

ALZHEIMER EUROPE NEWSLETTER

TABLE OF CONTENTS

- 01**
Welcome
- 02**
COVID-19 Situation
- 06**
Alzheimer Europe
- 08**
Alzheimer Europe networking
- 08**
EU projects
- 10**
EU developments
- 11**
Members' news
- 13**
Policy watch
- 15**
Science watch
- 20**
Living with dementia
- 21**
Publications and resources
- 22**
AE calendar
- 22**
Conferences

HIGHLIGHTS IN THIS ISSUE

3 Apr: Discriminatory COVID-19 triage decisions unacceptable	6
9 Apr: Iceland launches its National Dementia Strategy	14
14 Apr: Board adopts COVID-19 wellbeing recommendations	6
22 Apr: Biogen aims to complete aducanumab FDA filing in Q3	19

WELCOME



COVID-19 continues to affect our lives on a daily basis and in almost every aspect. It is a particularly trying time for people with dementia, and to help ensure the wellbeing of people with dementia and their carers during this pandemic, our Board has adopted a set of recommendations for Alzheimer associations, health and social care professionals. I am so impressed with the speed at which our members and other Alzheimer associations, as well as health and social care professionals, have responded to the current challenges and how they are able to continue providing essential services. They deserve the full support of their national governments.

At the start of this month, following an online meeting with our national member associations, we launched a call to governments and health systems to urgently increase the infrastructure for intensive care needed for people affected by COVID-19, and to ensure regulations around access to life-saving treatment are based on sound ethical principles. It is unacceptable to systematically restrict access to ventilators for people living with dementia or people living in nursing homes.

At the European level, 45 MEPs have signed an open letter, addressed to European Commission President Von der Leyen and EU Council President Charles Michel, demanding that the Coronavirus Response Investment Initiative ensures funding for support and care services for persons with disabilities.

At the national level, Iceland has launched its National Dementia Strategy this month. We send our congratulations to Iceland's Ministry of Health, and of course to our member Alzheimer Iceland, which contributed to the writing of this document. As well Board and membership meetings this month, we also held the first ever online meeting of the European Working Group of People with Dementia (EWGPWD). There was a fantastic turnout, with all but one group member participating, and there was a very productive discussion about possible improvements to our website section on COVID-19.

With online meetings being the order of the day, our ethics working group on intercultural care and support held a teleconference, to agree on the focus, scope and organisation work building on our 2018 report on the development of intercultural care and support for people with dementia from minority ethnic groups.

In research news, Biogen, which continues to have constructive engagement with the US Food and Drug Administration (FDA) and has an open Biological Licence Application with the FDA, has announced that it expects to complete the filing for its Alzheimer's disease drug aducanumab, in the third quarter of this year. The previous expectation was that it would complete the filing in the first half of this year.

Lastly, I would like to draw your attention to the deadline of 15 May (in two weeks) for submitting abstracts for our 30th Annual Conference #30AEC, which is still planned to go ahead.

Jean Georges
Executive Director

COVID-19 SITUATION

28 March: Bosnia publishes recommendations on supporting people with dementia during the COVID-19 pandemic

Demencija u vrijeme pandemije Covid-19



Centar za demenciju
Osman Kučuk



Alzheimer udruženje AiR
Amela Hajrić
Emina Kučuk

On 28 March, Osman Kučuk (Director of the Sarajevo Center for Dementia), Amela Hajric and Emina Kučuk (Udruženje AiR) published a document outlining their recommendations for supporting people with dementia during the

COVID-19 pandemic. The document was published in collaboration with the Bosnia Herzegovina Ministry of Health and the Sarajevo Institute for Public Health.

The aim of the publication is to outline “how to help and protect people living with dementia alone in their homes or with their partners”. Among other topics, the symptoms of caregiver burnout are discussed, and recommendations on how to avoid burnout are provided. The publication also describes possible symptoms of COVID-19 in people with dementia, which include physical exhaustion, increased aggression and disorientation.

Finally, specific recommendations to help families and caregivers of people with dementia during the COVID-19 pandemic are outlined. For example, reminders of hand hygiene techniques can be displayed prominently above bathroom sinks, and a caregiving backup plan could be created in case the usual caregiver becomes infected. The publication also lays out recommendations for measures to undertake in the event that the person with dementia is hospitalised, such as ensuring that nursing staff are trained in dementia care, and that cognitive and physical activity levels are maintained where possible. For more information, visit:

<https://bit.ly/3f30tve>

An English translation of the publication is available upon email request to info@alzheimer-europe.org

31 March: Alzheimer Society of Ireland teleworking staff report on how they are supporting people during COVID 19 crisis

COVID-19 is having a profound impact on the work of The Alzheimer Society of Ireland (ASI) and this, in turn, is greatly impacting those people for whom The ASI cares and provides support. 48 day-care centres have been closed and vital supports such as Social Clubs, Alzheimer Cafes and Support Groups have been suspended for the foreseeable future. Many people with dementia and their family carers are alone and feel isolated. But they are not forgotten.

The ASI’s Home Care, Dementia Adviser service, National Helpline and Online Family Carer Training are all still operating. In addition, new ways of providing support remotely to people with dementia and their families are being implemented, including regular telephone calls and activity packages for people to use in their own homes.

ASI Dementia Adviser, Maeve Montgomery said:

“I have been making phone calls and sending emails and everyone has been very understanding and delighted to get a call. Family members are protecting older members by staying out but keeping in touch. Many are delivering groceries to the doorstep and waving from a safe distance”.



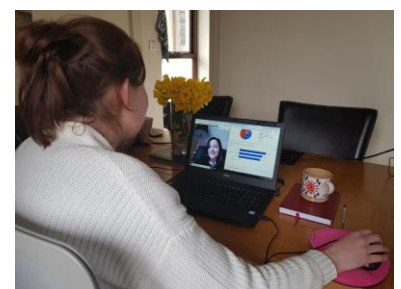
ASI National Helpline Adviser, Elaine Crocker said:



“It is a very worrying time for carers at the moment, their job is twice as difficult now as very often people with dementia may not have an understanding on the importance of cross infection control and carers are very worried about how best to protect their loved one from the virus, callers are needing a lot of support and reassurance with this”.

ASI Research Officer, Laura O’Philbin and ASI Policy and Research Manager, Bernadette Rock said:

“Last week we surveyed 147 people with dementia, family carers and community champions on their current challenges associated with COVID-19 and what they feel ASI could do to support them through this. From this, we wrote a brief report and recommendations that will help ASI to make informed decisions and take action in this pandemic”.



1 April: Research undertaken by The Alzheimer Society of Ireland indicates that lack of services due to COVID-19 is leading to a deterioration in the health of people with dementia

Research carried out by The Alzheimer Society of Ireland (ASI) to identify the current challenges brought about by the COVID-19 health crisis, as experienced by people with dementia and

family carers, has found a rise in the cases of isolation, loneliness, boredom, anxiety and fear.

The ASI's Dementia Advisers have reported an increase in responsive behaviour from people with dementia including confusion, paranoia, delusions, agitation, and other behavioural changes, with one Dementia Adviser comparing the deterioration of one person with dementia to "falling off a cliff edge".

The research, which included the views of 160 people with dementia, family carers, Dementia Advisers, and Dementia: Understand Together Community Champions, found that 73.3% of people with dementia feel they need some support at the moment with most requiring both practical (e.g. shopping) and emotional supports (e.g. regular telephone check-ins). Of note, only 31.3% were comfortable using the internet.

77.6% of family carers reported needing supports including practical supports (e.g. shopping, information) and emotional supports (e.g. peer support). Many cited heightened anxiety and stress, with feelings of helplessness, worry for their loved ones with dementia, and concerns about the impact of social isolation. In particular, carers expressed that they are worried about getting sick themselves and not being able to care for loved ones.

In addition, almost 95% of Dementia: Understand Together Community Champions feel that with local services such as daycare, Alzheimer Cafes and community activities suspended, people affected by dementia require alternative practical or emotional support, or both (e.g. advice on local supports, dog walking and regular check-ins). Community Champions were also asked about alternative sources of support that were already in place in their communities, with respondents identifying volunteer networks offering practical assistance and meals-on-wheels services that are currently in action.



The ASI continues to support people with dementia and their families, insofar as its Home Care, Dementia Advisers, Alzheimer National Helpline and Online Family Carer

Training are all still running. In addition, The ASI is implementing new ways of providing supports remotely, such as regular telephone calls and activity packages for people to use in their own homes. The full report can be found here:

<https://alzheimer.ie/wp-content/uploads/2020/04/FINAL-Research-survey-results-on-need-1st-April-2020.pdf>

Pictured: Pat McLoughlin, CEO of The Alzheimer Society of Ireland

2 April: Alzheimer Europe hosts online meeting of members to discuss responses to COVID-19

Alzheimer Europe hosted an online meeting of its members to discuss their responses to the COVID-19 pandemic. The meeting, attended by 22 associations, allowed members to discuss how they were operating during the crisis, as well as sharing examples of how they were continuing to support people with dementia and their carers throughout the pandemic.

During the meeting, Alzheimer Europe outlined work it had carried out to date, including the meeting of the Governmental Experts on Dementia which had been held on 24 March, as well as the dedicated section on its website which contains resources and information related to COVID-19. Additionally, members were asked to contribute to the development of a position paper that Alzheimer Europe was drafting in relation to the allocation of medical resources for intensive care during the pandemic.

Members then used the opportunity to share their ongoing work to support people with dementia. Whilst national organisations are unable to deliver services such as daycare or in-person supports as a result of restrictions, many organisations are utilising phone and video technologies to offer some level of support, as well as publishing information and resources online.

A number of members also highlighted that they continued to engage with decision makers to ensure that the rights of people with dementia were upheld during the crisis, particularly in relation to decisions on health and social care.

Alzheimer Europe's collation of different links to relevant COVID-19 resources can be found here: <https://www.alzheimer-europe.org/Living-with-dementia/COVID-19>

7 April: Alleviating boredom while staying at home: Alzheimer's Society suggests home-based activities for people with dementia



As part of their coronavirus information section, Alzheimer's Society (UK) has provided suggestions of digital, web-based and physical activities for people living with dementia, aiming to help them pass the time, keep engaged and stimulated whilst isolating at home.

These suggestions include using technologies such as smartphones and tablets to listen to music and audiobooks, or to access creative activity apps and digital assistants such as Alexa. The Alzheimer's Society also identify ways in which people with dementia can remain physically active in the home, either through online exercise programmes or via engaging in activities such as gardening, seated exercises or going for walks. More information can be found on the Alzheimer's Society resource pages:

<https://www.alzheimers.org.uk/get-support/coronavirus-activity-ideas-people-living-dementia#content-start>

9 April: “My Hero is You!” - the Inter-Agency Standing Committee produces a new storybook to help children understand the COVID-19 pandemic



On 9 April, the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergency Settings (IASC MHPSS RG) announced the

publication of ‘My Hero is You!’, an illustrated storybook aimed at helping 6-11 year-old children to understand the COVID-19 pandemic.

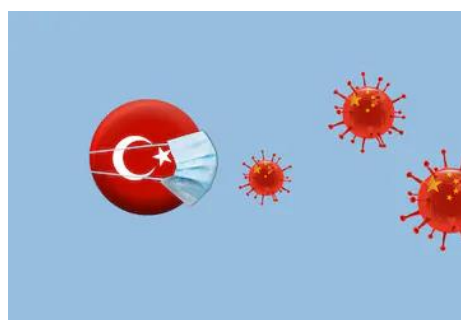
Co-chaired by the World Health Organization, the IASC MHPSS RG brings together over 50 organizations working in the humanitarian sector, including United Nations agencies, national and international nongovernmental organisations and international agencies providing mental health and psychosocial support in emergency settings. The book is designed to address key themes that were identified through a survey of over 1,700 children, parents and caregivers from 104 countries, which was aimed at assessing the mental health and psychosocial needs of children during the COVID-19 pandemic.

“My Hero is You!”, which will be released in over 30 different languages, tells the story of Ario, a magical creature who comes to the aid of a young girl called Sara. The book explains how children can protect themselves, their families and friends from COVID-19, and how to manage some of the tricky emotions that can arise whilst they navigate life at home during the rapidly-evolving COVID-19 pandemic. Central to the story is the concept that every child – irrespective of age, socioeconomic circumstance or gender - can be their own hero, by observing social distancing and hand hygiene measures.

The book was written and illustrated by Helen Patuck, and is available via this link as an online text or as an audiobook:

<https://bit.ly/3bMlqKE>

9 April: COVID-19 measures lead to Turkish Alzheimer Association postponing 3 major events planned for March 2020



March was anticipated to be the busiest time of 2020 for the Turkish Alzheimer Association, with three major events planned. The Annual Branch Meeting was

scheduled for 13-14 March, in Mersin. All 15 branches of the Association, plus a new one under development, were scheduled to gather together to exchange information on the past year’s activities, to discuss plans and opinions for the coming year, and to vote on the National Dementia Strategy, which is currently in its final draft stage. When the first case of COVID-19 was announced by the Turkish Ministry of Health on 12 March, the meeting was immediately cancelled. Members, some of whom were already on their way to the city of Mersin, were notified and recalled.

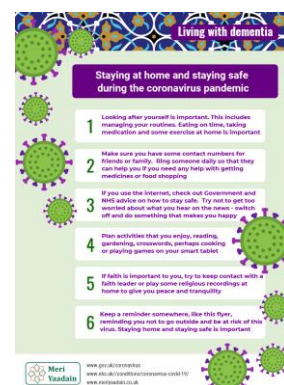
The 10th Annual Alzheimer Conference, a scientific conference held every year targeting professionals working in the field of dementia, was scheduled to take place on 24-28 March in Eskişehir. Unsurprisingly, this conference has also been postponed, provisionally until 24-28 June. Last, but not least, the General Assembly of the Association, which is normally carried out biennially in March, was also cancelled. Delegates had been invited to participate in the General Assembly on 31 March, but this also had to be postponed as part of the measures taken in Turkey to restrict the gathering of individuals, in an effort to limit the spread of the coronavirus.

On 16 March, the Turkish Ministry of Internal Affairs issued an additional circular which was delivered to 81 provincial governorships, whereby all meetings and activities, including general assembly meetings and trainings of non-governmental organisations such as associations and foundations, were temporarily postponed as from 17 March 2020 at midnight.

Along with the rest of the world, the Turkish Alzheimer Association remains uncertain as to when life will return to some semblance of “normality”. So far, the Association remains functioning with the same Board for an indefinite period of time, staying connected with its branches, ADI and Alzheimer Europe using digital tools. Although the day care centres are closed, staff continue to provide consultancy and counselling over the telephone, mail, WhatsApp, etc. and advice, tips, cheering messages, home entertainment and exercise posts are continuously published on social media and the web site of the Association.

12 April: Information regarding BAME Dementia communities and COVID-19 published by Meri Yaadain CiC

Meri Yaadain CiC, a UK-based community interest company that aims to support Black Asian Minority Ethnic (BAME) people living with dementia and carers, has developed some information regarding BAME Dementia communities and COVID-19. There are two posters, one aimed at organisations / communities and the second aimed at families / carers. There



are also two leaflets, one aimed at organisations / communities and the second aimed at families / carers.

Mohammed Akhlak Rauf MBE, founder and director of Meri Yaadain CiC points out that, while primarily aimed at BAME people, much of the information is applicable across all communities. Alzheimer’s Society (UK) has endorsed these resources, all of which you can access via the Alzheimer Europe website:

<https://www.alzheimer-europe.org/Living-with-dementia/COVID-19/Information-for-minority-ethnic-groups>

19 April: Alzheimer Croatia makes special provision for people with dementia during the COVID-19 lockdown



Alzheimer Croatia has arranged for the Croatian Red Cross to make necessary deliveries of food and medicines to those with dementia during the imposed lockdown period of the

coronavirus pandemic. They have also increased the number of SOS call centre lines and issued recommendations for all those caring for people with dementia in these strange and unsettling times.

Red Cross volunteers received instructions on identifying signs of dementia, in addition to advice on how best to communicate with people with dementia, so that volunteers were fully prepared when delivering medication and food. The Red Cross has also been advised to refer people to the SOS call centre of Alzheimer Croatia for further assistance, if required. Due to a large increase in the volume of SOS calls, the number of telephone lines were quadrupled.

Aware of the sensitive situation in which dementia carers now find themselves, Alzheimer Croatia released a special issue of its newsletter, which is sent to all nursing homes, food delivery and home help services, as well as thousands of family caregivers. This special edition draws attention to the difficulties that those with impaired cognitive functions may come up against, while complementing the official recommendations for the prevention of the spread of the virus and personal protection.

20 April: Alzheimer’s Society calls on organisations in 13 different sectors to make adjustments to help people affected by dementia during COVID-19

In light of the UK Government briefing on COVID-19, Alzheimer’s Society has called on organisations across 13 different sectors including retail, utilities, finance and pharmacies to make small adjustments that could have a huge impact in helping protect people affected by dementia and keep them connected to their communities in new and creative ways during this period.

Alzheimer’s Society called upon the retail sector to enable people to order deliveries over the phone by making local supermarket phone numbers available via posted letters, local newspapers and radio and to move towards priority systems for vulnerable groups and their carers to more easily complete their shopping.

Alzheimer’s Society has worked with finance experts and authorities to write a blog offering families affected by dementia advice on protecting against corona-themed scams, which are sadly already happening.

The Society has supported arts groups, physical activity projects and heritage organisations to adapt their normal activities so people can still access them virtually at home. These groups have also been encouraged to provide information on a range of activities people affected by dementia can enjoy at home, while in isolation. Alzheimer’s Society has also created home packs and activities for young people, linked to the syllabus for home schooling. These are available to download for free on the Alzheimer’s Society website.

The next few months are going to be challenging for everyone, but Alzheimer’s Society is committed to continue working for the benefit of people affected by dementia together with other organisations, to help and to protect the most vulnerable in society who are heavily impacted by the current situation.

Here are links to some of the resources and information mentioned:

- Information about corona-themed scams:
www.alzheimers.org.uk/blog/coronavirus-covid-19-scams-people-affected-dementia
- Activity ideas:
www.alzheimers.org.uk/get-support/coronavirus-activity-ideas-people-living-dementia
- Teaching resources:
www.alzheimers.org.uk/get-involved/dementia-friendly-communities/dementia-teaching-resources

28 April: New COVID-19 resource on home-based activities for people with dementia published by HSE and The Alzheimer Society of Ireland



A new resource on “At Home Activities” has been published, aimed at people living with dementia and their supporters, during the COVID-19 confinement period.

This extensive resource, which contains many suggested activities together with clear and concise information and instructions, is the result of a collaboration between The Alzheimer Society of Ireland

and Ireland’s Health Service Executive (HSE), as part of the “Understand Together” campaign.

It is really great to see the work being done, both by individual organisations and in collaborations such as this, during this difficult period. You can read and download the resource, here (free):

<https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/At%20Home%20Activities.pdf>

Sponsor of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2020 activities.

Read more about sponsorship opportunities here:

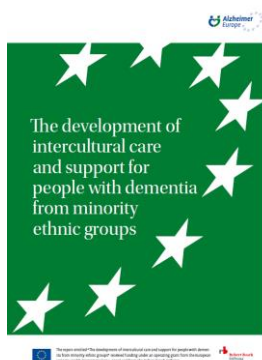
<http://bit.ly/sponsorAE>



Follow us on Twitter

ALZHEIMER EUROPE

27 March: Alzheimer Europe holds first meeting for continued work on intercultural care and support



On 27 March, Alzheimer Europe organised a 2-hour teleconference with members of the ethics working group on intercultural care and support. The group agreed on the focus, scope and organisation of the planned work, which builds on the 2018 report on the development of intercultural care and support for people with dementia from minority ethnic groups (pictured). This continued

work is funded by the Robert Bosch Stiftung.

The group will be producing two short publications (namely, a practical guide for health and social care professionals and a short report for policy makers), writing an article for a peer-reviewed journal targeted at clinicians and refining the current database of initiatives for intercultural dementia care and support within Europe. Despite the current situation with the coronavirus, it is hoped that the working group can still function well and that this work will be completed by the end of the year.

If readers would like to share any intercultural care initiatives, please contact Alzheimer Europe so that we can include them in the database. Dianne Gove and Jean Georges participated in this meeting.

3 April: Alzheimer Europe rings the alarm about discriminatory practices in intensive care settings during the COVID-19 pandemic

At an online meeting organised by Alzheimer Europe, representatives from 22 national Alzheimer’s associations from 19 European countries adopted a call to governments and national health systems to urgently increase the infrastructure for intensive care needed for people affected by COVID-19 and to ensure any access or withdrawal regulations to life-saving treatment are based on sound ethical principles which do not discriminate against people with dementia.

In its position adopted on 3 April, Alzheimer Europe considers it unacceptable to systematically restrict access to ventilators during the COVID-19 pandemic to people living with Alzheimer’s disease and other types of dementia or people living in nursing homes. Where triage decisions become necessary, these should always be based on a patient’s individual prognosis and not solely be based on a person’s age, diagnosis or place of residence.

In addition, the association stresses the need:

- to take into consideration a person’s expressed wishes, such as those expressed in an advance directive,
- to adhere to palliative care principles and guidelines,
- to develop clear medical protocols where triage decisions are taken by a team of healthcare professionals with expertise in intensive and palliative care,
- to regularly review and properly document any such triage decisions.

Commenting on the position, Helen Rochford-Brennan, chairperson of the European Working of People with Dementia, said: “I am grateful to Alzheimer Europe for coordinating this important response which is in line with the organisation’s commitment to a human rights based approach to dementia. Many people are able to live long and meaningful lives with dementia with a good quality of life. A diagnosis of dementia should never be a reason to be refused treatment, care or support”. The full position of Alzheimer Europe is online here:

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Triage-decisions-during-COVID-19-pandemic>

14 April: Alzheimer Europe Board adopts recommendations on how to promote the wellbeing of people with dementia and carers during the COVID-19 pandemic

Today, the Alzheimer Europe Board adopted recommendations for Alzheimer associations, health and social care professionals on how to promote the wellbeing of

people with dementia and carers during the COVID-19 pandemic.

Alzheimer Europe highlights how physical distancing rules affect people with dementia who may find their normal routines disrupted, lack cognitive stimulation, feel lonely and anxious and risk depression. Similarly, their partners, relatives and close friends involved in their care may encounter challenges due to the disruption of normal routines and the loss of support and closure of services. Finally, health and social care professionals are striving to provide appropriate and timely treatment, support and care despite fears for their own safety due to the lack of protective clothing in some countries.

For the development of its recommendations, the Alzheimer Europe Board built on in-depth discussions with its member organisations and ministry officials from the European Governmental Expert Group on Dementia who shared some of the innovative ways in which associations and governments continue to provide support to people with dementia, such as tailored and easy-to-understand information, online support, the use of new technologies to allow physical distancing and social interactions, coordinated home support for people with dementia through local branches and maintaining of routines at home and in residential care.

Commenting on these recommendations, Jean Georges, Executive of Director, said: "I am in awe at how quickly Alzheimer associations and health and social care professionals have responded to the COVID-19 challenge and continue to provide essential information, support and care to people with dementia and their carers. They deserve the full support of national governments and I hope our recommendations provide some guidance on how to promote the wellbeing of people with dementia and carers in these difficult times." The full recommendations adopted by the Alzheimer Europe Board are online here: <https://www.alzheimer-europe.org/Policy/Our-opinion-on/Wellbeing-of-people-with-dementia-during-COVID-19-pandemic>

15 April: European Working Group of People with Dementia has first zoom meeting



On 15 April, the European Working Group of People with Dementia (EWGPWD) held its first zoom meeting. There were two main objectives for this meeting. The first was to check whether everyone was OK and coping well during the pandemic and at the same time to give everyone the opportunity to say hello to each other. The second was to test whether this kind of meeting was feasible for such a large group of people with dementia. There was a fantastic turnout. All but one member of the group participated. Some had overcome difficulties with the technology. Some had never used it before and were on their own. Tomaž from Slovenia

had a very innovative solution. He was able to link up by Skype and for his supporter, Alenka, who was not with him, to transmit the video image to everyone on zoom.

The meeting lasted for 2 hours with a 15-minute break. There was a very productive discussion about Alzheimer Europe's work developing a section on its website for information about COVID-19. We are currently collecting feedback from each member of the group on how to improve such meetings, bearing mind the limitations of such an approach during a pandemic, with people dispersed across the whole of Europe, many isolated in their homes without their usual support. People have very different needs and we might not find a perfect solution for everyone so this will not be our only approach to keeping the group going during these difficult times. It was, however, a really nice experience and one possible approach, albeit with some tweaks to be made, to keeping in touch and continuing to work together as a group. Ana and Dianne from Alzheimer Europe took part in the meeting.

28 April: Only two weeks left to submit abstracts for #30AEC



During this time of uncertainty regarding COVID-19, the 30th Alzheimer Europe Conference #30AEC is still planned to take place in Bucharest from 20-22 October 2020. We continue to monitor the situation closely and will keep speakers and delegates informed regarding any relevant updates.

Our call for abstracts is still open, until 15 May 2020. Please read the abstract submission guidelines carefully before submitting an abstract. Find out more, here:

<https://www.alzheimer-europe.org/Conferences/Bucharest-2020/Call-for-Abstracts>

Registrations are also open, with Early Bird fees available until 15 July. Alzheimer Europe will reimburse people if the conference does not proceed.



Alzheimer Europe networking

- On 1 and 2 April, Ana attended an online PARADIGM WP3 workshop (metrics and impact of patient engagement).
- On 2 April, Alzheimer Europe organised an online meeting with its members to exchange information on how members are dealing with the COVID-19 pandemic.
- On 6 April, Jean attended the WHO webinar on “Essential mental health service delivery during the COVID-19 outbreak and response: lessons learned from Italy and Spain”.
- On 6 April, Jean had an online exchange with Sodexo Europe.
- On 10 April, Jean, Dianne and Owen attended the webinar of the European Disability Forum “COVID-19 pandemic: disability issues in Europe”.
- On 15 April, Alzheimer Europe organised an online meeting with the members of the European Working Group of People with Dementia to discuss the website information on the COVID-19 pandemic and how to function as a group during the pandemic.
- On 21 and 22 April, Ana and Angela attended the WP4 PARADIGM workshop (tools for patient engagement).
- On 25 April, Jean represented Alzheimer Europe at the online General Assembly of the European Patients’ Forum.
- On 25 April 2020, Gwladys attended the ICCA webinar: ICCA Global Conversations: Virtual Best-Practice Exchange for Associations.
- On 26 April 2020, Gwladys attended the ICCA webinar: ICCA Global Conversations in Collaboration with Simple view: How COVID-19 Changes Meeting Organizers’ Needs and Partner Relations.
- On 28 April 2020, Gwladys attended the ICCA webinar: ICCA Global Conversations: Understanding association challenges and finding solutions for new business practices Confirmation.
- On 29 and 30 April, Angela and Jean attended the online general assembly and technical coordination kick-off meeting of the VirtualBrainCloud project.

EU PROJECTS

1 April: The EPAD consortium congratulates two young researchers on successfully defending their PhD thesis

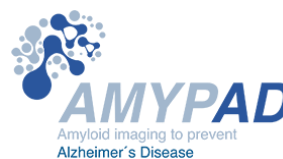


Two EPAD early career researchers successfully defended their PhD thesis in March 2020. On 13 March 2020, Lisa Vermunt successfully defended her PhD thesis entitled “Secondary prevention for Alzheimer disease – timing, selection and endpoint of clinical trials” at the VU University in Amsterdam (Netherlands). This work was conducted in the context of the EPAD project and was the first EPAD PhD to be completed including EPAD content. In this thesis, Lisa investigated the duration of the Alzheimer’s disease stages. The findings in this thesis improve the insight in the disease course of Alzheimer’s disease, including the pre-dementia period. On 16 March 2020, Lucy Stirland defended her thesis at the University of Edinburgh (UK). Her thesis is titled “Epidemiology of multimorbidity and polypharmacy in ageing: a complementary analysis of mental and brain health in three datasets”. Her thesis focused on the mental and brain health of people with multiple physical conditions. Most people with a long-term condition have more than one illness, so it's important to study combinations of diseases. Lucy

looked at data from three sources: EPAD, the PREVENT Dementia study and she also routinely collected data from the Scottish National Health Service.

<http://ep-ad.org/2020/04/20/two-epad-fellows-successfully-defended-their-phd-thesis/>

15 April: AMYPAD project published two new papers



The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project has published two new papers this month.

The first paper entitled “Simulating the effect of cerebral blood flow changes on regional quantification of [18F]flutemetamol and [18F]florbetaben studies” has been published in the journal of Cerebral Blood Flow & Metabolism and can be found at:

<https://doi.org/10.1177/0271678X20918029>

The second paper, published in the journal Alzheimer’s & Dementia, describes the design of the AMYPAD Prognostic and Natural History study. This study aims at understanding the role of amyloid imaging in the earliest stages of Alzheimer’s disease. The paper can be read here:

<https://doi.org/10.1002/alz.12069>

21-22 April: PARADIGM holds two-day virtual meeting to discuss its Patient Engagement toolbox



On 21 and 22 April, members of PARADIGM's work package 4 (WP4) organised an online

workshop to present their current work on the Patient Engagement (PE) tools and to discuss progress. Each day, a plenary session was organised, which was followed by three parallel breakout sessions.

On day one, the sessions were on the topics of Conflict of Interest; EUPATI guidance for industry when inviting patients

to events; and External reporting and dissemination of PE activities.

During the second day, participants discussed Community Advisory Boards; Identification of Patients for PE activities; and the PARADIGM Code of Conduct. In total each day, around 50 people from patient organisations, industry, HTA bodies and academia took part in the sessions.

Ana Diaz (Project Officer, Alzheimer Europe) co-facilitated the sessions on the reporting and dissemination of PE activities (day 1) and Community Advisory Boards (day 2), while Angela Bradshaw (Project Officer, Alzheimer Europe) participated in the sessions on EUPATI guidance for Industry (day 1) and the Code of Conduct (day 2).

EU project acknowledgement



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

AMYPAD - grant agreement 115952

PARADIGM - grant agreement 777450

EPAD - grant agreement 115736

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **94**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

Austria: Monika Vana (Greens/EFA). **Belgium:** Petra de Sutter (Greens/EFA); Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alamestä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciàran Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).



EU DEVELOPMENTS

1 April: European Medicines Agency publishes regulatory science strategy



EUROPEAN MEDICINES AGENCY
SCIENCE · MEDICINES · HEALTH

The European Medicines Association (EMA) has published its “Regulatory Science Strategy to 2025”, which provides a plan for advancing regulatory science over the next five years, covering both human and veterinary medicines.

The Strategy responds to the pace of innovation in recent years and the need for regulators to support the development of increasingly complex medicines that combine different technologies. The document identifies strategic goals for such engagement, proposing core recommendations and underlying actions to support these. The five key goals are:

- Catalysing the integration of science and technology in medicines development
- Driving collaborative evidence generation - improving the scientific quality of evaluations
- Advancing patient-centred access to medicines in partnership with healthcare systems
- Addressing emerging health threats and availability/therapeutic challenges
- Enabling and leveraging research and innovation in regulatory science.

The strategy will feed into the EMA’s overarching EMA “Regulatory Network Strategy to 2025”, which is currently under development. Additionally, its deliverables will be embedded in EMA’s multiannual work programmes and implementation plans of EMA’s scientific committees. You can find more information and the full regulatory strategy here:

https://www.ema.europa.eu/documents/regulatory-procedural-guideline/ema-regulatory-science-2025-strategic-reflection_en.pdf

8 April: 45 MEPs sign up to letter on support funding for disabilities



45 Members of the European Parliament (MEPs) have signed an open letter, demanding that the Coronavirus Response Investment Initiative ensures funding for support and care services for persons with disabilities.

The letter, addressed to European Commission President Von der Leyen and EU Council President Charles Michel, draws attention to the lack of funding for services that provide care

and support for persons with disabilities. In addition, the letter underlines that many organisations have adapted to the pandemic and continue to provide services but lack access to the necessary funding, as a result of fixed contracts with authorities.

MEPs specifically call on the European Commission “to take new actions to mobilise essential investments and resources to guarantee the continuity of care and support services” and that “the Coronavirus Response Investment Initiative (CRII and CRII+) must therefore include specific guidance to help Member States ensure such resources, including the European Social Fund, which are used to support persons with disabilities and other persons with support needs”.

The letter was signed by 45 MEPs from 17 countries and seven political groups, including the Vice -President for Gender Equality and Diversity, Dimitris Papadimoulis, and the Chair of the Employment and Social Affairs Committee, Lucia Nicholsonová. You can read the full letter here:

<https://bit.ly/35golsx>

21 April: European Disability Forum publishes human rights report



The European Disability Forum (EDF) has published the fourth edition of its Human Rights Report, which examines poverty and social exclusion of persons with disabilities in the European Union.

The report found that 28.7% of persons with disabilities living in the EU are at risk of poverty, as well as noting that this number is likely to grow in the aftermath of the COVID-19 pandemic. Furthermore, they note that the situation has worsened since 2010 in 11 EU countries: Czech Republic, Estonia, Ireland, Italy, Germany, Lithuania, Luxembourg, Malta, Netherlands, Spain and Sweden. The report makes a number of recommendations for both EU and national decision-makers, including:

- Fully implementing the EU Pillar of Social Rights by establishing an action plan that includes proposals for the inclusion of persons with disabilities.
- Developing a follow-up of the European Disability Strategy 2010-2020, for the coming decade, including measures to address poverty and social exclusion of persons with disabilities and their families.
- Favouring the use of disability assessment methods that follow a rights-compliant and holistic approach, as well as using a combination of impairment and functional considerations.
- Investing in the accessibility of all support structures and services provided to the general public to enable persons with disabilities to make use of them.

You can read the full report here: <https://bit.ly/3aMAruS>



**JOINING FORCES
FOR HEALTHIER POPULATIONS**
11-15 MAY 2020

GET INVOLVED!

#EUPHW
eupha.org/EUPHW



MEMBERS' NEWS

1 April: Report and recommendations published by National Dementia Action Alliance following its "From Seldom Heard to Seen and Heard" campaign



The National Dementia Action Alliance (NDAA) is an alliance of nearly 100 health and social care organisations across England. It is hosted by Alzheimer's Society.

The NDAA recently published its report "From Seldom Heard to Seen and Heard", setting out what has been achieved since the campaign's launch in 2017. The report also contains a set of recommendations.

The campaign aims to improve outcomes for people living with dementia and their carers who come from 'seldom heard', i.e. marginalised, groups. The research has largely focused on the

lesbian, gay, bisexual and transgender (LGBT+) community; on people with learning disabilities; and on the prison population. The NDAA has also been keen to include other marginalised groups, throughout the campaign.

People from the groups highlighted in this campaign often face barriers to accessing good health and social care, and even when they are able to access care, it sometimes fails to meet their needs. Challenges can include a lack of awareness and cultural understanding across health and social care settings. The NDAA therefore asked people in these sectors to pledge to take action and collaborate on the campaign objectives: raising awareness of the challenges faced by people with dementia from seldom heard groups; influencing system-wide change; and bringing about organisational change by implementing NDAA recommendations.

They interviewed experts, spoke with people affected by dementia, and reviewed existing research in their three areas of focus i.e. LGBT+, learning disabilities and the prison population. This research culminated in three roundtable meetings, where experts and people with dementia discussed key issues and formed a set of recommendations. A panel of people affected by dementia from seldom heard groups then discussed their experiences and what they wanted society to do differently to ensure that they are properly supported. In addition, representatives from nine seldom heard groups ran discussions on their area of expertise. You can read the full campaign report, and the set of recommendations here:

<https://nationaldementiaaction.org.uk/campaigns/report-from-seldom-heard-to-seen-and-heard/>

10 April: Turkish Alzheimer Association develops new dementia app, Mindhood, after long struggle for funding

The Turkish Alzheimer Association started a Dementia Friends initiative, called the "Blue Wave", in 2015 with the aim of

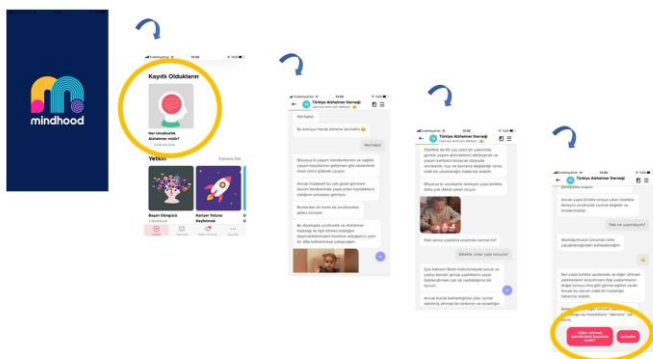
raising public awareness of dementia across the entire country.

The initiative was embraced by all the branches of the Association, with strong results. By the end of 2017, however, the programme was gravely impeded due to the lack of financial resources. The Association's aspiration of disseminating the knowledge using digital media tools involved in the initial projection, could not be realised because the necessary funding could not be provided until March 2019.

In February 2019, an invitation to enter a competition for a civil society project, was received from TUSEV (Third Sector Foundation of Turkey). Established in 1993, by Turkey's leading civil society organisations (CSO) and supporting over 100 associations and foundations, TUSEV built a network of CSOs that share a vision of strengthening the legal, fiscal and operational infrastructure of the services sector in Turkey.

Similar to the other 23 CSOs that were invited to the competition, the Turkish Alzheimer Association provided all the details required, including the budget of the Blue Wave App and e-Platform. A jury, chosen by TUSEV, examined the applications and chose the top three projects. The three winners were coached on how to present their projects most effectively, which they did during the "Destekle Değiştir Etkinliği" (Support & Change Event), addressing a gathering of philanthropists. Each explained how the donations were going to be used. An auctioneer then opened the bidding and the philanthropists declared the amount of money they would each donate. All the donations were transferred to the bank account of the relevant CSO within 2 months.

The best donation offered for the Blue Wave project of the Turkish Alzheimer Association was a ready-made app infrastructure. In addition, the cash value donated was 36,8% more than the Association had requested. In the 11 months following the "Destekle Değiştir Etkinliği" event, the app, "Mindhood", was adapted for the use of people with dementia. It contains a wealth of information, offered to the users in the form of dialogues.



Pictured: A jury chosen by TUSEV examined the applications and chose the top 3 projects, Turkish Alzheimer Association being one of them.

19 April: Alzheimer Croatia office is among historic buildings severely damaged during earthquake in Zagreb

On 22 March, two consecutive earthquakes hit Zagreb early in the morning (measuring 5.5 and 5.2 on the Richter scale) severely damaging many older buildings, the office of Alzheimer Croatia being amongst them. Located in the heart of Zagreb, the office's concrete ceiling was totally destroyed, leaving the office wide open to the elements. Entering the office was deemed to be extremely dangerous. It is unknown when the City of Zagreb, as the owner of the building, will begin repairs.

Despite the danger, IT equipment and all documentation from the office was moved to the homes of the Association's secretary and executive vice-president, so that the work of the Association could continue to be fully operational. Alzheimer Croatia is currently seeking solutions to re-house and re-start the valuable work of their counselling centre, which has not operated since the eruption of the COVID-19 pandemic.



Further substantial damage caused by the earthquake was the fall of the top of one of the towers of the famous Zagreb Cathedral (pictured), from a height of 108 m (354 ft). It is of interest to note that this neo-Gothic cathedral was built after the earthquake of 1880, which destroyed the previous Romanesque cathedral from the 13th century. It seems that history is repeating itself.

20 April: Greek Association of Alzheimer's disease and related disorders continues its participation in Erasmus + project "Story2remember"

The Erasmus+ project "Story2remember" is a consortium of six entities from five countries (Romania, Ireland, Bulgaria, Greece and United Kingdom). This project aims to increase the competency of professionals working in the field of dementia, and to support the communication skills of family carers of persons with dementia, through the use of creative drama and storytelling.

Two training cycles of the project were successfully implemented in the Alzheimer Hellas day care centre in



November 2019, involving 20 health care professionals and 12 people with dementia.

The “story2remember” workshops, based on creative drama, poetry and storytelling, aim to promote well-being, meaningful engagement and social inclusion for older adults with dementia. The Educational Handbook “Story2remember” can be downloaded from the project’s website:

<https://story2remember.eu/>

The next step of the programme is to develop a toolkit for caregivers of people with dementia in order to support their communication skills with their care recipients. More information about the project can be found on:

<https://story2remember.eu/latest-news-about-storytelling-in-dementia-care/>

20 April: Panhellenic Federation of Alzheimer’s Disease and Related Disorders take part in Erasmus+ project “iCONNECT”



iCONNECT - Intergenerational CONTACT between students and people with dementia through Creative education is a project under the umbrella of Erasmus+ KA2 - Cooperation for Innovation and the Exchange of Good Practices and KA203 - Strategic Partnerships for higher education.

This project started on 1 September 2017 and will finish on 30 August 2020. The consortium consists of 6 partners from 4 EU countries with complementary knowledge and backgrounds: Stichting National Ouderenfonds (Netherlands, coordinator),

Università degli studi di Udine – Corso di Laurea in Infermieristica (Italy), Hogeschool Utrecht Higher Education Institution (Netherlands), Lahti University of Applied Sciences (Finland), T.E.I. of Epirus Department of Nursing (Greece), Elliniki Etairia Nosou Alzheimer Kai Syggenon Diatarachon Somateio (Greece).

The aim is that, by implementing the results from this project, all European higher education institutions will be able to contribute to the creation of dementia friendly environments. Intergenerational contact is established through a creative learning module that combines theatre, poetry and music, tapping into the long term memory of older people with dementia. A core component of the module is the open blended learning platform (Moodle) that contains all the teaching material and makes it possible for students to exchange information, ideas and content, plan their own activities and report on their results and experiences. At the same time, it allows and encourages the open international exchange of information, thereby also communicating and collaborating with people from other countries, while making contact with people with dementia. The platform will be an innovative tool to bring dementia theory into practice and make it visible for students.

The main learning objectives of the module for the participating students will focus on obtaining transferable skills in communication, creativity, critical thinking and social competences; becoming more caring and compassionate towards older people with dementia; improving knowledge and competences about older people and dementia; developing a culture of support, openness and creativity in their future work environment.

Website: <https://www.icconnectdementia.eu/>

Website for module:

<https://www.icconnectdementia.eu/icconnect/module-variations>



POLICY WATCH

1 April: Portuguese Parliament unanimously approves Act on rights of informal carers but implementation is delayed due to COVID-19

After strong and persistent lobbying from several carers’ organisations, including Alzheimer Portugal, and with the support of the President of the Republic, members of the Portuguese Parliament have unanimously approved the Act of the Parliament nº 100/2019 of 06.09. This Act regulates the rights and duties of informal carers and of the people who need care, establishing the respective support measures.



At the beginning of 2020, Order nº 2/2020 of 10.02 from the Minister of Labour and Social Security was issued to (partially) regulate this newly-approved Act of Parliament. More recently, Order nº 64/2020 of 10.03 from the Ministers of Finances, Labour and Social Security, and Health defined the terms and conditions needed to implement the pilot projects mentioned in the Act, and named the 30 municipalities where they would take place, as of 1 April 2020.

The implementation of these pilot projects implies the adoption of several measures such as the appointment of a healthcare professional who will be in charge of organising the resources needed by the carer, namely information about rights and benefits, services and facilities available at health and social level; and the definition of an individual plan tailored according to the carer's specific needs (prepared by that health professional in collaboration with a social care professional). This individual plan will identify the care that will be delivered by the informal carer, his/her burden assessment, the relief period duration, identification of self-help groups, psychosocial support, training and capacitation, and availability of health and social measures needed to promote the autonomy, involvement and quality of life of the care recipient.

Carers' allowances are also accounted for (for the main carer, i.e. the one who delivers care permanently). The amount of the allowance is calculated according to the carer's income.

Unfortunately, due to the current COVID-19 pandemic, all human and financial resources are required elsewhere and pilot projects have, therefore, been delayed.

Alzheimer Portugal highlights the unfairness of this situation: These newly-promised measures, which - despite being far from enough and being applicable only to family carers - are now to be delayed due to COVID-19, are needed all-the-more at this moment. Carers are struggling (even more than normal) to support people with dementia, during a period that is detrimental to everybody, but particularly to those who are living with chronic health conditions and who may, therefore, require more support. Carers are permanently giving an essential contribution to society with very little recognition or support from the government. Fortunately, comments Alzheimer Portugal, the same is not true in the Regions of Madeira da Azores, where specific legislation is already in force.

9 April: Iceland launches dementia strategy



Iceland's Ministry of Health has published a national strategy on dementia, setting out a plan for services for people with dementia until 2025.

The action plan is the result of the policy work that Minister for Health, Svandís Svavarsdóttir, had instructed Jón Snædal, a geriatrician, to carry out. The work included consultation with

service providers, patient groups and relatives of people with dementia. International action plans, such as the World Health Organization's Global Action Plan on Dementia 2017-2025 were also considered. Additional considerations included the European Joint Action on dementia and Nordic co-operation on dementia under the auspices of the Norden Valfärdscenter (NVC).

The development of the strategy follows the Icelandic Parliament's Resolution of 2017, which mandated the Minister of Health to:

"Formulate a policy on the issues of individuals with dementia that involves raising awareness and education for the public and family members, increased emphasis on the gathering of statistical information and targeted information, an effort to improve the quality of care for the rapidly expanding patient population in the community".

The plan covers six areas and defines 48 actions, each with specific measurable goals. Some measures have already been implemented, as work began immediately following the report of Jón Snædal, on which the strategy was based.

The six areas covered in the Action Plan are:

- Self-determination, patient involvement and legal framework
- Prevention
- Timely diagnosis of dementia at the right place and follow-up after diagnosis
- Functionality, self-help and support
- Proper service based on the level of dementia
- Scope, research, knowledge and skills.

Under each area of focus are the Minister's emphases, the actions that have been determined, and their intended vision and impact on society.

The full strategy can be accessed here: <https://bit.ly/2xfVVSU>

22 April: Scope of euthanasia expanded in Dutch law

The Dutch Supreme Court has issued a ruling that doctors in the Netherlands can no longer be prosecuted for carrying out euthanasia on dementia patients who have previously given written consent, even where the person with dementia is no longer able to confirm their previous wishes.

The decision comes after a doctor was taken to court in 2016 for carrying out assisted suicide on a person with Alzheimer's, who had previously asked for the procedure in a written statement. Prosecutors had said that the doctor did not properly consult the person, however, the family supported the doctor's decision, and the doctor was acquitted last year.

The Supreme Court's ruling clarifies the law, maintaining the current conditions for euthanasia requiring patients to be enduring "unbearable and endless suffering", with at least two

doctors agreeing to the procedure. However, the new ruling sets out that doctors "may carry out a prior written request for euthanasia in people with advanced dementia." It further notes that patients must also have made this request before their dementia was so advanced that they could "no longer express their will". You can read the full judgement (in Dutch) here: <https://bit.ly/2Szf8GX>



SCIENCE WATCH

24 March: Study reports that exercise could reduce caregiver's fatigue in dementia care



On 24 March, German researchers from Cologne published a paper in the Journal of Alzheimer's disease, showing that physical exercise could be beneficial for the caregiver, given challenging behaviours caused by neuropsychiatric symptoms in acute dementia care.

The researchers conducted a randomised clinical trial with 70 research participants. Half of them received an exercise program with 20 minutes of activity twice in the morning and twice in the afternoon. The control group received a social stimulation program. Findings showed clinical improvements in neuropsychiatric symptoms compared to the control group. In addition, the exercise reduced the fatigue of the caregivers. Researchers suggested that physical exercise programs may not only be beneficial for the patients but also for their caregivers.

<https://content.iospress.com/articles/journal-of-alzheimers-disease/jad191102>

24 March: Two studies published in Science Translational Medicine show that APOE4 is directly linked to Lewy body dementia

Previous studies have described that APOE4 is the most common genetic risk factor for Alzheimer's disease (AD) that can also play a role in the accumulation of amyloid-beta and tau. Two recent articles, published simultaneously in the journal Science Translational Medicine, showed that APOE4 is directly linked to Lewy body dementia such as Parkinson's disease. APOE4 has been found to directly regulate levels of alpha-synuclein, an unfolded protein that can accumulate and

form fibrils in pathological conditions such as dementia with Lewy body and Parkinson's disease.

In each of these studies, researchers tested the APOE2, APOE3 and APOE4 genes in different groups of mouse models of Lewy body dementia. In the first study, Davis and colleagues from Washington University, St. Louis, found that APOE4 mouse models had more alpha-synuclein than APOE3 or APOE2 mouse models, at 12 months of age. In addition, they showed that alpha-synuclein spread more rapidly through the brains of mouse models that have APOE4. Mouse models carrying the APOE2 gene survived longer and had improved motor performance compared to other APOE genotypes. In the second study, Zhao and colleagues from US Mayo Clinic, found that the mouse models expressing APOE4, but not APOE2 and APOE3, had increased alpha-synuclein pathology at 9 months of age. These APOE4 mouse models also had impaired behaviour, greater neuronal and synaptic loss.

<https://parkinsonsnewstoday.com/2020/03/24/apoe-variants-affect-alpha-synuclein-levels-in-lewy-body-dementias-2-studies-report/>

25 March: Clinical study shows no benefit of low-dose aspirin for risk reduction of dementia, mild cognitive impairment or cognitive decline



On 25 March, Dr Joanne Ryan and the ASPREE Investigator Group published a paper in Neurology, showing that low doses of aspirin do not reduce the risk of mild cognitive impairment (MCI), cognitive decline or dementia.

Low-dose aspirin is a widely-prescribed treatment for cardiovascular disease, aimed at reducing the risk of heart attacks and strokes. Classed as a non-steroidal anti-inflammatory drug (NSAID), aspirin reduces inflammation by inactivating pro-inflammatory enzymes called cyclooxygenases (COX). Aspirin also suppresses the normal function of platelets, which accounts for its anti-coagulant, blood-thinning activity. Observational studies have found some evidence to suggest that NSAIDs such as aspirin may be neuroprotective, reducing cognitive decline and diminishing the risk of vascular comorbidities that contribute to the development of dementia.

To solidify this evidence base, the Aspirin in Reducing Events in the Elderly (ASPREE) randomised, placebo-controlled, community-based trial aimed to study the efficacy of low-dose aspirin for the prevention of MCI, cognitive decline or dementia in healthy older individuals. A total of 19,114 community-dwelling, healthy individuals aged ≥70 years were enrolled in the ASPREE trial, randomised 1:1 to daily doses of 1-100mg aspirin or placebo. Cognitive and functional tests were performed at baseline and at regular follow-up intervals, with an average follow-up duration of 4.7 years.

During the follow-up period, 488 participants in the aspirin group were diagnosed with dementia, compared to 476 in the placebo group. Similar numbers of individuals in each group were diagnosed with MCI (205 in aspirin group, 184 in placebo group) and cognitive decline (838 in aspirin group, 816 in placebo group). Subgroup analysis did not reveal any differences in treatment effect according to gender, ethnicity, comorbidities or age. Together, these data show that treatment with low-dose aspirin, for a median period of 4.7 years, is not effective in reducing the risk of cognitive decline, MCI or dementia in healthy older adults. Link to article:

<https://n.neurology.org/content/early/2020/03/25/WNL.000000000009277.full.pdf>

26 March: Study reports that people with Alzheimer’s disease may need different dosage of drugs than prescribed for other conditions



On 26 March, Liang Jin and colleagues from Monash University in Parkville (Australia) published a paper suggesting that people with Alzheimer’s disease (AD) may need a different dosage of drugs than that prescribed for other conditions. Findings were reported in the journal ACS’ Molecular Pharmaceutics.

Using mouse models, the researchers investigated the absorption process of compounds across the digestive tract into the bloodstream. They showed that AD mouse models had less compounds in their plasma compared to the control mouse models. They reported that the intestinal drug transporters may be disrupted in AD.

Authors of the published study suggested that dosages might need to be adjusted for people with AD to ensure that their

plasma concentrations remain effective. People with AD are often prescribed multiple drugs for other conditions such as hypertension and diabetes. These medicines are prescribed to people with AD using the same dosing regimens as those used in people without AD.

<https://pubs.acs.org/doi/abs/10.1021/acs.molpharmaceut.9b01227>

30 March: Clinical study in JAMA Neurology shows that long-term exposure to air pollution is associated with a higher risk of dementia



On 30 March, Dr Giulia Grande and colleagues published a paper in JAMA Neurology, identifying an association between long-term exposure to air pollution and an increased risk of dementia. Having a cardiovascular disease diagnosis amplified this association, with heart failure and ischemic heart disease enhancing the dementia risk.

Recent evidence from clinical studies points to a link between air pollution and diseases associated with ageing. A 2015 Lancet article which analysed data from global epidemiological studies revealed that ambient, particulate air pollution (which is produced when burning household fuels, for example) might contribute to over 17% of ischemic heart disease cases and 16.5% of lung cancer cases. In addition, studies indicate that high levels of pollutants in the air might be linked with faster cognitive decline in older individuals.

To verify whether the association between air pollution and dementia, and to identify any health-related cofactors that may modify this association, Dr Grande and colleagues used longitudinal data from the SNAC-K study (Swedish National Study on Aging and Care in Kungsholmen). The SNAC-K longitudinal study recruited Stockholm-based participants aged over 60 years between 2001 and 2004, following them up until 2013. All 2927 participants resided in the same district in central Stockholm, Kungsholmen. Yearly air pollution levels were estimated by analysing emission inventories compiled by the Swedish authorities, which were mapped to specific streets within the Kungsholmen district.

By referencing the SNAC-K longitudinal data to the air pollution levels (defined as particulate matter or nitrogen oxide) associated with the addresses of the individual participants, the researchers were able to identify a significant

association between the amount of exposure to air pollution in the preceding 5-year period and dementia risk. Specifically, higher levels of particulate matter air pollution (PM_{2.5}) was associated with a 75% increased odds of dementia, while higher levels of nitrogen oxide were associated with a 66% increased odds of dementia. Both of these air pollution measures are linked to vehicle emissions and burning of fuels. Stratification analyses revealed that heart failure and ischemic heart disease enhanced the risk of dementia in individuals exposed to high air pollution levels, by 38% and 14% respectively. As well as highlighting the damaging effects of air pollution, these data underline the importance of optimizing the treatment of cardiovascular disease for older individuals living near roads in urban environments.

The original article was published in JAMA Neurology and can be found here:

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2763459>

2 April: Additional data from the DIAN-TU trial show that gantenerumab had positive effects on brain biomarkers, decreasing amyloid and tau levels

On 2 April, data from the Dominantly Inherited Alzheimer's Network trial (DIAN-TU) were presented at the Advances in Alzheimer's and Parkinson's Therapies (AAT-AD/PD™) Focus Meeting. Top-line results announced in February 2020 reported that the Phase II/III trial missed its primary endpoint, which was a slowing cognitive decline as measured by multiple tests of thinking and memory.

This adaptive platform trial is a randomised, double-blind and placebo-controlled clinical trial assessing the safety, tolerability and efficacy of two drugs, solanezumab (made by Eli Lilly) and gantenerumab (made by Roche), in people at risk for and with a type of early-onset form of Alzheimer's disease (AD) caused by a genetic mutation, called autosomal dominant AD.

Researchers explained the top-line results of the DIAN-TU prevention trial with solanezumab and gantenerumab. They reported several limitations to the study such as the small sample size, the disease stage and the dose. While not demonstrating positive benefit on cognitive scores, findings reported that gantenerumab reduced amyloid plaques from the brain and that Tau levels were significantly improved.

As a result, Roche will be launching an open-label extension trial with DIAN-TU participants to explore the effects of high dose of gantenerumab for several years.

<https://www.alzforum.org/news/conference-coverage/dian-tu-gantenerumab-brings-down-tau-lot-open-extension-planned>

3 April: Oryzon Genomics presents positive results from ETHERAL-EU and REIMAGINE-AD Phase IIa trial in AD

On 3 April, the biopharmaceutical company Oryzon Genomics, which develops epigenetics-based therapeutics in oncology

and neurodegenerative diseases, presented data from its two Phase IIa clinical trial of vafidemstat in Alzheimer's disease (AD) at the virtual AAT-AD/PD 2020 conference. Vafidemstat (ORY-2001) is an oral and brain penetrant drug that may reduce cognitive impairment, memory loss and neuroinflammation.

REIMAGINE-AD is a single centre and open-label Phase IIa study assessing the efficacy, safety and tolerability of vafidemstat in agitation and aggression in moderate and severe AD. 12 participants were recruited and treated for 2, 4 and 6 months with vafidemstat. The drug was safe and well tolerated. The treatment showed a significant clinical improvement in agitation and aggression after six months of treatment. A statistical improvement in memory and cognition (measured by the MMSE test) was detected in severe and moderate AD participants by month 2, but the improvement was not maintained at 4 and 6 months. The company noted that these data are preliminary and support further clinical investigations.

ETHERAL is a Phase IIa multicentre, randomised, double-blind and placebo-controlled study evaluating the safety, tolerability and preliminary efficacy of two doses of vafidemstat in participants with mild-moderate AD. The company made an oral presentation of the 6-month data. 117 participants were enrolled in Europe, of which 96 completed the first 6 months of treatment. The trial met its primary endpoint at 6 months as vafidemstat was found to be safe and well tolerated. Some inflammatory and neuronal-damage biomarkers were reported to be reduced in the participants who received the drug. However, preliminary efficacy analyses showed no significant differences in cognition between groups after six months of treatment. The ETHERAL study is still ongoing and participants are to be treated up to 12 months.

<https://bit.ly/2YdaWQJ>

3 April: Axon Neuroscience announces positive results from Phase II ADAMANT trial of AADvac1, an anti-Tau immunotherapy

On 3 April, AXON Neuroscience, a biotechnology company at the forefront of treating and preventing Alzheimer's disease (AD), presented the results of its Phase II trial for AADvac1 at the virtual AAT-AD/PD 2020 conference. AADvac1 is a tau vaccine that functions by priming the immune system to attack and clear damaging tau proteins that accumulate during the development of AD.

ADAMANT was designed as a randomised, double-blind and placebo-controlled trial, evaluating the safety and efficacy of AADvac1 in participants with mild AD. Axon recruited 196 participants with mild AD from 8 European countries and 163 participants completed the trial.

Findings showed that the ADAMANT trial met its primary endpoint, as AADvac1 was confirmed to be safe and well-tolerated. AADvac1 was also able to induce a robust immune response, with anti-tau antibodies detected in more than 80%

of participants receiving the vaccine. Significant results from biomarker tests were also reported. Participants who received AADVac1 showed a reduction in neurofilament light chain (a marker of neurodegeneration) and tau compared to those who received the placebo control. Positive signals from cognitive endpoints were reported in younger ADAMANT participants.

<https://prn.to/3fc8qjM>

6 April: Cross-sectional analysis of screening data from A4 trial identifies elevated amyloid in the brain as an early marker of Alzheimer’s disease



On 6 April, Dr Reisa Sperling and co-investigators published the results of a cross-sectional analysis of participants in the Anti-Amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4) prevention trial. These results indicate that elevated amyloid-beta is an early marker of Alzheimer’s disease (AD) in the brains of older individuals, associated with lower scores on cognitive tests and correlated with family history and ApoE4 risk factors.

The A4 study is an interventional Phase 3 multi-centre study testing the anti-amyloid drug, solanezumab, in cognitively normal older adults who have brain PET scans showing evidence of amyloid buildup. The trial is funded as a public-private partnership between the US National Institute of Health (NIH), Eli Lilly and several philanthropic organisations. Prescreening of participants from 67 clinical sites started in early 2014, and by 2017 investigators had identified 1323 individuals aged >65 with elevated brain amyloid (Aβ+) who were eligible to continue in the A4 study. Clinical and brain imaging data were also collected from 3163 age-matched, prescreened participants who did not have positive PET scans for amyloid (Aβ-). By comparing clinical, cognitive, demographic and lifestyle characteristics between these two groups (Aβ+ and Aβ- individuals), the researchers hoped to

tease out any potential associations between these characteristics and elevated amyloid in the brain.

When the demographic characteristics of Aβ+ and Aβ- groups were compared, no differences due to sex, education, marital or retirement status were observed. Moreover, the researchers did not find any differences between the two groups in self-reported lifestyle parameters such as exercise, walking, sleep time, alcohol or caffeine intake. However, those in the Aβ+ group were more likely to have a family history of AD, and within the Aβ+ group, carriers of the ApoE4 genetic risk allele showed a higher level of amyloid deposition in the brain, as measured by PET scans. Consistent with previous reports demonstrating its protective effect against AD, ApoE2 was underrepresented in the Aβ+ group. Finally, Aβ+ individuals did not perform as well in the PACC cognitive tests, also reporting greater subjective cognitive declines in cognitive function over the last year.

Together, these cross-sectional findings provide additional support for the hypothesis that elevated brain amyloid deposition in cognitively normal people represents a preclinical stage of AD, identifying a group of high-risk individuals for clinical trials of disease-modifying treatments.

The original article was published in JAMA Neurology and can be found here:

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2763540?resultClick=3>

13 April: Analysis of public repository data identifies a Klotho gene variant that reduces the risk of AD in carriers of the ApoE4 risk allele



On 13 April, Dr Michael Belloy and colleagues published a paper in JAMA Neurology, reporting a lower risk of developing Alzheimer’s disease (AD) in ApoE4 carriers heterozygous for the VS variant of the Klotho gene.

ApoE4 is one of the strongest and most prevalent genetic risk factors for AD, associated with increased amyloid beta deposition in the brain and earlier onset of disease. Genetic risk factors such as ApoE4 are thought to interact with each other, as well as with other factors such as age, lifestyle and

health status – leading to alterations in the AD risk profile. Two recent, small-scale studies identified a potential interaction between the *Klotho* gene and *ApoE4*. However, the studies revealed opposing results, with the *Klotho* VS variant (denoted as *KL-VS^{Het+}*) conferring some or no protection against amyloid accumulation. The *KL-VS^{Het+}* genotype is thought to be relatively common, with an estimated prevalence of 20%.

To evaluate the interaction between *Klotho* and *ApoE4* with greater confidence, Dr Belloy and colleagues analysed the publicly-available, anonymized data from 25 independent case-control, family-based and longitudinal AD cohorts, including the ADNI (Alzheimer’s Disease Neuroimaging Initiative) and ROSMAP (Religious Orders Study and Memory and Ageing Project) cohorts. In total, analyses of datasets from 24,743 participants were performed, evaluating (among other criteria) *ApoE4* status, *Klotho* genotype, age, amyloid beta burden and conversion to AD. Their analyses revealed that *ApoE4* carriers who also carried the *KL-VS^{Het+}* variant were at reduced risk of developing AD, particularly between the ages of 60 and 80 (odds ratio of 0.69). Moreover, in cognitively normal *ApoE4* carriers, possession of the *KL-VS^{Het+}* genotype was associated with lower amyloid beta deposition in the brain, as measured by PET scans.

The original article was published in *JAMA Neurology* and can be found here:

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2763599?resultClick=1>

22 April: Biogen expects to complete the FDA filing for its AD drug aducanumab in Q3

On 22 April, the biotechnology company Biogen presented its first-quarter earnings report for 2020. One of the announcements was that it would complete its Food and Drug Administration (FDA) filing for its Alzheimer’s disease (AD) drug aducanumab in the third quarter of the year.

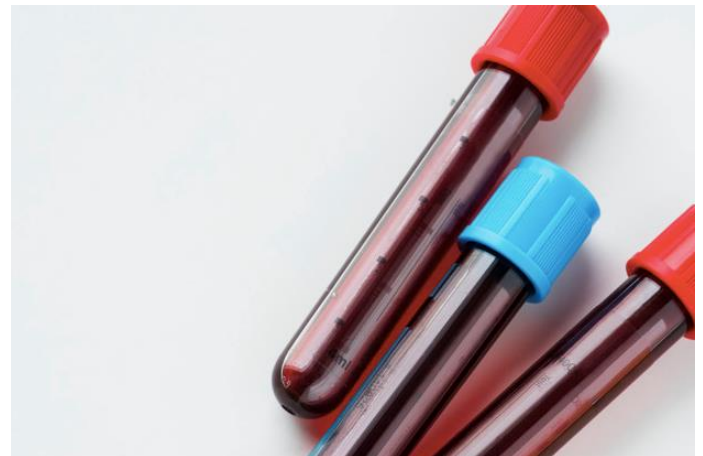
In March 2019, Biogen announced the discontinuation of its global Phase III clinical trials, ENGAGE and EMERGE, of aducanumab in people with mild cognitive impairment due to AD and mild AD dementia. The decision to halt the trials was based on results from a futility analysis conducted by an independent data monitoring committee, which reported that the trials were unlikely to meet their primary endpoint. However, in October 2019, the company announced plans to pursue regulatory approval for the drug. The Phase III EMERGE trial met its primary endpoint, showing a significant reduction in clinical decline. Findings were presented at the CTAD conference in December 2019.

Biogen provided an update on its aducanumab drug. It has participated in several meetings and continues to have constructive engagement with the FDA. It has an open Biological Licence Application with FDA and expects to complete the filing in the third quarter, despite a previous expectation that it would complete the filing in the first half of

this year. In March 2020, the first US research participant was re-dosed in the Phase III EMBARK study, which aims to provide access to aducanumab to eligible participants who were previously enrolled in aducanumab clinical studies such as EMERGE and ENGAGE.

<http://investors.biogen.com/static-files/60eda571-f103-42ee-8b03-5c64571dfc13>

22 April: Clinical study published in *Lancet Neurology* validates a plasma p-Tau181 assay as a diagnostic test for Alzheimer’s disease



On 22 April, Dr Thomas Karikari and colleagues published a paper in the *Lancet Neurology* journal, reporting on the clinical validation of a blood-based assay for p-Tau181, a biomarker for Alzheimer’s disease (AD).

The accumulation of disordered, phosphorylated Tau proteins in the brain is a defining neuropathological feature of AD. Previous studies have shown that measurement of phosphorylated Tau proteins in cerebrospinal fluid (CSF) can help diagnose AD, distinguishing between dementias caused by AD and those caused by other neurodegenerative diseases such as Parkinson’s or Lewy Body disease. However, CSF-based tests are reliant on invasive, time-consuming and costly lumbar punctures, unlike plasma-based assays that measure the presence of protein biomarkers in blood. In the present study, Dr Karikari and colleagues report on the development of an ultrasensitive plasma immunoassay for phosphorylated Tau-181 (p-Tau181), which they validate in four independent prospective cohorts.

The new p-Tau181 immunoassay was first evaluated in a discovery cohort consisting of 18 cognitively unimpaired older adults and 19 individuals with AD. Here, the average p-Tau181 concentrations were three times higher in plasma from individuals with AD compared to matched controls. When the immunoassay was evaluated in the first validation cohort (TRIAD; including younger adults, cognitively unimpaired older adults, people with MCI, AD or frontotemporal dementia), p-Tau181 levels were highest in individuals with AD compared to all other groups. p-Tau181 plasma tests were also able to distinguish between amyloid-positive and amyloid-negative cognitively unimpaired older adults, showcasing the ability of

this test to selectively identify at-risk individuals. Similar results were observed in the second validation cohort (BioFINDER; n=763) and a primary care cohort of 1131 individuals. Across all cohorts, plasma p-Tau181 was detected at increasing levels along the AD continuum, from healthy young adults at the lower end to amyloid-positive, cognitively impaired individuals with AD at the upper end. In addition, the immunoassay was able to distinguish between AD dementia and dementias associated with other neurodegenerative disorders, such as Parkinson’s disease, vascular dementia and multiple systems atrophy. The researchers also reported that the p-Tau181 assay performed better than many well-known

risk factors in predicting AD diagnosis, including age and ApoE4 genotype.

Together with two recent studies published in Nature Medicine, this study underlines the utility of blood-based p-Tau assays for the diagnosis of AD, and for the recruitment of at-risk individuals to interventional clinical trials. This article was published in Lancet Neurology and can be found here:

<https://www.sciencedirect.com/science/article/pii/S1474442220300715#bib14>



LIVING WITH DEMENTIA

31 March: Helen Rochford-Brennan, Chair of the European Working Group of People with Dementia, shares her experiences of the COVID-19 pandemic

We recently spoke to Helen Rochford-Brennan, Chair of the European Working Group of People with Dementia (EWGPWD), about her experiences of living through the COVID-19 pandemic.

“I am a patient advocate and before COVID-19 my life was extremely busy, going to meetings in Ireland and travelling abroad to participate in events. I was probably away from home for 1 or 2 days every week, which gives you an idea of how busy I was! Now, however, my diary is blank: I still have teleconferences and emails about my work, but I’m not travelling at all. This is a huge difference when you’re used to being out and about and engaging with people, which keeps your brain very active.

I have found some aspects of this situation really hard to deal with, and the anxiety and stress can be overwhelming at times. My husband is part of the high-risk group and my son lives and works in London. I’m worried about keeping us safe, and about my son being at a distance. The news is also a huge source of anxiety: when you hear about food shortages, suffering and deaths due to COVID-19 your head goes in a million directions at once. Another aspect we’re both finding hard to deal with is the lack of human connection. For example, we used to go out for lunch regularly, and that doesn’t happen now. We miss going out to socialise, even going to the supermarket and meeting people there! We Irish love celebrating and I really miss those fun times, when communities come together.

At the same time, there are positives to the situation, and there are things we can do as people with dementia to help us cope. When I focus on the here and now, rather than what could happen in the future, it is like an injection against anxiety. I go out for a drive every day, and seeing all the daffodils and crocuses in bloom, and the swans on the lake, reassures me that spring is on its way. I can go out into my garden, hear the birds singing and feel grateful for what I have. Even though we can’t see each other face-to-face, I can speak to my family on the phone, and messaging them through WhatsApp keeps those valuable connections alive. In the early days after my diagnosis, I was lucky to receive cognitive and behavioural therapy, and that knowledge has sustained me in terms of managing my dementia. Something that has been extremely helpful is keeping a structured daily routine: I plan my walks, what I’m going to cook, I try to speak to somebody every day and I also try to write to someone each day. Together, all these measures help me cope with the isolation, anxiety and stress.

However, even though we’re isolated we can still influence change. For example, when speaking to a former Alzheimer’s Society employee, who is now a county councillor, I explained how letters can be very meaningful to people with dementia. She then contacted An Post (the Irish postal service), who are now considering giving everyone a stamp to send a letter to a loved one. So, we people with dementia can do our bit. We can be positive, and say this too will pass. We can find different ways to keep making those valuable human connections.”



21 April: Sean Mackell, a member of the Irish Dementia Working Group, shares his experiences of the COVID-19 situation



Memo to Self: Do not move to a different country during a global pandemic, especially if you are living with dementia.

It all started well. We were living in the Republic of Ireland and decided to move a few kilometres further north to Northern Ireland so that we would be closer to family as my dementia progressed. We chose a house about 15 minutes' drive from the Irish 'border' and we moved to a different country. And then the pandemic occurred!

The government of the Republic of Ireland took a very tough position on how to combat the virus. On 12 March they began by closing schools, encouraging as many people as possible to work from home, asking people to exercise social distancing and to stay at home as much as possible, as well as advising people to wash their hands and implement other hygiene protocols to help stop spreading the infection.

As a family, we decided to follow the more stringent advice of the Republic of Ireland. In short, we have been on lockdown in our new home since 13 March, plenty of time to hang our pictures, start a garden and sort out the right places for our furniture. We have had a few visits from relatives to welcome us into our new home. They stood in the mud of the new front garden and shouted encouragement to us and left presents on the front doorstep.

I have also been using the internet and through the delights of virtual networking platforms, I have been able to participate in meetings of the Irish Dementia Working Group (IDWG). This new concept of virtual

meetings has also enabled me to gather up all my children from across the four corners of Ireland to take part in a family quiz. My youngest daughter was the winner. She was delighted. I was stunned!

I also meet my friends virtually for our weekly "seisiún", an Irish sing song. We just recently gathered together to sing beautiful songs by the great John Prine, who sadly passed away last week with the COVID-19 virus.

Like everyone else, I also have bad days but I work very hard not to become low in spirits. I try to stay positive and take heart that things are not too bad for me. I am determined to make the best of what I have for as long as I can.

The IDWG is supported by The Alzheimer Society of Ireland.

NEW PUBLICATIONS & RESOURCES

3 April: Global Brain Health Institute launches online audio series called "Dementia is Global"



The Global Brain Health Institute (GBHI) has launched a series of eight podcasts on the website SoundCloud. Each podcast consists of an interview by Fionnuala

Sweeney, journalist and Atlantic Fellow at GBHI Trinity College Dublin. During each interview, lasting between 13 and 22 minutes apiece, Ms Sweeney speaks to a different person involved in the field of dementia. Each interviewee gives their own unique perspective on dementia and on their work in this area. The eight podcast interviewees are (in series order):

1. Victor Valcour: Executive Director of Global Brain Health Institute
2. Bruce Miller: Co-Director of Global Brain Health Institute
3. Brian Lawlor: Deputy Director of Global Brain Health Institute
4. Ian Robertson: Co-Director of Global Brain Health Institute
5. Helen Rochford Brennan: Dementia Advocate (Chairperson of the European Working Group of People with Dementia - EWGPWD)
6. Elizabeth Mutunga: Founder and CEO of Alzheimer's & Dementia Organization Kenya
7. Maria Carillo: Chief Science Officer of Alzheimer's Association
8. Cheyenne Mize: Musician and Atlantic Fellow for Equity in Brain Health

You can listen to them all, here:

<https://soundcloud.com/search?q=dementia%20is%20global>

Contact Alzheimer Europe:

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org; www.alzheimer-europe.org

Alzheimer Europe Board:

Chairperson: Iva Holmerová (Czech Republic); **Vice-Chairperson:** Charles Scerri (Malta); **Honorary Secretary:** James Pearson (UK, Scotland); **Honorary Treasurer:** Maria do Rósario Zincke dos Reis (Portugal). **Members:** Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (Ireland), Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:

Executive Director: Jean Georges; **Communications Officer:** Kate Boor Ellis; **Conference and Event Coordinator:** Gwladys Guillory; **Director for Projects:** Dianne Gove; **Project Officers:** Cindy Birck, Angela Bradshaw, Ana Diaz; **Policy Officer:** Owen Miller; **Finance Officer:** Stefanie Peulen; **Administrative Assistants:** Aideen O'Brien; Grazia Tomasini.

AE CALENDAR

Date	Meeting	AE representative
4-5 May	EPF consultation webinars on response to the EU's Data Strategy and AI	Angela and Owen
7 May	First meeting of Alzheimer Europe's ethics working group on legal capacity (online)	Dianne and Jean
7 May	EPF and other European NGOs to discuss relaunch of EU4Health campaign	Owen
8 May	EDF webinar on disability assessment	Owen
11 May	Joint EAN/EADC meeting of European Academy of Neurology and European Alzheimer's Disease Consortium (online)	Jean
12 May	PARADIGM online workshop in CEE region	Ana
13 May	DataSavesLives meeting (online)	Angela
15 May	EAN Dementia Panel Management Board (online)	Jean
18 May	Roche Steering Committee (online)	Jean
23 May	EAN Dementia Panel (Online)	Jean
25 May	Roche Steering Committee (online)	Jean

CONFERENCES 2020

Date	Meeting	Place
23-26 May	Congress of the European Academy of Neurology (EAN), https://www.ean.org/paris2020/6th-Congress-of-the-European-Academy-of-Neurology-Paris-2020.3833.0.html	Online
26-30 July	Alzheimer's Association International Conference (AAIC), https://www.alz.org/	Online
2-5 October	The 14 th World Congress on controversies in neurology, http://cony.comtecmed.com/	London, UK
20-22 October	30 th Alzheimer Europe Conference "Building bridges"	Bucharest, Romania
10-12 December	34 th International Conference of ADI "Hope in the age of dementia", https://adi2020.org/	Singapore
26-29 June 2021	Brain & Brain PET 2021, http://brain2021.scot/	Glasgow, UK
11-13 October 2021	31 st Alzheimer Europe Conference	Helsinki, Finland


30th Alzheimer Europe Conference

Building bridges

Bucharest, Romania

20–22 October 2020

www.alzheimer-europe.org/conferences

 #30AEC

