ve always believed that life and knowledge are both enriched when we engage with people from a range of cultural backgrounds and living in different countries. As a carer for my wife who has dementia I found that, whilst I learnt hugely from specialist dementia charities and organisations, I always gained more from interacting with other carers in the same position as me. But my knowledge and theirs was always limited by known best practice and government policies in our own country.

So, when I was approached to be nominated for the EDCWG, I jumped at the opportunity. I realised it was exactly the right forum for me to understand how dementia carers across Europe were managing the stress and challenges of looking after someone with dementia and also to learn about what support was available from their governments, both financial and otherwise. Equally I would be able to share my experiences and speak about the benefits available from the UK Government.

My hope and aspirations for the group are therefore the emergence of personal best practices which everyone can consider and potentially adopt, and policy support which may be embraced by local Alzheimer’s societies to lobby government in-country. In terms of chairing or being Vice-Chair of the group I was happy to put myself forward because I’ve been used to managing European and global teams throughout my career as an International Marketing Director. The key word here though is “team”.

First and foremost I am a team player and I really don’t mind what role I undertake, provided I am making a contribution for the greater good.
The members of the EDCWG

Sonata Mačiulskytė (Chairperson)
Sonata Mačiulskytė lives in Klaipeda, Lithuania. She has been a caregiver since 2014, when her mother was diagnosed with Parkinson’s disease, and the first signs of pre-dementia started to show up in her behaviour in 2015. Sonata was nominated by Demencija Lietuvoje (Dementia Lithuania).

Trevor Salomon (Vice-Chairperson)
Trevor Salomon lives in London, England. He chose to step away from his job in 2011 to devote time to his wife Yvonne and her emerging memory problems, which were eventually diagnosed as early-onset Alzheimer’s disease when she was 57 years old. Trevor was nominated by Alzheimer’s Society.

Peter Banda (Slovakia)
Peter Banda is from Slovakia and now lives in Graz, Austria. In 2018, his mother was diagnosed with Alzheimer’s disease and experienced a rapid disease progression. Peter was nominated by the Slovenská Alzheimerova spoločnosť (Slovak Alzheimer’s Society).

Paola Borghesi (Italy)
Paola Borghesi, lives in Rome, Italy. She was a carer for her mother who lived with Alzheimer’s disease from the age of 75 until her death at the age of 89, in 2021. Paola was nominated by Alzheimer Uniti Onlus.

Paddy Crosbie (Ireland)
Paddy Crosbie lives in Dublin, Ireland. He was a carer for his husband Derek, who was diagnosed with early-onset Alzheimer’s disease at the age of 58. Derek passed away in November 2021. Paddy was nominated by The Alzheimer Society of Ireland.

Sylva Dneboská (Czech Republic)
Sylva Dneboská is from Prague, Czech Republic. When her husband Miloš was diagnosed with Alzheimer’s disease, she became his carer, which she did for more than seven years, until he passed away in May 2022. She was nominated by Česká alzheimerovská spořitelna (Czech Alzheimer Society).

Chris Ellermaa (Estonia)
Chris Ellermaa is from Tallinn, Estonia. Her journey as carer lasted more than six years, while she supported her mother who was diagnosed with Alzheimer’s disease. Chris was nominated by Elu Dementia susega (NGO Living with Dementia).

Zornitsa Karagyozova (Bulgaria)
Zornitsa Karagyozova is originally from Sofia, Bulgaria. Her journey as a carer began in 2020, when her father was diagnosed with Alzheimer’s disease, aged 78. Zornitsa was nominated by Alzheimer Bulgaria.

Magnús Karl Magnússon (Iceland)
Magnús Karl Magnússon lives in Reykjavík, Iceland. He has been a carer to his wife Elly, since 2016, when she was diagnosed with early-onset Alzheimer’s disease at the age of 51. Magnús was nominated by Alzheimer Iceland.

Filomena Martins Cunha (Portugal)
Filomena Martins Cunha lives in Lisbon, Portugal. She was a carer for her mother, who was diagnosed with Alzheimer’s disease. Filomena was nominated by Alzheimer Portugal.

Katarzyna Mazuruk-Russ (Poland)
Katarzyna Mazuruk-Russ (Kate) is from Warsaw, Poland, where she has lived her entire life. For several years, she helped care for her aunt who had Alzheimer’s dementia and who sadly passed away in early 2023. Kate was nominated by Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera (Polish Alzheimer Association).

Barry Northedge (Scotland, UK)
Barry Northedge lives in the Highlands of Scotland, near Loch Ness. His wife Margaret was diagnosed with early-onset Alzheimer’s disease about eight years ago when she was 55 years old and he retired just over three years ago to support her. Barry was nominated by Alzheimer Scotland.
Liv Thorsen (Norway)

Liv Thorsen is from Gjøvik, a small town north of Oslo, Norway. She is carer to her husband Kjell, who received a diagnosis of Alzheimer's disease eight years ago. Liv was nominated by Nasjonalforeningen for folkehelsen (Norwegian Health Association).

Roslynn Vella (Malta)

Roslynn Vella lives in Żebbuġ, Malta. Nine years ago, she came to the realisation that her mother Elizabeth, also known as Alice, had early-onset dementia, at the age of 58. She, her father and brother are Alice’s carers. Roslynn was nominated by Malta Dementia Society.

Alternates

The group has three alternates, Eileen Deehan (Scotland, United Kingdom), Jayne Goodrick (United Kingdom) and Aisling Harmon (Ireland).

“This is truly an exciting step for Alzheimer Europe and will help us to ensure we can continue to give a voice to carers of people with dementia and to improve and extend how we do this, throughout all our activities.”

Jean Georges

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

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The VirtualBrainCloud: paving the way for personalised diagnostics and interventions for Alzheimer’s disease

VirtualBrainCloud was launched in December 2018, aiming to accelerate brain research and enable personalised clinical decision-making. As VirtualBrainCloud draws to a close, we look back at some of the project highlights, and speak to the VirtualBrainCloud Coordinator, Prof. Petra Ritter, about her reflections.

The last decade has seen a dramatic expansion in the use of artificial intelligence (AI) across sectors, organisations and applications. From vehicle navigation tools to algorithms that predict the performance of financial markets, AI is powering solutions that help us work smarter and make our lives easier.

The VirtualBrainCloud project, which is now drawing to a close, was built around this premise, aiming to harness AI to accelerate brain research and improve personalised clinical decision-making. Personalised medicine is often touted as the future of modern healthcare, with prevention and treatment strategies that are tailored to individual patients. Personalised approaches, which have the potential to be much more effective for individuals than existing “one size fits all” therapies, could dramatically improve the lives of patients – and are sorely needed in the Alzheimer’s disease (AD) field, where there is a major lack of effective disease-modifying treatments.

Unfortunately, the scale of unmet medical need in AD is paralleled by its biological complexity. As an age-related neurodegenerative disease, AD is commonly accompanied by multiple comorbidities, and is characterised by dysfunction in many areas of the brain, affecting a wide range of cells, biological processes, and molecular pathways. This complexity is a major challenge for researchers and clinicians alike, making it hard to develop representative models of AD, and identify specific disease mechanisms that could be targeted therapeutically. VirtualBrainCloud was designed to address this challenge head-on, and pave the way for personalised diagnostics and interventions to improve the lives of people with AD, dementia and other neurodegenerative disorders.

VirtualBrainCloud: personalised recommendations for neurodegenerative disease

VirtualBrainCloud was launched in December 2018, funded for a period of 4½ years by the Horizon 2020 EU Research and Innovation programme, and involving 17 partner organisations from 10 countries in Europe. Coordinated by Professor Petra Ritter of the Berlin Institute of Health at Charité University Hospital, VirtualBrainCloud merged the efforts of two high-profile EU initiatives: The Virtual Brain simulation platform of the Human Brain Project, and the Innovative Medicines Initiative AETIONOMY project.

Alzheimer Europe was a partner in VirtualBrainCloud, contributing to public involvement, dissemination and ethical activities and working alongside clinicians, bioinformaticians, biologists and computer scientists to deliver the VirtualBrainCloud platform: a cloud-based environment that leverages the potential of big data and AI for personalised prevention and treatment of AD and other neurodegenerative diseases.

The Virtual Research Environment

One of the major results of VirtualBrainCloud is its Virtual Research Environment, or VRE. Built on the FAIR guiding principles – making data Findable, Accessible, Interoperable and Reuseable - the VRE was developed as a secure environment for complex biomedical analyses of data from brain imaging scans, medical tests and more.
A cornerstone of the VRE is ensuring the privacy and rights of data subjects are respected, and as such the platform has undergone an external General Data Protection Regulation service readiness audit, which confirms its compliance with EU data protection laws. The VRE is also embedded in the European Open Science Cloud (EOSC), a federated, multi-disciplinary research environment which links VirtualBrainCloud to almost 50 other EU projects and initiatives.

The goal of the VRE is to enable researchers to find, securely access and use clinical datasets in innovative ways. It provides a rich ecosystem of tools, integrations and support resources, such as a segregated “green room” zone to capture and pre-process sensitive data, and an analysis workbench powered by high-performance compute resources. The VRE helps researchers extract insights from their data by supporting them through all stages of the data lifecycle, from ingestion and pseudonymisation to harmonisation, analysis, visualisation and storage. Importantly, the VRE provides pathways for data sharing; de-identified datasets can be securely discovered and reused in the cloud, multiplying the impact of clinical research studies and maximising the societal benefit of data.

**Brain simulations to help classify Alzheimer’s disease**

James Watson, who won the 1962 Nobel prize for his work on the structure of DNA, said “the brain is the most complex thing we have yet discovered in our universe.” This was no understatement: the brain has 86 billion neurons and over 150 trillion connections, organised into two hemispheres, four lobes, and eleven distinct areas, controlling every process that happens in our bodies. The brain is also a very inaccessible organ, presenting researchers with a unique challenge when trying to understand its functions – and dysfunction – in health and disease. Digital simulations offer a unique window into the brain: by pooling and analysing data from tests such as EEG and MRI scans, it is possible to simulate the multi-scale interactions that occur between neurons deep within the brain. However, this requires enormous data and energy resources, far beyond the capacity of even the most sophisticated and high-powered data centers.

Instead, VirtualBrainCloud harnessed a more efficient, streamlined approach to simulate individual brains. Building on efforts in The Virtual Brain and BrainModes projects, VirtualBrainCloud created accessible pathways and tools for personalised brain simulations with sufficient complexity to enable practical research and clinical applications. Using AI, VirtualBrainCloud created dynamic network models of different neuronal populations and then used these simulations to infer biological processes happening in the brain during the development of neurodegenerative diseases.

To explore the value of this approach for clinicians and patients, VirtualBrainCloud researchers constructed brain simulations based on data from the Alzheimer’s Disease Neuroimaging Initiative (ADNI) study, including brain scan data from 10 participants with AD, 8 participants with mild cognitive impairment (MCI) and 15 healthy peers. Integrating features from these brain scans into the VirtualBrainCloud simulation framework improved the classification of participants into different stages of disease. This shows how the VirtualBrainCloud approach can increase the sensitivity and specificity of clinical analyses, and might one day enhance patient stratification and diagnosis.

**Building theories from data and knowledge**

Another key achievement of VirtualBrainCloud has come through collaboration with the teams of Martin Hofmann-Apitius and Holger Fröhlich at Fraunhofer SCAI (Germany). These groups developed AI algorithms for automated literature searches, which have generated complex inventories of disease mechanisms based on decades of peer-reviewed scientific research. Building on these tools, VirtualBrainCloud mapped AD pathways and cascades from the published literature to specific locations in the brain, integrating biological knowledge with multi-scale brain simulations. This added biological accuracy and disease specificity to the VirtualBrainCloud models, an enormous and innovative step forwards for the field, taking us closer to more personalised approaches to AD diagnosis, treatment and prevention.

For more information about VirtualBrainCloud, see: https://virtualbraincloud-2020.eu

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**Petra Ritter is the Johanna Quandt Professor for Brain Simulation at the Berlin Institute of Health, Charité University Hospital. She leads a research team working at the cutting edge of network-based brain simulation, computational neuroscience and its clinical applications. Petra coordinated the VirtualBrainCloud project and here we present her reflections on project highlights, collaborative engagement, and future plans.**

**What is a personal highlight of the project for you?**

I am particularly proud that we reached our goal of developing a secure GDPR-compliant cloud environment where simulations of complex brain twins of patients can be generated. This secure Virtual Research Environment is discoverable via the European Open Science Cloud (EOSC) marketplace and at the service to researchers in Europe.

**There were 17 partner institutions in VirtualBrainCloud. How valuable was this collaboration for the project?**

Collaboration was key for the success of the project. We organised bi-weekly meetings where our technologies were developed together with users, lawyers, data protection specialists and data providers; everyone was welcome and provided input.
We also actively reached out to sister projects and initiatives such as EBRAINS, the Human Brain Project and AI-Mind, developing external collaborations as well as building a solid internal network.

I am pleased that the majority of partners of VirtualBrainCloud were collectively able - together with additional new partners - to secure significant funding for continuing their joint work in the two large-scale EU projects, eBRAIN-Health and TEF-Health (Testing Digital Europe Project Testing and Experimentation Facility Health AI and Robotics) – with a total funding of EUR 73 million.

After 4.5 productive years, VirtualBrainCloud will finish at the end of May. What are the plans for its future?

The subsequent EU projects eBRAIN-Health and TEF-Health will scale up results of the VirtualBrainCloud project. The open-source Virtual Research Environment will be ported to additional data centres and more data sources are being integrated.

These are crucial steps towards developing a digital ecosystem for data-driven dementia research. Lawful access to health data is key for the validation and certification of simulation and AI based technologies; our ultimate goal is improved diagnosis, prediction and treatment of dementia.

I am proud that we reached our goal of developing a secure, GDPR-compliant cloud environment where simulations of complex brain twins of patients can be generated.”

At Novo Nordisk, we are thousands of passionate colleagues that are advancing research and development in Alzheimer’s disease. This is a devastating disease that robs a person of their independence and the family of their loved one.

Together, we have an ambition of improving the lives of people impacted by Alzheimer’s disease through meaningful innovation.
European Platform for Neurodegenerative Diseases launches Cohort Catalogue featuring more than 60 research studies

The European Platform for Neurodegenerative Diseases (EPND) has launched its Cohort Catalogue featuring more than 60 research studies on Alzheimer’s disease and other neurodegenerative disorders. The Catalogue is a central, open, accessible repository for researchers to discover ongoing studies and search metadata by disease area, biosample availability, imaging and cognitive data and more.

The European Platform for Neurodegenerative Diseases (EPND) integrates existing initiatives to build, grow, and deliver a scalable and self-sustainable platform for storage and analysis of high-quality clinical samples and data collections. It is a public-private partnership funded by the Innovative Medicines Initiative (IMI), aiming to become a future European infrastructure, facilitating access to biological samples and data to accelerate biomarker discovery and validation and eventually support the development of therapeutics for neurodegenerative diseases.

The Cohort Catalogue

On 14 March 2023, the EPND launched its Cohort Catalogue. Featuring an extensive list of international cohorts across the neurodegenerative disease spectrum, the Cohort Catalogue is a central, open, accessible repository for researchers to discover ongoing studies and search metadata by disease area, biosample availability, imaging and cognitive data, and more.

The development of effective treatments and accurate diagnostics requires biomarkers for early detection of neurodegenerative disease in individuals. As measurable indicators of disease processes, biomarkers can also help clinicians to assess treatment efficacy, and stratify patients according to their specific disease profiles. Thanks to funding from the IMI, EPND is establishing a data-and sample-sharing platform for collaborative, large-scale biomarker research. Alzheimer Europe is one of 29 public- and private-sector partners in EPND, and is proud to co-lead its stakeholder engagement, public involvement and communications activities.

According to Niranjan Bose of Gates Ventures, a member of EPND’s Project Management Team, “EPND is committed to revolutionising scientific breakthroughs in the effort to diagnose, treat, and prevent neurodegenerative diseases. The Cohort Catalogue is a first step towards data and sample sharing, by increasing visibility and awareness of neurodegenerative research studies, to maximise the benefit and impact of neurodegeneration research.” The Cohort Catalogue represents an important milestone towards establishment of EPND’s data- and sample-sharing platform. Bringing together metadata on 67 research cohorts, with sites in 17 countries across Europe, the Catalogue offers a view on a diverse landscape of neurodegenerative disease research. Encompassing 12 disease areas, including Alzheimer’s disease and dementia with Lewy bodies alongside rarer conditions such as Huntington’s disease and multiple system atrophy, the cohorts in the Catalogue represent 159,675 research participants. This makes the Catalogue a hugely valuable resource for large-scale research studies aiming to develop or validate new biomarkers for neurodegenerative diseases, allowing researchers to pinpoint useful cohorts, data and samples, then use the “Contact Cohort” feature to initiate collaborations.

“To ensure the Cohort Catalogue would be as useful as possible, we incorporated a vast array of metadata for each cohort, including whether plasma and cerebrospinal fluid samples are included, or MRI or amyloid PET scan images,” said EPND co-Coordinator and clinical epidemiologist, Pieter-Jelle Visser. “This way, researchers have a single location to easily search and discover the complete landscape of neurodegenerative disease cohorts across Europe, and beyond.”

Visit the Cohort Catalogue at: https://discover.epnd.org/

Acknowledgement

The EPND project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 101034344. The JU receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.
Armenia launches first national dementia plan

Armenia has taken a significant step towards improving the lives of people living with dementia, as the country launched its first national dementia plan on 20 March 2023. In this article, Founder and Chairman of Alzheimer Care Armenia, Jane Mahakian, talks about the development of the strategy, its key objectives and the next steps for its implementation.

Congratulations on the development of Armenia’s first national dementia plan. Can you tell us a bit about the development and the work of Alzheimer’s Care Armenia to get to this point?

Alzheimer’s disease is a global problem, and Armenia is no exception. Beginning in 2002, I began to make numerous fact-finding visits to Armenia to assess first-hand what the needs and resources were for people with Alzheimer’s and other dementias. I found nursing homes for frail older adults and a few day programmes for the elderly. Focused health and care services were non-existent. For the most part, memory loss was dismissed as normal aging. No doubt, Alzheimer’s was under-recognised, undertreated and undermanaged. In 2017, I took a formal step to do something about the situation. I founded Alzheimer’s Care Armenia (ACA), a California based 501 (C) (3) charity and registered NGO in Armenia. One of the first steps was to educate healthcare professionals related to the diagnosis and care of the individual with dementia. At the time of ACA’s inception, there were no resources available for people with dementia in the country, as well as no idea of its prevalence. Armenia’s health care gatekeepers, the primary care physician lacked awareness to identify early signs of dementia and were not trained in conducting memory screenings. In 2018, ACA was launched with a successful ground-breaking Alzheimer’s disease conference for healthcare professionals at Yerevan State Medical University. The conference created a great deal of interest about Alzheimer’s amongst healthcare professionals. We began to develop sustainable and targeted Alzheimer’s programmes, services and initiatives that would create visibility and awareness of the disease, such as the National Alzheimer’s Disease Helpline and Healthy Ageing Memory Clubs.

Next, ACA engaged with Armenia’s Ministry of Health and formed a working group that would assess existing resources to identify the issues and assess current strengths and gaps. This was imperative to the development of the national dementia plan. A collaborative working relationship with Armenia’s Minister of Health, Anahit Avanesyan, Deputy Minister, Lena Nanushyan, and Senior Specialist, Kristina Galstyan, spearheaded the process of developing the plan. Achieving progress on the development of the strategy was shared among the government, as well as stakeholder community organisations, healthcare specialists, people living with dementia and their caregivers. Building up to the development of the plan, various projects were implemented to create even more visibility and awareness of Alzheimer’s, including conceiving the Robin the Robot Research Project at a nursing home and developing the first Alzheimer’s Caregiver Guide for family caregivers.

What really put dementia on the map was the Brain Health Armenia Project – a ground-breaking mobile country-wide early detection memory screening in collaboration with the Armenian EyeCare Project and Alzheimer’s disease training programme for primary care physicians and nurses funded by Davos Alzheimer’s Collaborative (DAC). These programmes and services laid the groundwork for achieving the milestone of launching the first-ever National Dementia Plan Armenia on 20 March 2023.
POLICY WATCH

What was the role of people with dementia, their families and carers in shaping the strategy?

The Republic of Armenia, Ministry of Health and ACA facilitated focus groups to assess the current gaps and needs of the person with dementia as well as their carers. Their input played an important role on policy formulation, future initiatives, and campaigns. The national dementia plan was commissioned from a working group coordinated by ACA and the Ministry of Health. The working group consisted of stakeholders including non-governmental organisations, physicians, other healthcare specialists, as well as people caring for people with dementia. A series of focus groups were held with the stakeholders. The working group was tasked with preparing a national dementia strategy, including objectives for promoting healthy ageing, for ensuring the early detection and treatment of cognitive disorders, for establishing a system for ensuring the availability of timely support and services for people with dementia and their families, and for formulating an action plan for implementing the necessary measures (including details about coordination and timescales).

What are the primary objectives and priorities of the plan? What are the dedicated measures identified to help achieve these objectives?

The national dementia plan was created with the overarching goal of improving the quality of life of people with dementia and a memory-friendly society that promotes brain health and early detection. The government of Armenia’s primary strategic objectives and priorities of the plan include developing country-wide campaigns that focus on promoting awareness, visibility and decreasing stigma; encouraging early detection, diagnosis, and healthy strategies to reduce risks, as well as making systemic changes on the public’s view about dementia and supporting ways to improve the quality of life for the person. The plan identifies the stages of the work that needs to be carried out, the important steps in raising awareness of risk factors, policies to be developed and the periods during which each phase will be implemented.

The Ministry of Health adds: “Dementia touches all of us, only under an organised healthcare system it is possible to defeat the disease. We are here to support the person with Alzheimer’s and their families”.

What do you consider will be the key factor for the successful implementation of the plan?

The key factors for the successful implementation of the action plan are identifying the champions - i.e. those who take on an active role with dementia reform and support the strategic plan both individually as well as organisationally. The key actions described in the plan are to organise awareness raising initiatives, drive direct population-level interventions and develop public policies to improve care and dementia-related outcomes. Together, we will lead the implementation of the plan and prioritise the actions and its execution in cooperation with stakeholders.

Now that the plan has been published, what are the next steps for Alzheimer's Care Armenia?

ACA is at a pivotal point with the success of the Brain Health Armenia Project and other initiatives developed over the past five years since its inception. With 3,600 individuals screened so far since 2022, there is a clear need to increase the detection screening in the rural areas of the country. The screening has found 33.17% of individuals tested have some degree of cognitive impairment.

ACA’s next steps are to expand the Brain Health Armenia Project by developing a multidisciplinary mobile in-home cognitive and healthcare programme for people with Alzheimer’s disease and their families as well as develop a memory Café in every region of the country. Given the outcome of the project, there is a clear need to increase the detection of individuals with cognitive impairment especially in the rural areas of the country. We will continue our work in early detection memory screening in collaboration with the Armenian EyeCare Project which may serve as a model for other countries.

We will continue to work on the development of multi-level partnerships with governmental organisations, NGOs, healthcare institutions and research institutes to provide care and support for all those affected by Alzheimer’s and other dementias. With ongoing partnerships and collaborations, ACA is well-positioned to continue to lead the way in making a positive impact on the lives of individuals with Alzheimer’s and their families in Armenia for years to come.
French National Assembly establishes dedicated working group on Alzheimer’s disease

Following the French presidential and legislative elections in April and June 2022, France Alzheimer fought for the creation of a working group at the National Assembly dedicated to Alzheimer’s disease. The working group is designed to create a community of parliamentarians aware of the condition and relevant policy issues.

Following the elections, France Alzheimer sent a significant number of targeted emails and letters to newly-elected and re-elected parliamentarians, to ask for action considering the issues at stake regarding the fight against dementia. Official letters were also sent to the new President of the French national Assembly, Yaël Braun-Pivet and the members of the designation committee of working groups.

Despite the considerable reduction in the number of working groups recorded at the start of the current legislature, France Alzheimer won its case and believes that its bi-annual review “Let’s act together” undoubtedly played a role in this institutional recognition.

Benoît Durand, Executive Director of France Alzheimer stated: “The working group makes it possible to consider regular parliamentary activities on the main issues at stake in the field of dementia, to concretely improve the daily lives of people living with dementia and their caregivers.”

For France Alzheimer, it is also a hope for progress for millions of people concerned at a time when the French government has only been regressing regarding the fight against dementia. After a few months of setting up, on 8 March 2023, France Alzheimer finally met French Deputy Chantal Bouloux, President of the new Alzheimer’s working group of the National Assembly and other members of the group.

As a Director of a nursing home prior to her election as a French Deputy in August 2022, Chantal Bouloux noted during the meeting, that she is a nurse by profession and that through her professional background, she is familiar with the subject of Alzheimer’s and the issues related to taking care of and supporting people living with dementia.

This first meeting allowed France Alzheimer to present its missions, its network and to take stock of the current political context relating to the fight against dementia, with the current context clearly not up to the challenges.

The demands and needs of families in the field are numerous and the figures relating to the evolution of the disease have particularly left an impression on Chantal Bouloux who stated: “I would like a strong mobilisation of deputies of the working group around this public health priority, which is relevant for us all.”

“Alzheimer’s is a major societal issue that must be addressed today. Given the number of people affected and the projections for 2050, I am particularly concerned about the question of the day-to-day care of the people, patients and caregivers. Staying at home is one thing, but the situation quickly becomes complicated when support and necessary arrangements are not sufficiently structured around the family.

As for the place of people living with dementia in nursing homes, I have often found that professionals are insufficiently trained to bring the necessary specific support.”

These essential subjects echo the daily lives of families. The members of the Alzheimer’s working group, set up at the very beginning of the 16th legislature, is finalising its Bureau before establishing its objectives and its roadmap. The group currently has 23 members, a number that could increase during this term of the National Assembly.

France Alzheimer will remain attentive to this work, will be a source of proposals for the group and will always respond to the group’s requests for hearings in order to move forward together towards concrete improvements in the day-to-day lives of people living with dementia and their caregivers.

Link to the presentation of this working group: https://www2.assemblee-nationale.fr/instances/resume/OMC_PO810607?force
Alzheimer’s Society calls on UK Government to make dementia a priority

In January 2023, the Alzheimer’s Society led a high-profile campaigning moment at 10 Downing Street, handing in an open letter signed by over 36,000 people calling on the UK Prime Minister, Rishi Sunak, to deliver on previous Government commitments on dementia. National Influencing Manager, Alex Osborne, tells us more about the campaign and how the organisation responded swiftly to the changing UK political landscape, with a contribution from Debbie Abrahams MP.

The Alzheimer’s Society welcomed each of these three commitments as positive steps forward for people living with, and affected by dementia in the UK, and has worked ardently to support the Government in their development and delivery. But with this positive progress in jeopardy through the high-profile changes in UK Government, our open letter campaigning for dementia to be a political priority was born.

The path to 10 Downing Street

Our journey to 10 Downing Street has not been straight-forward! It began in August 2022, in the height of the Conservative Party’s leadership election. Following Boris Johnson’s resignation as party leader in July, a contest swiftly commenced to choose which Conservative MP was to be the UK’s next Prime Minister. In response to this, our Campaigns Team launched an action for Alzheimer’s Society campaigners to sign our open letter, which called on all leadership candidates to prioritise dementia and deliver on the 10-year plan, the National Dementia Mission, and social care reform if they successfully became Prime Minister.

When Liz Truss was elected on 6 September, we hoped to hand in our open letter swiftly the following week, joined by one of our campaigners, Ananga Moonesinghe, who lives with dementia. However, following the passing of Queen Elizabeth II just two days later, our scheduled date had to be postponed.

This presented us with an opportunity to go back to the drawing board and consider how we could further boost the number of signatories to the open letter.

Working closely with our Ambassador and Celebrity team, we secured the support of BBC actor and Alzheimer’s Society Ambassador, Vicky McClure, for our open letter and its calls. On 19 October, Vicky posted a poignant video directed at MPs asking them to picture swapping their lives in politics for life as an unpaid carer to a person living with dementia. As part of her fantastic support, Vicky also encouraged people to sign our open letter, securing thousands more signatures as we approached our rescheduled hand-in date of 27 October.

Working in public affairs and campaigns, you quickly learn that the path of politics rarely runs smoothly – and the year 2022 in British politics is a textbook example of that principle! Following the suspension of parliamentary business for a 10-day period of national mourning for Queen Elizabeth II, then-Chancellor, Kwasi Kwarteng, presented a ‘Growth Plan’ that announced significant borrowing and tax cuts which were widely criticised and subsequently reversed.
Under mounting pressure and lack of confidence in her leadership, Liz Truss resigned on 20 October after just seven weeks in office, which meant that once again, we needed to find a new date for our open letter hand-in at Downing Street.

#PlanD Campaign

Following a much shorter leadership election, Rishi Sunak was elected as Conservative Party Leader on 24 October, officially becoming Prime Minister the next day. While our open letter call to make dementia a priority remained pertinent throughout this period, we could not let further commitments, including the publication of the 10-year plan, fall through the cracks. With our third hand-in date of 19 January 2023 set, we wanted to make sure we made best use of the additional time we had.

Having noted the Government’s repeated use of the vague phrase “in due course” in response to Written Parliamentary Questions (WPQs) on when the 10-year plan for dementia would be published, in December 2022, we launched a new campaign called #PlanD. Counting 26 WPQ responses to this effect, we called on the Government to publish the 10-year plan as soon as possible, amplified by the tagline “Dementia doesn’t wait for due course.” With our open letter re-opened for signatures, and our #PlanD campaign running in tandem, we conducted a final push for support with revitalised messaging that was relevant to how the political situation had developed i.e. additional months had passed without an update on the 10-year plan, with the original deadline for publication looming. This also helped contextualise ongoing conversations with Vicky McClure, and with our Ambassador Dame Arlene Phillips, both of whom were keen to engage in more political opportunities and to be involved in the open letter hand-in at Downing Street. We were also lucky to have the support of our campaigner, Ananga, throughout, who stood ready to attend at the drop of a hat!

Knocking on the Prime Minister’s Door

Finally, the third scheduled date for the hand-in of our open letter approached. I must credit the determination of all the teams involved in the event, but particularly our Campaigns Officer Isabel Thomson, who led on the hand-in and adapted to all manner of political upheaval along the way.

On 19 January, with the support of Ananga, Vicky, Arlene, and All-Party Parliamentary Group on Dementia Chair and Vice-Chair Debbie Abrahams MP and Elliot Colburn MP, we finally knocked on the door of 10 Downing Street and handed over our open letter, signed by 36,297 people. Off the back of our campaigning, over 15,000 new people have joined our campaigning network and our activity received significant media coverage in national, regional and broadcast press.

What’s Next?

On 24 January 2023, just days after our hand-in, the Government announced it would scrap the 10-year plan for dementia (and other condition-specific plans) in favour of a Major Conditions Strategy covering six conditions including dementia.

As yet, we don’t have enough detail on the Major Conditions Strategy to ascertain whether it’ll be suitably bold and ambitious for dementia. What we do know, though, is that our #PlanD doesn’t change. Therefore, our calls to the UK Government are:

- Diagnosis of dementia should be improved through a funded GBP 70 million plan to recover diagnosis rates to above 66.7% target, with all diagnosis inclusive of sub-type
- Delivery for people affected by dementia navigating the health and social care system, including coordination of care, care plan reviews and standards of training for the social care workforce
- Development of new methods of diagnosis, to administer breakthrough dementia treatments as they become available
- Data should underpin the work of the Major Conditions Strategy, with better data collected on all aspects of dementia diagnosis and care.

For more information on Alzheimer’s Society’s work and the support it can provide, visit: https://www.alzheimers.org.uk

The petition delivered to Downing Street gathered more than 36,000 signatures
As part of Alzheimer’s Society’s open letter hand-in on 19 January, two members of the APPG on Dementia joined campaigner Ananga and Ambassadors Vicky McClure and Dame Arlene Phillips at 10 Downing Street. APPG co-chair, Debbie Abrahams MP, reflects on the day.

I’m proud to co-chair the APPG on Dementia with my colleague Baroness Browning. Together, we lead the Group, which is cross-party and brings together Members of Parliament and Peers (Members of the House of Lords) united by a common interest in dementia.

When the team at Alzheimer’s Society invited me and APPG Vice-Chair Elliot Colburn MP to attend its open letter hand-in at 10 Downing Street, both of us jumped at the chance. While the Government has made lots of commitments on dementia, from a programme of social care reform to doubling dementia research funding in the UK, it has been slow to deliver. That’s why the open letter’s key call to make dementia a political priority is so important. With over a million people forecast to be living with dementia in the UK by 2025, we can’t let progress stall.

One of the real strengths of the hand-in back in January was the mix of attendees who came to Downing Street on the day. Myself and Elliot’s attendance demonstrated strong cross-party political support for the cause, while having Vicky and Arlene there helped drum up media interest and support. All of us have personal connections to dementia which inform our advocacy and mean that when we speak about dementia, we’re speaking from the heart. I think that’s very powerful.

Meanwhile, being able to have campaigner Ananga Moonesinghe, who lives with dementia, attend and share his story was crucial in putting people’s lived experiences of the condition front and centre. Seeing Ananga knock on the door of Downing Street and hand over the open letter to the Prime Minister’s team was definitely the highlight of the day, and I know it meant a great deal to him.

Shortly after the hand-in, the Government announced that the 10-year plan for dementia was being scrapped and replaced with a Major Conditions Strategy. With dementia diagnosis rates stagnating, the social care system under immense pressure, and exciting research breakthroughs on the horizon, we have to ensure that the Government dedicates appropriate time, space and resource to dementia. We know from the open letter that at least 36,000 people agree, so along with my fellow APPG members, we’ll keep pushing the Government to make dementia a priority and ensure people living with dementia are involved in the Strategy from the outset.
Irish Alliance of Age Sector NGOs calls for appointment of Commissioner for Ageing and Older People

The Alliance of Age Sector NGOs launched, “Telling It Like It Is; Combatting Ageism” at the Irish Parliament Buildings at the start of 2023. Hugh O’Donoghue, Communications Manager at The Alzheimer Society of Ireland, tells us more.

The Alliance of Age Sector NGOs launched its 2023 Report, “Telling It Like It Is; Combatting Ageism”, at the Irish Parliament Buildings on 25 January 2023. Members of the Irish Parliament, Alliance staff and advocates attended the event. The report sets out why Ireland needs to take ageism seriously, highlighting the nature and impact of ageism and offers several evidence-informed strategies to reduce it.

The Alliance of Age Sector NGOs

The Alliance represents the collective thinking of seven significant Irish NGOs working in the age sector, uniting their learning from working with the diversity of older people and the issues they face.

The seven-member organisations are:
- The Alzheimer Society of Ireland (ASI)
- Active Retirement Ireland
- Age & Opportunity
- ALONE
- Irish Hospice Foundation
- The Irish Senior Citizens Parliament
- Third Age.

The Alliance was established in acknowledgement that Ireland is ageing fast, and our economy, health service, communities and families must adapt. Although many Government Departments and Agencies play an important role, we still need a coherent, active and measurable national strategy supported by a structured, whole-of-government, cross-Departmental approach with senior-level Government engagement and oversight.

Ageism explained

Ageism arises when age categorises and divides people in ways that lead to harm, disadvantage and injustice.

Ageism is ever-present and has considerable harmful effects, including a shorter lifespan, diminished mental and physical health, isolation, lost commitment to the workplace, cognitive decline, and reduced quality of life.

The new report “Telling It Like It Is; Combatting Ageism”

The report includes nine actions that will reduce the stigma and ill effects associated with ageing when implemented. The most pressing of these actions is the appointment of an Independent Commissioner for Ageing and Older People - similar to that in Northern Ireland and Wales. The Alliance believes that doing so would support the ageing population by implementing a programme for the government that prioritises older people. It would ensure that the commitment to mainstreaming ageing is kept to the fore of policy and decision-making and that there is an enhanced investment in programmes and services to combat ageism nationally.

A few words from ASI CEO Andy Heffernan

“The pandemic, in many ways, created a simplified view of older lives in public discourse – as homogeneous, vulnerable, isolated units readily cut off from families, friends and activities. I look forward to continued engagement and collaboration between our fellow alliance members and our elected officials as we move forward to ensure people affected by dementia are active and valued members of their communities.”

“Telling It Like It Is; Combatting Ageism” is available to download at: https://alzheimer.ie/creating-change/awareness-raising/alliance-of-age-sector-ngos/
Swedish Presidency hosts high-level meeting on active and autonomous ageing

As part of its Presidency of the Council of the EU, the Swedish government arranged a “High-level meeting on active and autonomous ageing” on 13-14 February 2023, in Gothenburg, Sweden. In this article, Director-General of the Swedish National Board of Health and Welfare, Olivia Wigzell, talks about the high-level meeting and the current policy context around ageing.

Why did the Swedish EU Presidency decide to organise a “High-level meeting on active and autonomous ageing”?

This is an important issue for many EU Member States in view of the demographic development and increasing life expectancy. We have a demographic challenge facing our union and we need to facilitate longer and more sustainable working lives as well as provide social care of high quality, which is accessible and tailored to the needs of the individual. We identified the need to attract and retain care workers in the long-term care sector as key for Europe. We want, and need, resilience in the care sector, and in this regard both numbers and skills in the care work force are crucial.

Ageing is often described in terms of limitations and costs, how can policy makers change this to a more positive perspective?

It is important to address the issue of ageing not only in terms of illness and needs of assistance, but also from the perspective of the life experiences and skills that older people can contribute. The more we invest in using available expertise, the better we can tackle the challenges in our societies: unemployment, addressing health and well-being throughout the life course, ensuring active participation in society and reducing socioeconomic differences. There is a need to involve people in decisions that concern them – the more we listen and discuss, the more we learn when it comes to improving our policy decisions. Involvement is also important to address the issue of age discrimination, which is still prevalent both in the labour market and elsewhere. Age doesn’t have to be an obstacle – we need to see it as an asset, which many NGOs working with these issues have pointed out time and again.

In his introductory presentation, Professor Ingmar Skoog said that 70 is the new 50. What does that mean for retirement and social security policies?

It means that we need to ensure that our labour markets are inclusive, that we allow individuals to keep working until they wish to stop, and not just stop because they reach a certain age of retirement. There needs to be a whole-of-society approach that is based on health promotion and functional ability, as well as increased self-determination. If you are healthy and willing to work, this should be encouraged. We should also improve our spatial planning to ensure that there are possibilities to get together and enjoy activities in all age groups, indoors and outdoors.

The second part of the meeting was dedicated to long-term care staff. How would you describe the current situation of the long-term care sector?

The situation is grave. In many countries, we see that both required skills and experience is lacking in this sector, and it’s difficult to find and recruit people who want to work there.
What is needed is a targeted effort to increase education and training, implement better working conditions, strengthen leadership and make more efficient routines and processes for service delivery.

**How can countries adopt policies to attract and retain professional carers with the right skills?**

Sweden has chosen to focus efforts on education and training, to move away from detailed governance to give the workforce more space to tailor care delivery to the needs of the patient. We need to give the staff more flexibility to use their own judgement, knowledge and experience, and to increase collaboration between the healthcare system and the social care services. This means that we have and will continue to legislate to achieve the goal of coordinated medical and care plans for the individual in order to reach our goal of integrated and patient-centered care.

**How was dementia included and discussed during the high-level meeting?**

In Sweden, around 74,100 people with dementia are cared for in the municipal healthcare services, who provide care for over 396,000 people. Dementia patients have specific needs, regarding for example good and integrated care, support for families and next of kin, an inclusive approach to digitisation and disease prevention based on early screening. We are glad to have had the photo exhibition in the meeting venue to showcase care for older people and how to adapt living conditions to the needs of people with dementia. It is important to show available solutions and to share experiences, such as the work of Silviahemmet (a Swedish non-profit foundation which spreads knowledge about cognitive diseases, including dementia, through various educational activities) and their work to retain healthcare workers, specifically in dementia care.


> “There is a need to involve people in decisions that concern them – the more we listen and discuss, the more we learn when it comes to improving our policy decisions.”
EU news in brief

In this article, Alzheimer Europe provides a brief overview of some of the key developments which have taken place across health, social policy and research at an EU level in recent months.

European Commission launches consultations on European Disability Card

In late 2022 and early 2023, the European Commission consulted on the development and implementation of the European Disability Card, an initiative which is expected to be adopted by the Commission in the fourth quarter of 2023.

It is intended that the card will overcome many of the issues faced by persons living with disabilities by facilitating the mutual recognition of disability status across Member States. In particular, it is hoped that issues around mobility and free movement of rights for persons with disabilities in the EU will be addressed, as well as improving access to services and ensuring the same preferential conditions for access to relevant services in all Member States, irrespective of where a person’s disability status was granted.

The proposal for the European Disability Card is a flagship action of the EU Strategy for the Rights of Persons with Disabilities 2021-2030. It also builds on the experience of the European Disability Card pilot project, which Petri Lampinen, Finnish Member of the European Working Group of People with Disabilities (EWGPWD), has written positively about before. Alzheimer Europe has responded to these consultations, welcoming the scheme and noting its potential benefit for persons with invisible disabilities, such as people with dementia or other cognitive conditions.

However, we also noted some potential barriers to the success of the scheme, including that the Parking Card Scheme, on which the EU Disability Card Scheme builds, has been hindered by its optional nature, meaning that not all persons with disabilities can benefit.

More information on the scheme is available at: https://ec.europa.eu/social/main.jsp?catId=1139&langId=en

High-Level Group launches report on the future of social protection and of the welfare state in the EU

On 7 February 2023, the European Commission held an event to launch the findings and recommendations from a report by the High-Level Group (HLG) on the future of social protection and of the welfare state in the EU.

The expert group was chaired by the former European Commissioner for Employment, Social Affairs and Equal Opportunities, Anna Diamantopoulou, and examined ways to reinforce social protection both at national and European levels, to respond to issues such as demographic change, the impact of new forms of work, and the digital and green transitions.

The report outlined the implications of these issues for the design and scope of social protection systems and the financing of social protection.

Furthermore, it develops strategic recommendations to both Member States and the EU. Beside longer-term trends, the report reflects on the lessons from the COVID-19 pandemic and from the Russia’s war of aggression against Ukraine and its repercussions, such as the growing challenge of energy poverty.

In total, the HLG made 21 recommendations to improve social protection systems and welfare states in six areas:

- Support to children, young people and families
- Ensuring inclusive social protection and lifelong learning
- Supporting adequate income and high-quality long-term care in old age
- Promoting inclusive and high-quality services
- Ensuring sustainable financing for a resilient welfare state
- Stepping up EU capacity to secure social protection in the future.

The report provides insights that will inform European and national policymakers, in parallel with the implementation of the European Pillar of Social Rights.

The full report can be accessed at: https://op.europa.eu/en/publication-detail/-/publication/842d8006-c3b3-11ed-a05c-01aa75ed71a1
Horizon Europe calls for health research proposals

On 7 March 2023, the European Commission published eight single-stage calls and issued 29 topics under the Horizon Europe Health cluster, including one on structuring brain health research in Europe.

The aims of cluster 1 (Health) include improving and protecting the health and wellbeing of citizens of all ages by generating new knowledge, developing innovative solutions, and integrating a gender perspective to prevent, diagnose, monitor, treat, and cure diseases.

The funding calls were published under six different destinations, each focused on a different broad theme:

Staying Health in a rapidly changing society:
1. Living and working in a health-promoting environment
2. Tackling diseases and reducing disease burden
3. Ensuring access to innovative, sustainable and high-quality health care
4. Unlocking the full potential of new tools, technologies and digital solutions for a health society
5. Maintaining an innovative, sustainable and globally competitive health industry.

Of specific relevance for dementia, under destination three, is HORIZON-HLTH-2023-DISEASE-03-06 which is titled: “Towards structuring brain health research in Europe”.

More information on the calls is available at: https://hadea.ec.europa.eu/news/8-single-stage-calls-29-topics-have-been-published-under-horizon-europe-health-2023-01-19_en

EU Fundamental Rights Agency publishes UNCRPD indicators report


The report focuses on the design and use of indicators for assessing the progress implementing the UNCRPD at a national level. In particular, it highlights that indicators for the UNCRPD are a way to break down legal standards into measurable elements and clearly defined questions, into which quantifiable data and information can be fed. In addition, it is noted that such indicators support evidence-based policymaking grounded in human rights, allowing for gaps to be identified and progress to be tracked.

It is further explained that indicator frameworks provide a strong evidence based for a number of groups to establish the extent of unequal outcomes and identify where policy intervention is required, including:

- Policymakers
- Independent monitoring bodies
- National human rights bodies
- Persons with disabilities and representative organisations
- Wider civil society.

The report is broken down into the following sections:

- The role of independent national monitoring frameworks
- Filling the gaps in data
- Using human rights-based indicators to assess progress in implementing fundamental rights obligations
- Data sources for populating outcome indicators
- Monitoring UNCRPD implementation across the European Union – national practice examples
- Challenges and ways forward.

Global Ageing Network calls for action on ageing and long-term care

A new report from the Global Ageing Network (GAN) has warned of the impact of aging populations, combined with declining numbers of caregivers and insufficient government support for services older adults, and calls for governments to provide greater policy focus on the issue. In this article, GAN Chairperson and European Ageing Network (EAN) President and CEO, Jiří Horecký, highlights some key points from the report.

Background to the report

On 16 February 2023, the Global Ageing Network (GAN) issued a “Call to the Governments of the World on Long-term Care and Ageing” demanding urgent attention to and reform of long-term care systems for older people. For over a year, experts from around the world have been working on this document in response to the increasing risk of future inaccessibility and unaffordability of long-term care services, with at least half of all older adults expected to need long-term care services at some point in their lives. An increasing number of older people need daily, often demanding care, in part due to the increase in the number of people with dementia.

The report has been distributed and disseminated to social and health care ministries and other relevant stakeholders across all the countries and continents, including Europe.

Action by governments all over the world is needed now, say the report authors, as the demographics of global ageing are driving a need for attention to and prioritisation of policies, programmes and infrastructure to ensure access to care and services. Issues including approach to care, funding, workforce development and training, also must be addressed.

The report was authored by Dr Jiří Horecký, President of the European Ageing Network (EAN), and Board chair, GAN; Stuart Kaplan, CEO, Selfhelp Community Services in New York, NY; Dan Levitt, Professor and CEO, KinVillage, Delta, British Columbia, Canada; Katie Smith Sloan, Executive Director, Global Ageing Network; Megan Davies, PhD, University of Basel and Maastricht University; Dr Freek Lapre, Professor, TIAS Business School, Tilburg University, Netherlands, and Donald Macaskill, PhD, CEO, Scottish Care.

The impact of COVID-19 on older adults around the globe, and abundant lessons that became apparent from that experience, such as the negative effects of longstanding neglect of infrastructure needed to serve older adults as they age, served as the impetus for GAN’s action. Katie Smith Sloan explains: “Chronic underfunding, understaffing, low prioritisation of aging services by governments around the globe revealed how urgently the long-term care sector does need attention, reforms, changes, and support.

The sector has been overlooked and under-appreciated – and the collective work of GAN members is needed, now more than ever.”

Following an overview of long-term care practices in countries around the world, the paper addresses major challenges, from an overreliance on informal caregivers, the growing challenge of dementia among older adults and workforce challenges to long-term care infrastructure and policy needs. A roadmap of opportunities, challenges and action includes sustainable funding models, reshaping long-term care systems and country-specific needs assessments.

Older people living with dementia represent a huge care strain for formal and informal caregivers. In the professional care sector, in some countries, the majority of new residential settings being built are specialist nursing homes for people mainly with dementia.

“Among other things, the recent COVID-19 pandemic has shown how fragile, undervalued, under-funded and unprepared for the future the current systems are globally.”

Jiří Horecký
When talking about long-term care settings and its sustainability for the decades to come, we have also to understand the costs and challenges of caring for someone with dementia.

**Challenges of caring for someone with dementia**

Informal caregivers sometimes have great difficulty caring for family members until the end of their lives, especially without professional support, help, and relief. These caregivers often need adjustments to their living environment. They often do not know how to communicate with and understand people with dementia or how to provide care and support for them. In addition, caregivers face the extreme mental demands of watching their loved one’s personality change due to dementia.

Older people with dementia represent a big care responsibility for society at large, health and social systems, families, and caregivers. It has a significant impact on what long-term capacities are needed now and in the future and how the social protection and social services systems should be organised and focused.

While governments are proposing long-term care systems reforms or modifications, they must take into account this significant group of people living with dementia that is projected to grow in large numbers.

Therefore we have to keep in mind three main aspects:

1. Public budgets, including costs for social services, health care services, social protection etc.
2. Informal caregivers, mostly family members facing reduced quality of life, increased costs, impacts on their physical and mental health, withdrawal from the labor market, etc.
3. Human resources, as the rising number of people with dementia will require more and more caregivers, nurses, social workers, and other related professionals.

A number of countries, whether at the level of professional associations, professional societies or governments, are addressing the challenges of sustainability of long-term care systems because of the increasing number of older people who need daily, often demanding care – not only because of the erratic increase in the number of people with dementia, but also because of critical shortages of staff in social services.

Australia is calling for changes in the long-term care system, the Netherlands is announcing possible long-term unsustainability of the current system and capacity and England is talking openly about the crisis in the long-term care system. Additionally, all EU countries have workforce shortages, with a need of more than one million workers in Europe, whilst the care workforce continues to age.

**Dignity for people with dementia**

The Call to the Governments of the World on long-term care and ageing contains not only a description of the major problems and current challenges of long-term care, an emphasis on the importance of providing care and support to older people as a guarantee of their fundamental right to live with dignity, but also concrete directions for solutions and important principles.

A number of countries are addressing the need for changes and reforms in the systems of support and long-term care for the elderly, and many countries are still developing such systems. Among other things, the recent COVID-19 pandemic has shown how fragile, undervalued, underfunded and unprepared for the future the current systems are globally.

We have not only described the main risks, challenges and current issues related to long-term care provision, including the accessibility of long-term care as one of the element human rights to live independently and with dignity, we have also outlined potential solutions.

This activity is in accordance and complimentary with other recently introduced initiatives like the United Nations Decade of Healthy Ageing 2021 – 2030, the World Health Organization’s framework for an integrated continuum of long-term care, as well as the EU’s recently developed Care Strategy.

The full Call to Action paper is available at: [https://www.ean.care/en/articles/gan-call-to-the-governments](https://www.ean.care/en/articles/gan-call-to-the-governments)
As a member of the Irish Dementia Working Group, Frank Golden has participated in numerous engagements and projects. Mr Golden, who is 83 years old, recently celebrated his lifelong goal of publishing a book. This is an achievement for anyone, even more so for someone living with Alzheimer’s disease. His book “The Irish Job” is set in Dublin during the Irish War of Independence 1919–1921, specifically in the months leading to the assassinations and reprisals in Croke Park by the British Auxiliaries on Bloody Sunday (Bloody Sunday, 21 November 1920, was a day of dramatic bloodshed in Dublin, not to be confused with Bloody Sunday on 30 January 1972).

With the support of Saoirse Kelly, from The Alzheimer Society of Ireland, we asked Mr Golden to tell us more about the book and what it was like to publish it after his diagnosis of dementia.

Your book “The Irish Job” is a novel but is based on real events. Can you tell us a bit more about the reason for the title, the subject matter and how much it is fiction/non-fiction?

The book is fiction, but I was anxious to make it as true to its roots as possible. I drew on direct quotes before each chapter from prominent people who lived in that time. The title is drawn from a comment made by Lloyd George, then Prime Minister of the United Kingdom and Ireland, and recorded by the Cabinet Secretary, when the ‘Irish Problem’ was being discussed.

This was a tempestuous time in Irish history when, at last, the 800-year-old occupation by England seemed close to ending. For the first time, the Irish side were confident that they could outwit a superior military force through sophisticated intelligence and the skills to wield an international propaganda campaign. The timeline is factual. Some of the events are either fictional, or are drawn from publicly-recorded events.
What prompted you to write the book and how was the experience of writing about such a difficult and important period in your country’s history?

My father’s vital contribution to the work of Michael Collins, Chief of Staff of the Irish Volunteers, formed a very personal background to what, as children, we learned in school about the struggle for Irish freedom. Although Papa was not a talkative man, we learned enough from him to realise just how dangerous his work had been. Over the years, I read many accounts of those times and carried out research in detail. I have always enjoyed writing, and gradually, realised that I could incorporate my research together with my father’s experiences in a novel.

Would you say that achieving the goal of publishing this novel, after your diagnosis of dementia, made it all the more special?

Certainly. The diagnosis wasn’t a huge shock as several members of my extended family had earlier been diagnosed. I was determined to continue doing the things I wanted to do and not to sit down and say “woe is me!” I had things to do. Given my age, I decided not to hang around waiting to be accepted by a publishing house. With the help of my wife, I identified a suitable company to print and distribute my book, a talented photographer to provide the front cover, and I was in business.

How did your colleagues in the Irish Dementia Working Group and your family and friends react?

I was delighted with their reaction. At first, people were congratulating me just on producing the book. The delightful bit was when people came to me with their positive responses when they had read it. I was especially pleased with the reaction of my surviving siblings and our collective nieces and nephews who were amazed, and a bit shocked, to realise what their grandfather had accomplished and the risks he had run.

You have plans to write a second book, we hear. Can you tell us a bit about it?

As there is no copyright in an idea or a title, I’m saying nothing! But it’s underway! “The Irish Job” is set in the past, but what can policymakers do to improve the situation for people with dementia and their families, in today’s Ireland?

Everyone has a story to tell. If policymakers work to create communities that respect and support people living with dementia to develop their talents and interests so that the person is seen, not the dementia, that would be wonderful!

“My father’s vital contribution to the work of Michael Collins, Chief of Staff of the Irish Volunteers, formed a very personal background to what, as children, we learned in school about the struggle for Irish freedom.”
Our Dementia Choir: How music can help people with dementia

“Our Dementia Choir” started out as a BBC TV programme five years ago, fronted by BAFTA award-winning British actress Vicky McClure who is also an Ambassador for the Alzheimer’s Society. The third series of the show, called “Our Dementia Choir Sings Again”, aired in late 2022. The Choir is a registered charity and we spoke to Charity Manager Karen Bonser to learn more. Ms McClure also comments.

Can you tell us a bit more about “Our Dementia Choir” – both the BBC television series and the charity - when and how did it all start?

The choir was formed in 2018, by the BBC with Curve Media and Vicky McClure, when they were asked to create a choir for people living with dementia in and around the Nottingham area, Vicky’s home city. There was a recruitment process via medical practitioners, to bring together a 20-strong choir, which would perform at the end of the two-part series and also go through research validating and showing the power of music along the way. Following the end of the two-part series the choir carried on with rehearsals and performances and Vicky, together with a Board of Trustees, formed the Our Dementia Choir charity.

What sparked your own interest and decision to become involved as Charity Manager?

In 2020, after the choir was formed into a charity, I took early semi-retirement from being a Business Executive in a multi-academy Trust, having had a career in education for over 35 years. This was, in the main, to give me more time to care for Mick, my husband, who has Alzheimer’s and is also a member of Our Dementia Choir. Vicky asked if I would help out with the business element of the charity and as I was already involved with the choir anyway, I said that I would support the Board. There has been a lot to do and whilst it did start off as a few hours per week, the popularity and strength of the choir has been massive! I have since had to recruit a crew and volunteers to help support the ongoing work of the choir as we continue to raise awareness across the United Kingdom.

How important has it been to have Vicky McClure, who is both a well-known television actress and an Ambassador for Alzheimer’s Society, as both founder and figurehead of the Choir?

Vicky is one of the most amazing women I know. Not because she is a celebrity (although she is one fabulous actress!) but because she cares! She is kind, compassionate and full of love for everyone involved in the choir. She is so proud of what the choir has become and gives of her time as best she can, even with the heavy, demanding workload that she has. She is the best ambassador for a charity you could wish for because she feels it, she is passionate about supporting and fighting for everyone living with dementia. She has given an amazing group of people memories to cherish that we could never have dreamed of and she continues to fight for dementia care in many ways.

The Choir outside the famous Abbey Road Studios

Karen Bonser

Karen Bonser
Aside from singing, both on and off television, the Choir has also participated in a number of scientific studies. Can you tell us a bit about what some of these studies have shown about music and dementia and about the capabilities of people living with dementia?

During the first series of Our Dementia Choir there were a number of research studies undertaken involving choir members in a number of scenarios. Under the supervision of Seb Crutch (Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology, University College London), electronic devices worn at rehearsals and surveys were undertaken to register mood and feelings before and after rehearsal. This showed what a positive impact and feel-good factor music was having on individuals. Scans and images of the brain were also carried out whilst choir members listened to and played music. Again, these showed the change in brain function that music triggered.

However, you don’t need complicated equipment to see for yourself what a change music can make to people. You can feel it, see it and hear it at each rehearsal, with everyone – it is AMAZING to see the change in some of the choir members. We have one member who is so anxious he won’t come into the building but as soon as he hears the music, he is there, front and centre: singing, dancing and joining in. It can be a remarkable and moving transformation which brings to life our loved ones living with this dreadful disease.

“...We have one member who is so anxious he won’t come into the building but as soon as he hears the music, he is there, front and centre; singing, dancing and joining in.”

A few words from Vicky McClure

British actress Vicky McClure has starred in a number of films and television shows, including “This is England” (film and miniseries) and “This is England ’86” (miniseries) for which she won both a British Academy Television Award (BAFTA) for Best Actress and a Royal Television Society Award for Best Actress and more recently taking a leading role in popular police drama "Line of Duty" which has now been running for six seasons.
Her grandmother was diagnosed with vascular dementia at the age of 75, and lived with the disease until her death in 2015. Inspired by her memory, the actress became involved in Our Dementia Choir and is both its figurehead and the Chair of the charity of the same name.

Ms McClure said: “From the first day filming our BAFTA nominated BBC One documentary ‘Our Dementia Choir’, I can safely say the choir and their loved ones have changed my life. What’s more they have changed many lives across the UK and now stretching to other countries around the world. Everyone involved in the choir, past and present, choir members and loved ones, have shown enormous strength and honesty in allowing us to document their lives and very much prove ways in which you can live well with dementia whilst not shying away from the difficulties it can bring.”

“When the cameras aren’t there the members of the choir are still very much active in showcasing the power of music, making trips all over the UK to perform at various organisations and fundraising events, keeping our choir going and spreading an important message along the way.

I am so incredibly proud and grateful to everyone involved, the choir, their families and carers, our volunteers, trustees and supporters. I honestly believe with the right hearts and minds you truly can change people’s lives for the better. Music is medicine.”

“"I can safely say the choir and their loved ones have changed my life."
Alzheimer Portugal and 11 other institutions create new informal network “Museums for Inclusion in Dementia”

There are very few museum offers in Portugal designed specifically for people with dementia and their carers. Now, a national network of “Museums for Inclusion in Dementia” has been created. Catarina Alvarez, Clinical psychologist and Head of Institutional Relations, and Filipa Aniceto, Clinical psychologist responsible for the implementation of the project "Marcar o Lugar – Encontros no Museu" aimed at people with dementia and caregivers, both from Alzheimer Portugal, share the details.

There are currently around 200,000 people with dementia in Portugal and, according to projections from Alzheimer Europe, this number will rise to around 350,000 by 2050. At national level, there are few museum offers that are designed specifically for people with dementia and their carers. A national network of museums for inclusion in dementia has therefore been created to develop and share good practices, train the teams from cultural institutions and raise awareness in the community about the subject of dementia.

New paradigms, new answers

Culture and art have been a progressively explored resource in public health interventions and have contributed to addressing complex problems for which there are no adequate solutions, and can provide a holistic lens and response, and situate health problems within their social and community context.

INTERDEM, a network of researchers interested in psychosocial interventions, has highlighted the importance of adopting arts-based interventions to address the psychosocial needs of people with dementia, promoting dignity, autonomy, reciprocity, decreased stigma and social inclusion. Several studies highlight the benefits that art provides, including studies on cognitive functioning, perceived well-being, self-esteem and self-confidence, avoidance of self and everyday problems, new learning, and personal growth, established bonds, and social participation and inclusion.

Museums as agents of change

Museums project themselves as institutions intended to serve society, to have an impact and value within their communities and which should be involved in the main problems of contemporary society. By their unique characteristics they are spaces that offer: a ‘restorative’ environment, which mirrors tranquillity and stillness, in contrast to the increasing and vibrant confusion of everyday life; a space in which similarities and differences, past and present, continuity and change can be contemplated; and a non-stigmatising environment where people feel valued and safe. They are not disease-focused, nor are they environments where one feels embarrassment, shame or criticism for participating.

At the international level, intervention programmes through art for people with dementia and their carers are widely used, for example “Meet Me at MoMa”, at the Museum of Modern Art in New York. At national level, there are few museums that provide a cultural and artistic offer of their own, designed specifically for this public.
The Portuguese informal network Museums for Inclusion in Dementia (MID)

Taking into consideration the situation and needs described above, 12 organisations decided to join forces to create a national network to increase cultural offers aimed at this target audience, disseminating it across the country, making museums active agents of change and ensure they contribute to making society more inclusive.

The MID network was created in January 2023. There are ten museums that constitute the founding members:

- Calouste Gulbenkian Foundation - CAM (Centro de Arte Moderna)
- Botanical Garden of the University of Coimbra
- MAAT - Museum of Art, Architecture and Technology
- Calouste Gulbenkian Museum
- Science Museum of the University of Coimbra
- Museum of Lisbon
- Pombal Municipal Museum
- Grão Vasco National Museum
- Machado de Castro National Museum
- Viseu Mercy Treasure Museum.

In addition to these museums, two other organisations are founding members of this network:

- Acesso Cultura, an association that promotes access, physical, social and intellectual, to cultural participation and which, in this context, has the role of collaborating in the creation and implementation of appropriate programmes and contributing to the proper functioning of the network.
- Alzheimer Portugal which has, within this scope, the purpose of sharing the experience and technical-scientific knowledge acquired over 34 years of existence and of helping to bridge the gap between these specific cultural/artistic offers and the respective target audience.

MID’s main objectives are, in its initial phase, to implement specific programmes for people with dementia and their carers, according to tested and validated models; jointly evaluate results; develop and share good practices; empower teams from cultural institutions; disseminate existing offers; and raise awareness in the community on the subject of dementia, which is increasingly relevant from a social and public health point of view.

At a later stage, the intention is to produce a manual of good practices, to contribute to supporting/evaluating the programmes in museums with the possible use of external consultants with proven experience and skills, including Network consultants, people with dementia and their carers, and to work in partnership with universities to produce and publish joint technical/scientific knowledge.

In addition to the intention to extend the network to other museums in 2024, it is also planned to expand the scope of the MID by considering the eventual integration of other cultural facilities, such as theatres and libraries.

In conclusion: looking for a better future

Museums are a valuable resource for public health interventions and, in collaboration with third sector organisations, they can respond to increased social inclusion and, in this sense, act as catalysts for positive social change. Furthermore, the establishment of bridges with this sector is fundamental for the continuity of projects involving specific target audiences, as well as their integration in “social prescription” approaches, in partnership with health services, a reality that is starting to be implemented in Portugal.

The MID network was created with a collaborative and transformative vision and the ultimate purpose of contributing to ensuring that people with dementia and their families can live better, in Portugal.

Acknowledgement

This text was adapted from the article published in the online magazine “Património” released by Acesso Cultura (https://www.pati-monio.pt/post/a-rede-de-museus-inclusiva-na-dem%C3%A9ncia) and written by Catarina Alvarez, clinical psychologist and Head of Institutional Relations for Alzheimer Portugal and Filipa Aniceto, clinical psychologist who collaborates with Alzheimer Portugal and is responsible for implementing a specific programme for people with dementia and their carers, in partnership with Acesso Cultura, MAAT Museum and the Museum of Lisbon.

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“Pad cultures”: How continence care impacts on people with dementia in acute hospital settings

"Pad cultures: An ethnography of continence care and its consequences for people living with dementia during a hospital admission" was recently published in the journal Dementia. Katie Featherstone, Professor of Sociology and Medicine and Director of the Geller Institute of Ageing and Memory and Andy Northcott, Senior Lecturer in Sociology of Medicine at the Geller Institute of Ageing and Memory discuss their findings.

There is little research examining how continence care is organised and delivered to people living with dementia across an acute hospital admission, despite the prevalence of this patient population and their vulnerability within these settings. With this in mind, a study funded by the UK National Institute for Health Research, Health and Social Care Delivery Research Programme, was completed by Andy Northcott, Paula Boddington and Katie Featherstone from the Geller Institute of Ageing and Memory, University of West London. They observed the organisation and delivery of continence care to people living with dementia, in acute medical units and wards within three hospitals across England and Wales, over a period of 12 months.

The aim of the study was to shine a light on this invisible problem and ensure that people with dementia are given the best possible care, to improve their chance of recovery and a good quality of life. The authors conclude that continence care for people living with dementia admitted to acute hospital wards is dominated by what they have termed “pad cultures”, i.e. the everyday use of continence pads for patients living with dementia regardless of their continence status. This practice was described by staff as a precautionary strategy, essential to preventing ‘accidents’ or incontinence episodes. However, once adopted as a ‘just in case’ strategy, the routine use of pads in the care of people living with dementia resulted in the maintenance of their continence being deprioritised, and an expectation that patients living with dementia not only wear pads but that they could and should use the pad.

While the organisational rationales for these approaches were clear, their consequences for people living with dementia, for staff, and for a wider population of older patients within these acute wards were significant, creating significant distress.

Their data, the authors note, suggests that independent and supportive continence care can have benefits for both people living with dementia and for staff in hospital wards.

The methodology used for this study was ethnography, which involves observing everyday life within an organisational setting. It is particularly useful to examine topics where measurement is either not easy or inappropriate, and where the topic is complex and highly sensitive. We, the researchers (Katie Featherstone and Andy Northcott), spent time on each ward, observing the work of the ward staff and recording field notes by hand. We also talked to the staff, patients, and their families about their experiences in the ward.

The study included the views of people living with dementia, their care partners and hospital workers. We recruited 108 participants during their time on the wards, and conducted 568 brief in-situ interviews.

Can you tell us about the methodology used for this study? Were the views of people with dementia and hospital workers included, or was this purely an observational study?

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Read the full study, here: https://journals.sage-pub.com/doi/10.1177/14713012221116490
These were not traditional formal sit-down interviews but rather brief conversations during periods of observation. These conversations covered topics such as why staff responded to an incident in a certain way, or how a person living with dementia felt about their care and what was happening around them.

Overall, the data set comprised over 500,000 words of field notes, which were analysed to gain insights into the experiences of people living with dementia in hospitals and the challenges faced by hospital staff in providing care.

**Your findings comprise of five themes. Can you tell us more about them?**

Our study identified five themes (visibility of continence, rationales of continence care, containment and contagion, consequences of continence care, and supporting continence) that shed light on the broader context and cultures of care in which continence care for people with dementia is delivered. This culture failed to support people living with dementia and those responsible for caring for them.

The first theme, the visibility of continence, was immediately apparent to anyone who has ever spent time on a ward. The prevalence of bedpans and pads in every corridor and bay serves as a constant reminder of the issue. In addition, the absence of older patients leaving their beds and walking to the toilet is equally visible, and this speaks to the larger issue of patients being confined to their beds.

The other themes we identified in our study rationales of continence care, containment and contagion, consequences of continence care, and supporting continence provided additional insight into the reasons behind this pervasive issue. Pressures on staffing, patient flow, and ward routines contribute to the use of containment practices, which overlook the impact on the patient’s experience and health outcomes. These cultures of care prioritise the institution’s needs over those of the patient and staff expertise.

Our study reveals that a shift in the culture of care is necessary to improve the care provided to people living with dementia. Providing ward staff with the necessary resources and space to work beyond the current pad cultures will allow them to prioritise the needs of the patients and provide better care. It is our hope that our findings will inform policy and practice changes in healthcare and ultimately improve the quality of life for those living with dementia.

**When you say that continence care for people living with dementia in acute hospital wards is dominated by “pad cultures”, what do you mean?**

The term “pad cultures” refers to engrained ward practices wherein incontinence is assumed to be a feature of a dementia diagnosis, with people living with dementia routinely put in continence pads regardless of their independence or continence. Staff often described the rationale that this is ‘just in case’ and to prevent ‘accidents’. However, once the person was wearing a very visible pad, incontinence was assumed and they were then expected to use these pads rather than being assisted with bathroom visits, especially on busy and understaffed wards. In this way, maintaining continence, a crucial but hidden part of everyday life, was reduced and minimised to aid the wider management and smooth running of the ward.

However, this practice has wider consequences and can lead to significant numbers of people being discharged from hospital with incontinence. We know that between 17% - 36% of older people and people living with dementia who are continent upon admission to hospital leave incontinent. This is a significant issue for their future, their dignity, their families and society at large.

You found that this “pad culture” approach has a hugely negative impact on the wellbeing and dignity of some of the people with dementia in hospital settings and that it constitutes a human rights issue. How so, and what needs to change to ensure people’s human rights are respected?

Crucially it must be remembered that people living with dementia should have the same opportunity and support to go to the toilet, as any other patient. The dignity of people living with dementia can quickly be lost in hospital settings, overshadowed by a diagnostic category which sees their continence reduced to something to be managed rather than enabled.

As a result of “pad culture”, family members may not be able to support the needs of their loved ones at home, and many people are then not able to return home and instead move into long-term care. This is tragic and avoidable, and highlights the importance of recognising continence care as a crucial and integral feature of dignified, high quality care.
Do your findings apply specifically to the United Kingdom, or might they also apply in other countries?

While our evidence is limited to the National Health Service in England and Wales, we have spent the last 12 months ‘touring’ our findings, presenting our research to a global audience, including at Alzheimer Europe’s most recent conference in Bucharest. Unfortunately our findings reflect how continence care is delivered across Europe, North America and Australasia.

Is there any advice you could give to policymakers aiming to improve the experience of continence care for people living with dementia in hospitals?

During the research we found no indications that continence care was recognised by these hospitals and institutions as critical for care quality and having significant implications for the many people living with dementia in their care. Instead, in these settings continence care is regarded as ‘low status’ and often described as ‘basic’, rather than essential care or dignity work. Our advice for policy makers and practitioners is to recognise the central role continence care plays in supporting patient dignity, well-being and quality of life, and its critical role in maintaining patient independence and improving health outcomes.

What further research is needed and will the Geller Institute be conducting any further studies?

Further research is needed to develop interventions and training to support high quality continence care and the importance of providing dignified care and we are currently working with one hospital to use our findings to improve care. At the Geller Institute of Ageing and Memory we have an ongoing study, funded by the NIHR, which explores how continence care, and ‘pad cultures’, form one part of a wider culture of restrictions in the care of people living with dementia, and the impacts this has on their experiences and health outcomes.

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Recommendations to help prevent Alzheimer’s disease published by international task force

On 31 January 2023, an international task force, led by the University of Geneva (UNIGE) and Geneva University Hospitals (HUG) and including Alzheimer Europe, published a set of guidelines for innovative services to help prevent Alzheimer’s disease. The guidelines are detailed in an article titled “Dementia prevention in memory clinics recommendations from the European task force for brain health services”, published in the journal Lancet Regional Health Europe.

Alzheimer’s disease can lead to a dramatic loss of autonomy for those affected, due to the memory loss, behavioural changes and cognitive deficits it causes. On top of this, related health costs are high, leading to a heavy financial impact on many people. Its prevention has become a real social challenge. With 10 million people in Europe affected by Alzheimer’s disease, it is the most common neurodegenerative disease and is characterised by progressive, disabling memory loss and cognitive deficits caused by an accumulation of toxic proteins in the brain. Its social and economic impact is enormous, with the latter estimated at around EUR 1,386,780,000 per year, on a global scale.

Large-scale preventive protocol

With an ageing population in Europe, the prevalence of dementia continues to rise in our region. However, improved lifestyles (physical activity, better nutrition, cardiovascular health) have the potential to reduce the risk of developing Alzheimer’s disease and other types of dementia.

An international task force led by UNIGE and HUG, composed of experts from 28 institutions and including Jean Georges, Executive Director, Alzheimer Europe, is laying the foundations of a preventive protocol that could be deployed on a large scale.

The full article can be read here: https://doi.org/10.1016/j.lanepe.2022.100576

Interview with Professor Giovanni Frisoni, Full Professor of Clinical Neuroscience at the UNIGE Faculty of Medicine and Director of the HUG Memory Centre

What are some of the main challenges currently faced in clinical practice, regarding prevention and risk-reduction in Alzheimer’s disease and other types of dementia?

First of all, there is a lot of confusion when people talk about prevention and risk reduction in Alzheimer’s disease and dementia. It is therefore important to be clear about the different types of prevention, and the different groups that could benefit from risk-reduction measures.

Patients who already have cognitive impairment, such as mild cognitive impairment (MCI) or Alzheimer’s dementia, could benefit from tertiary prevention measures. These measures aim to slow the progression of disease, for example by alleviating cognitive or behavioural symptoms of Alzheimer’s disease. Tertiary prevention measures include treatments we’ve been using clinically for the past 20 years, such as cholinesterase inhibitors, cognitive rehabilitation, and drugs to treat agitation.

Achieving tertiary prevention is already a challenge. However, the major challenge - the holy grail of prevention - is secondary prevention. Secondary prevention measures aim to prevent cognitive impairment (be it MCI or dementia) in persons who have no cognitive impairment, but may be at high risk of developing MCI or dementia in the future. Secondary prevention measures are a new development for the Alzheimer’s field, and they have yet to be implemented in clinical practice.

How can we achieve secondary prevention of cognitive impairment? There are a number of possible strategies. Firstly, the FINGER (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) trial showed the benefit of making lifestyle changes, such as improving nutrition and physical health, and remaining cognitively and socially active. Other strategies currently being evaluated in clinical research studies include probiotics, transcranial stimulation therapies, and anti-amyloid drugs such as lecanemab and other anti-amyloid drugs.

Can you tell us more about the new preventive protocol and about the four “pillars” it identifies?

In our article, we make recommendations on the deployment of secondary prevention...
measures in memory clinics, many of which are not equipped to evaluate and treat high-risk individuals, who do not currently have cognitive impairment. We identify four pillars, or cornerstone interventions, for secondary prevention memory clinics, termed “Brain Health Services”:

1. **Risk assessment**: The individual level of risk should first be ascertained using an array of tools and tests, including biomarker measurements, genotyping certain genes, and assessment of clinical and lifestyle risk factors.

2. **Risk communication**: The second pillar is risk communication, which is not an easy task, as risk is a fuzzy concept and risk disclosure can impact the psychological and mental health of individuals. Effective and ethical risk communication should be tailored to be understandable and meaningful to the individual.

3. **Personalised prevention**: This pillar involves the deployment of multidomain lifestyle interventions (such as those used in the FINGER trial), with, where available, personalised pharmacologic and non-pharmacologic therapies that target the underlying causes of disease.

4. **Cognitive enhancement**: The fourth pillar aims to improve cognitive performance, with particular benefits for cognitively normal individuals who are at high risk of cognitive impairment. Strategies and tools include non-invasive brain stimulation, for which there is some evidence of cognitive enhancement.

**How did you come up with these guidelines; what search strategy and selection criteria were employed?**

We started from our own experience in the field, then complemented these experiences with a literature review, which included scientific publications on risk profiling, risk communication, personalised prevention, and cognitive enhancement.

In memory clinics, we often see patients with normal cognition. Why do we see them in memory clinics if they have normal cognition? Well, they attend because their subjective perception is one of declining memory performance. A common refrain is “Doctor, my memory is not what it used to be”. We then carry out memory and other cognitive assessments and they score at normal levels in all tests. In other words, they do not have MCI, never mind dementia. They have “subjective cognitive decline”. This means that they perceive a decline in cognition, but there are no objective clinical signs - hence terming the decline “subjective”. Our guidelines and recommendations were informed by our experiences from treating, diagnosing and talking about risk with individuals who have subjective cognitive decline.

How important was it to involve a wide variety of co-authors (28, including Alzheimer Europe’s Executive Director)? What were their contributions, broadly speaking?

We know that there are at least three classes of risk factors for Alzheimer’s disease and dementia:

1. **Lifestyle risk factors**, such as the 12 lifestyle risk factors described by the Lancet Commission in 2020; these include poor sleep, social isolation, obesity, hypertension, diabetes, depression, smoking and so on.

2. **Genetic risk factors**: apart from the autosomal dominant mutations that cause early-onset Alzheimer’s disease, the strongest genetic risk factor for Alzheimer’s dementia is the epsilon 4 allele of apoE.

3. **Biological risk factors**: these risk factors include the accumulation of amyloid plaques in the brain; tau tangles; or the two together, which is termed comorbid amyloidosis and tauopathy. There are plenty of older people who live perfectly well in the community but who...
have amyloid, tau or both in their brain. We also know that these people have a high risk of developing cognitive impairment, further down the road.

To develop effective and useful recommendations we needed experts in these three domains. We also needed experts in risk communication, and experts in the different types of lifestyle and drug interventions for cognitive impairment and Alzheimer’s disease; experts in transcranial brain stimulation; experts in probiotics; and we needed epidemiologists who could tell us about the impact and prevalence of the different risk factors at a population level and for individuals.

Of course, we also needed the point of view of patients and caregivers, to understand how relevant dementia prevention and risk reduction is to them, the value of understanding and decreasing risk for people who have relatives with Alzheimer’s, and who may be afraid of developing Alzheimer’s. Hence, the involvement of Alzheimer Europe.

What are the main target populations that would be helped through these new services? Are these populations currently being supported by existing clinics?

The answer to the second question is no. People with subjective cognitive decline do not currently receive satisfactory answers or support in memory clinics. Standard clinical practice for individuals with subjective cognitive decline is to carry out a battery of neuropsychological tests and once the tests are performed within normal limits, we reassure the patient that everything is okay. Sometimes we can do an MRI and it is almost invariably within normal limits for age. Often times, it doesn’t even show any vascular changes or brain atrophy. So, patients are basically reassured, but they do not receive any solutions or treatments for their memory complaints.

In our recommendations for brain health services and with this paper, we tried to flesh out an answer, and a meaningful one, for this population. Not only for those with subjective cognitive decline, but also the 3-5% of memory clinic patients whom we label the “worried well”.

These people come to memory clinics with no cognitive complaints, but with concerns. They might be 50 or 60 and while their memory is fine, they want to keep it that way for as long as possible, and possibly enhance it. They may have had a parent or parents with Alzheimer’s, and are keen to reduce the risk of also developing Alzheimer’s as they age.

Could the recommended interventions be implemented right away or is there some ground work to do first?

Some of the recommendations could be implemented right away. For instance, we already have all the clinical tools to estimate risk in cognitively healthy persons. We understand the relative weight of each risk factor and we can stratify persons into low-risk, intermediate-risk and high-risk groups. We also know how to communicate risk, and already have some risk-reduction interventions, such as the FINGER intervention I mentioned earlier, as well as cognitive training. At the moment, however, we do not have a drug that can prevent cognitive decline, which would be an ideal complement to lifestyle interventions, and the efficacy of transcranial stimulation is not fully ascertained.

So, while there are already measures we can adopt, there is also a lot of work to do in the future, not only to develop risk-reduction interventions, but also to implement simple and cheap screening methods to assess risk at scale. As mentioned above, we already have tools to assess lifestyle and genetic risk. However, biological risk is currently more challenging to assess at scale.

Current tools such as PET scans or lumbar punctures can help, however these strategies are costly, invasive and hard to deploy at scale. Blood biomarkers may form part of the solution to this challenge. Blood biomarkers are already widely used in research, and they may become a clinical reality in the coming two to three years. The horizon is very close.

What actions can we take until new tests and interventions become a clinical reality? In our paper, we propose the establishment of pilot Brain Health Services, which will work with the tools and knowledge that are already available and established in clinical practice. Then, once new tests, tools and treatments become available, these technologies will be implemented into their armamentarium. We already have a blueprint for brain health services in Europe, thanks to the recently-launched Brain Health Scotland initiative, whose services were co-designed with marginalised communities. This model shows that it is possible to deliver prevention and risk-reduction measures, to decrease the prevalence and societal burden of dementia.
Our members are helping people with dementia and their carers in 37 countries

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- Estonia – Tallinn: NGO Living with Dementia
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- Germany – Berlin: Deutsche Alzheimer Gesellschaft e.V
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- Hungary – Budapest: Social Cluster Association
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- Ireland – Dublin: The Alzheimer Society of Ireland
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- Jersey – St Helier: Dementia Jersey
- Lithuania – Vilnius: Demencija Lietuvieje
- Luxembourg – Luxembourg: Association Luxembourg Alzheimer
- Malta – Msida: Malta Dementia Society
- Netherlands – Amersfoort: Alzheimer Nederland
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- Norway – Oslo: Nasjonalforeningen for folkehelse
- Poland – Warsaw: Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera
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