

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



As our June newsletter is going out on 1 July, I can share with you some great news from Germany, where the government has just adopted its first national dementia strategy. Our colleagues at Deutsche Alzheimer Gesellschaft were involved in writing the strategy and we congratulate them on their important contribution. Details of the strategy were presented in June at a meeting of the European Group of Governmental Experts on Dementia, convened by Alzheimer Europe. As well as national dementia strategies, good practices to support people with dementia and their carers during the COVID-19 pandemic, were on the agenda.

We also held a series of online meetings with our Board, sponsors and members, to exchange on activities during the pandemic, as well as on dementia policy developments and updates in the area of dementia research. Our latest "Dementia in Europe" magazine, issue 33, was launched to coincide with these meetings.

In other national-level news, the prospective Government coalition in Ireland has published its Programme for Government, with a specific section on dementia, which is a positive step.

Good news too, at the European level, as Rapporteur for the EU4Health programme, Cristian-Silviu Busoi MEP, publishes a draft report welcoming the Commission proposal for a standalone health programme, with a significantly increased budget. The report

reiterates that only a separate and robust programme can ensure the EU has the capacity to respond to future pandemics and to make health systems more resilient.

On the research front, the Innovative Medicines Initiative has launched the last Calls for Proposals under the IMI2 programme, with topic areas including neurodegenerative diseases research.

Congratulations are in order for the current Vice-chairperson of the European Working Group of People with Dementia, Chris Roberts, who has been elected as the next Chairperson. Helen Rochford-Brennan, the current Chairperson, will continue in her role until October this year.

The Alzheimer's Society (UK) recently welcomed a new CEO Kate Lee and Alzheimer Switzerland has announced a new Chairperson, Catherine Gasser. She succeeds Ulrich Gut, who held the position for the past 11 years. I would like to bid him a fond farewell. It has been a real pleasure to work with him.

In our own team, we also have a change, with Administrative Assistant Aiden O'Brien having left at the end of June. We wish her well for the next chapter, back in Ireland.

Finally, I am pleased to announce that the detailed programme for our virtual Conference #30AEC is now online. Keep an eye on the Conference pages of our website, for details about registrations, coming soon.

**Jean Georges**  
Executive Director

## COVID-19 SITUATION

### 25 May: People with MCI or mild AD in Spain report a worsening in neuropsychiatric symptoms during COVID-19 lockdown



On 25 May, Dr Beatriz Lara and colleagues published a Short Communication in the European Journal of Neurology, reporting on the neuropsychiatric symptoms and quality of life in Spanish people with Mild Cognitive Impairment (MCI) or mild Alzheimer’s disease (AD) during the COVID-19 lockdown.

On 14 March, the Spanish Government implemented lockdown measures that confined people to their homes, restricting public activities and closing day care centres for people with cognitive impairment. The researchers aimed to evaluate the effect of these confinement measures on people with mild AD or MCI, administering neuropsychiatric tests and questionnaires to assess their neuropsychiatric symptoms and quality of life compared to the period prior to lockdown. In total, 20 people with mild AD and 20 people with MCI were recruited to the small-scale study from the Cognitive Disorders Unit at the Hospital Universitari Santa Maria in Llieda, Spain. Participants had previously been evaluated at the clinic, providing baseline measures.

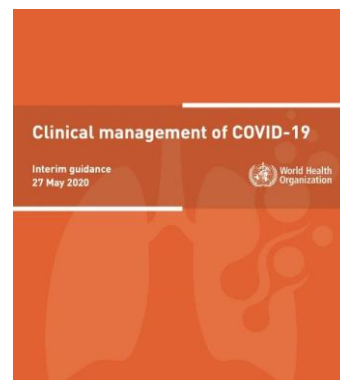
Statistical analyses showed a significant increase in several neuropsychiatric symptoms, including apathy and anxiety in participants with MCI, and apathy, agitation and aberrant motor symptoms in people with dementia. No differences in quality of life measures (EuroQoL-5D) were observed, although approximately 30% of participants and 40% of caregivers reported a worsening of their health status during confinement.

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/ene.14339>

### 27 May: WHO releases updated interim guidance on clinical management of COVID-19, including on neurological and mental health manifestations

On 27 May, the World Health Organization (WHO) released updated guidelines for clinicians caring for COVID-19 patients during all phases of their disease (from screening to discharge). This update has been expanded to meet the needs of frontline clinicians and promotes a multi-disciplinary approach to care for patients with COVID-19, including those in mild, moderate, severe, and critical stages of the disease.

There are some entirely new sections: COVID-19 care pathway, treatment of acute and chronic infections, management of neurological and mental manifestations, non-communicable diseases, rehabilitation, palliative care, ethical principles, and reporting of death. Previous chapters have also been updated and expanded. Find out more and download the guidelines, here:



<https://www.who.int/publications/i/item/clinical-management-of-covid-19>

### 28 May: Jersey Alzheimer's Association criticises government's handling of COVID-19 pandemic

The Jersey Alzheimer's Association (JAA) has criticised the Government of Jersey for its handling of the



coronavirus crisis in relation to those living with dementia. It has expressed frustration at its advice being “ignored” and said that the Government has “overlooked care and support” for Jersey residents, including people with dementia, carers and people awaiting test results. The JAA also warned that lockdown measures preventing contact between people with dementia and their families have had a detrimental effect. Social or physical distancing is causing people to lose recognition of loved ones and to deteriorate more rapidly, according to reports the JAA has received from families and care home staff. The association urges the Government to take action.

Providing support for islanders started to become increasingly difficult for the JAA after the temporary closure of its Memory Assessment Clinic, with staff being redeployed.

“We understand the need to consider all options at this unprecedented time however no skeleton staff team was left to support people with dementia, those waiting for results of tests or carers in crisis. JAA became the main signpost for all dementia support and only because of the good will and absolute commitment of key Health & Social Care practitioners to go the extra mile have clients had anywhere close to the support needed” the association commented.

A “different style of communication” was also suggested for the Government’s messaging around lockdown measures. The JAA recommended, for example, that messages be sent in an easy-to-understand manner via newspapers and local radio rather than on social media. As a result of what has been, in the association’s view, a less than optimal approach to communication and the fact that details of its supports were excluded from the Government’s “Connect Me” support hub,

despite repeated requests, the JAA has had to spend “significant amounts” of its own funds. These have been used on print advertising, informing Jersey residents about available services and support.

Health and Social Services Minister Deputy Richard Renouf responded to the JAA’s criticisms, saying that the Government of Jersey has used a wide range of non-digital communication channels to reach islanders.

“We hugely value and appreciate the tremendous impact that voluntary and charitable organisations make and the increase in demand many have experienced over recent months. We have been and continue to help them to access additional resources – both human and financial – to support them in continuing their invaluable work.

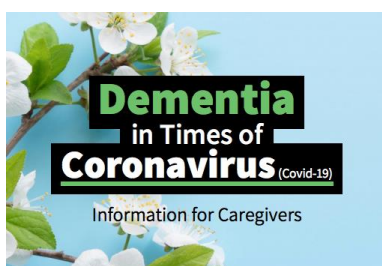
“While some of our usual services for those suffering from cognitive difficulties or dementia have temporarily closed for the safety of their clients and staff, we are working on ways to start reopening them soon”, said Mr Renouf.

“Protecting our most vulnerable Islanders has been the Government’s priority since the start of the pandemic. There are many factors that have led large numbers of people to be considered ‘vulnerable’ and the Government has sought to consider and address these as comprehensively as possible.”

Deputy Richard Renouf also insisted that the Government had been working together with Jersey Alzheimer’s Association and other voluntary organisations, since the beginning of the pandemic.

<https://www.itv.com/news/channel/2020-05-28/jersey-alzheimer-s-association-criticises-government-support-for-its-services/>

### **29 May: Israel Ministry of Health publishes a COVID-19 booklet for caregivers of people with dementia**



On 29 May, the Israel Ministry of Health, in collaboration with JDC Israel Eshel, published a COVID-19 booklet for caregivers of people with dementia. Entitled “Dementia in Times of

Coronavirus”, the booklet is co-authored by Neta Cohen (Dementia Program Manager, Joint-Eshel) and Dr Iris Rasooli (Director of the National Program for Addressing Alzheimer’s Disease and other types of Dementia), among other co-authors that include gerontologists, occupational therapists, and psychiatrists. Dr Dana Peer from EMDA - The Alzheimer’s Association of Israel also contributed to this publication, as well as translating it to English.

The booklet compiles information from professionals to help caregivers maintain an active and healthy routine for the people with dementia they care for. It provides suggestions for physical activities in the home, idea for cognitive and craft activities and guidance on modified day planning during the

pandemic. Nutritional guidelines for people with dementia are included, along with suggestions on how to support the emotional wellbeing of people with dementia.

Finally, the booklet provides advice on how caregivers can maintain their own emotional wellbeing, listing self-care and relaxation activities that can take place in the home. The booklet can be downloaded here:

[https://www.health.gov.il/English/Topics/SeniorHealth/DEMENTIA/Documents/Dementia\\_Corona\\_EN.pdf](https://www.health.gov.il/English/Topics/SeniorHealth/DEMENTIA/Documents/Dementia_Corona_EN.pdf)

### **29 May: Scottish Government publishes new SIGN guidance with advice on presentation and management of COVID-19 in older people**

On 29 May, the Chief Medical Officer of the Scottish Government published a rapid guidance document for NHS Scotland, aiming to provide advice on the presentation and management of COVID-19 in older persons in acute care.



The guidelines include descriptions of common symptoms of COVID-19 in older people, which do not always include fever, cough or influenza-like illness. Instead, they identify delirium, anorexia, vomiting, low-grade fever, fatigue and falls as more common symptoms in this age group. The document also recommends that all patients over 65 years should have a frailty assessment upon admission to hospital, to identify those who are most vulnerable and therefore require comprehensive geriatric assessment.

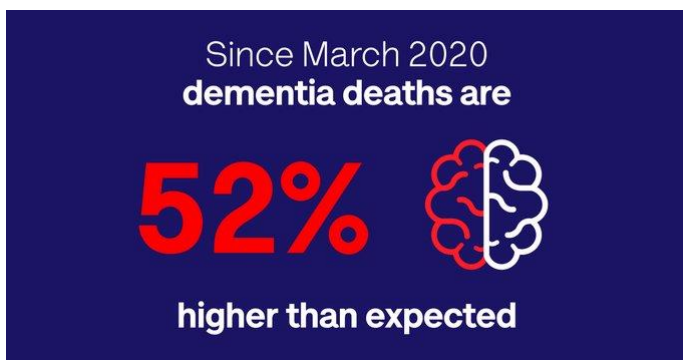
A further recommendation is made to ensure communication is promoted between patients and family members using digital tools such as smartphones and tablets. Anticipatory care plans should be put in place, taking into account their current situation, previous health and what matters to the patient and their family.

Finally, the guidance document outlines how isolation for the purposes of infection control could be managed in acute care, with recommendations on what to do when discharging patients to their homes, to nursing homes or to other care settings. The guidelines can be downloaded here:

[https://www.sign.ac.uk/assets/sg\\_presentations\\_and\\_management\\_of-covid-19\\_in\\_older\\_people.pdf](https://www.sign.ac.uk/assets/sg_presentations_and_management_of-covid-19_in_older_people.pdf)

### **5 June: UK Office for National Statistics reports 50% increase in excess deaths of people dying of dementia during COVID pandemic**

A new report on death, from the Office for National Statistics, gives insight into the number of excess dementia deaths in England and Wales during the pandemic. While the deaths registered are not directly attributed to the virus, the 50% increase in excess deaths of people dying of dementia during



the pandemic is the largest surge in deaths of any health condition.

The Alzheimer’s Society (UK) suspects that isolation and loneliness during confinement, the resulting onset of depression, as well as the interruption to vital health services have contributed to this. The Society also draws the conclusion that there has likely been some underreporting of COVID-19 deaths.

Fiona Carragher, Director of Research and Influencing at Alzheimer’s Society said: “From the start, people with dementia have been worst hit by coronavirus, with thousands dying from both the virus and its wider impact.”

“The Government’s new Social Care Taskforce must address the complex needs of people with dementia in this crisis, and its first urgent task should be to understand why so many people with dementia have died since the pandemic started.”

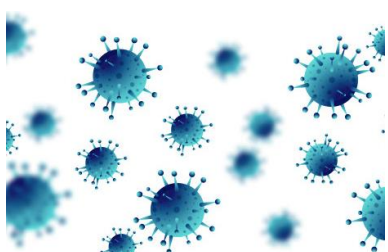
Early research is showing that many people with dementia do not necessarily display typical symptoms, or may even be asymptomatic. Alzheimer’s Society has therefore also stressed the importance of regular testing of all care home staff and residents, to ensure the safest environment possible. The UK Government must learn lessons from this and consider how best to protect the lives of people with dementia, should there be a second peak of the virus.

Read the ONS report: <https://bit.ly/ONSReportNonCOVID>

Read Alzheimer’s Society’s responses:

<https://bit.ly/AlzSocResponse1> and <https://bit.ly/AlzSocResponse2>

**8 June: Review in the Journal of Alzheimer’s Disease proposes a three-stage ‘NeuroCOVID’ classification scheme**



On 8 June, Dr Majid Fotuhi and colleagues published a review article in the Journal of Alzheimer’s Disease, summarising the evidence for neurological manifestations of COVID-

19 and proposing a three-stage classification scheme for neurological symptoms in COVID-19.

The COVID-19 pandemic has expanded rapidly across the globe, with over 8 million cases and 486,000 deaths reported

to date. Initially presented as a respiratory disease, recent studies and case reports indicate that there are also many neurological manifestations of COVID-19, including loss of smell (anosmia), seizures, stroke, delirium and paralysis, among other symptoms. In their review article, Dr Fotuhi and colleagues sought to summarise these studies and case reports, focusing on how SARS-CoV2 (the virus that causes COVID-19) impacts the central and peripheral nervous systems.

Their review of the literature revealed that dysfunction of smell and taste was widely reported across studies; for example, an Italian study showed that over 64% of patients with mild COVID-19 reported an impaired sense of smell. Cerebrovascular disease was also identified in several studies, with 13 of 221 patients in one study having imaging-confirmed ischemic infarcts (strokes) in large or small cerebral vessels. Several case reports described patients presenting with seizures, confusion or delirium, often associated with cerebrovascular changes. The authors described some of the pathophysiological mechanisms underlying these symptoms, including inflammatory changes in cerebral blood vessels (which express ACE2, the receptor for SARS-CoV2) and ‘cytokine storms’ that can cause more widespread damage. They postulated that direct infection of brain cells by SARS-CoV2 may also play a role, however they also underline that there is currently insufficient scientific evidence to support this theory.

In their review, the authors propose a classification scheme for neurological involvement of COVID-19. In Stage I, SARS-CoV2 is restricted to the nasal or gustatory epithelium, which causes taste and smell impairments, but few severe symptoms. In Stage II, SARS-CoV2 is more widespread and causes a more robust inflammatory response, leading to vascular changes that predispose patients to strokes. In Stage III, SARS-CoV2’s cytokine storm damages the blood-brain barrier, resulting in greater infiltration of inflammatory cells and more severe neurological involvement, including strokes, delirium and seizures. Finally, the authors called for neurologists to be mindful of COVID-19 issues that can directly impact their care of people with Alzheimer’s disease and other neurological disorders, such as the increased risk of stroke and delirium.

The original article was published in the Journal of Alzheimer’s Disease and can be found here:

<https://content.iospress.com/articles/journal-of-alzheimers-disease/jad200581>

**12 June: Clinicians at Fundació ACE share their experience of adapting their model of care during the COVID-19 pandemic**

On 12 June, clinicians at Fundació ACE in Barcelona published an article in the Journal of Alzheimer’s Disease, reporting on their experience of adapting their model of care in line with COVID-19 lockdown measures. Prof. Mercè Boada, leader of the MOPEAD project and Director of Fundació ACE, is the corresponding author for the article.



Established in 1996, Fundació ACE is a private, non-profit organisation that provides holistic, patient-centred care to people with dementia and other cognitive

disorders. Based in Barcelona, Spain, it is located in one of the most affected European regions for COVID-19, with an estimated 500 deaths per million people. At the height of the pandemic, the Spanish government imposed strict lockdown measures, confining people at home, closing public spaces and imposing severe restrictions on non-essential movements. In their article, the clinicians share their experiences of dealing with this major challenge, and the way their patient-centred model was adapted to provide telemedicine support rather than face-to-face care.

The main priority for the organisation was to guarantee the protection and safety of their staff and the people they care for, whilst maintaining continuity of care. Fundació ACE is organised into a Memory Unit, a Day Care Unit, a Clinical Trials Unit and a Research Unit. The article outlines the actions undertaken by the different Units prior to and during lockdown. Before lockdown, Fundació ACE took steps to ensure prevention and protection measures were in place throughout all Units, also progressively reducing clinical activities in anticipation of the evolution of the pandemic. Following lockdown, it closed the Day Care Unit and stopped the face-to-face activities of the Memory Unit, instead transitioning to a telemedicine system. Secure access to medical records was provided through a virtual private network, while consultations were carried out using videoconferencing platforms or on the phone. Where possible, neuropsychological and neurological assessments were performed using these platforms, and the health status of all patients from the Day Care Unit was monitored via daily phone calls using a checklist system. Similarly, the health of clinical trial participants was regularly monitored, and courier services were used to deliver medication as required.

Using these modified care approaches, monitoring numbers revealed that almost 78% of Memory Unit activities had resumed within 6 weeks of the start of lockdown. Feedback collected from Fundació ACE staff was very positive, showing high levels of satisfaction with the telemedicine model. Patient and family carer feedback was also generally positive, although the article highlighted the fact that not all patients had the required digital devices or expertise to use the telemedicine system.

In conclusion, the authors found that the implementation of telemedicine and remote monitoring systems could help deliver dementia care to remote locations or to areas lacking memory clinics or day care facilities.

<https://content.iospress.com/articles/journal-of-alzheimers-disease/jad200547>

## 16 June: Study finds neurochemical evidence of neuronal injury in patients with moderate or severe COVID-19

On 16 June, Dr Nelly Kanberg and colleagues published an article in the journal *Neurology*, showing that COVID-19 may cause damage to the central nervous system (CNS).



While it is still unknown whether SARS-CoV2 (the coronavirus that causes COVID-19) can directly infect the brain, several lines of evidence now show that COVID-19 is associated with neuropathological changes in some affected groups. To examine the extent of CNS involvement in patients with COVID-19, the study authors set out to measure two established plasma biomarkers of CNS damage: neurofilament light chain (NfL; biomarker of neuronal injury) and glial fibrillary acidic protein (GFAP; biomarker of astrocyte injury).

The researchers analysed plasma samples from a total of 47 patients with COVID-19, 9 of whom had moderate symptoms (hospitalisation and oxygen supplementation) and 18 of whom were severely affected (requiring admission to intensive care and ventilation). None of the patients were affected by psychiatric or neurological disease, and samples were collected at presentation and again after a mean of 11 days after presentation.

Patients with severe COVID-19 had significantly higher plasma concentrations of NfL and GFAP compared to a control group. GFAP was also increased in patients with moderate COVID-19. In patients with severe COVID-19, levels of GFAP substantially decreased between the first and last samples taken, with the opposite pattern observed for NfL. Together, these results suggest that astrocyte damage may be a common feature in moderate and severe stages of COVID-19, while neuronal injury happens later in the disease course, in severely-affected patients.

The authors concluded by stating that further studies in larger patient cohorts are now required, with longer follow-up and more extensive clinical phenotyping.

<https://n.neurology.org/content/early/2020/06/16/WNL.0000000000101111.long>

## 17 June: Portuguese memory cafés launch an online format

The Memory Café sessions in Portugal are currently suspended to prevent the spread of the new coronavirus. Despite the demanding times we are all going through, Alzheimer Portugal has



not lost the determination to continue to support people with dementia and their caregivers and family members, albeit at a distance. This is the reason why the organisation has implemented a new online format: “Memory Café stays at home”, in collaboration with the teams of the 20 Memory Cafés that exist in Portugal.

Every Saturday, at 11am, one of these teams coordinates an online session. These meetings have a maximum duration of one hour and have a guest speaker who addresses a specific topic related to dementia.

Since these are normally face-to-face meetings, participants have the opportunity to ask questions in the informal and cheerful spirit that characterises Portugal’s memory cafés us. At the end of each session, participants are invited to evaluate the session by filling out an online form, before saying goodbye to everyone. With this new format, Alzheimer Portugal wants to contribute to reducing the social isolation we find ourselves in by sharing information, support and experiences. They also want to make the community more aware.

To date, 9 sessions have taken place, the first of which was on 18 April. Nuno Antunes, a psychologist from Alzheimer Portugal, was the first guest speaker and he presented a set of tips to help people get through these trying times, at home.

Attendance has far exceeded initial expectations, with meetings attracting the maximum number of participants (100) that the online platform allows. This means there have been almost 1,000 participants already, a fact that highlights one of the positive aspects of this format – it reaches people who may not ordinarily be able to attend face-to-face sessions, due to not being geographically close to any Memory Cafés.

Given the success of this online initiative, Alzheimer Portugal is thinking of extending it after the end of the current pandemic.

<https://www.cafememoria.pt/cafe-memoria-fica-em-casa>

### **18 June: Fundación Alzheimer España stresses how different the experience of bereavement is for people losing a loved one with dementia during COVID-19**



Alzheimer España

Being bereaved by the loss of a loved one with dementia during this very exceptional time of crisis entails a plethora of vicissitudes of COVID-19’s own making. In this scenario of unexpected fallout on the mental health front, a poignant need has emerged for dedicated bereavement support to be provided to people who have experienced the passing of a loved one with dementia during the pandemic. Being unable to say their proper good-byes or pay their respects because of coronavirus-related restrictions can be devastating and requires the sort of help that does not quite

fit the standards of a bereavement within a more normal social context.

As a carer, looking after oneself is of the utmost importance in order to be able to cope, at this very challenging time. But a number of unaccounted-for encumbrances could get in the way of dealing with the grieving process and overcoming the loss. Feelings of remorse, guilt, regret, and many more, can surface as a reaction to the little amount of control one has over the way the deceased have had to experience their final days. Confinement, loneliness, distance...all these add to the already harrowing task of recovering from the shock of losing someone close.

Care from others can make this ordeal easier and, over time, can help the bereaved person to make a full recovery – this care and support is fundamental to the well-being of the people we at Fundación Alzheimer España are working for, and this is why we are currently rolling out bereavement-support sessions in a group-therapy format. We are glad to provide a highly-specialised time and adapted space, where grieving, dementia and loss all come together to be dealt with in an atmosphere of friendliness and understanding.

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### **22 June: Research project investigates loneliness and social isolation during the COVID-19 pandemic – Take the survey!**

A research project which is investigating loneliness and social isolation during the COVID-19 pandemic, is calling for responses to its online survey. It is part of a larger global survey led by Prof. Roger O’Sullivan in the Institute of Public Health, at the University of Ulster, Northern Ireland. The survey is open to anyone, anywhere, as long as they are over 18 and have access to the internet. It is available in English, French, Spanish, Greek, Brazilian Portuguese, Arabic and Finnish.



**CLIC**

Survey on Coping with Loneliness, Isolation and Covid-19

This project is coordinated by Carol Rogan, Scientific Project Manager at the Dementia Research Network Ireland and is led by Prof. Iracema Leroi, Trinity College Dublin, Ireland. The survey includes specific questions relevant to family carers of people living with dementia.

The survey can be found here:

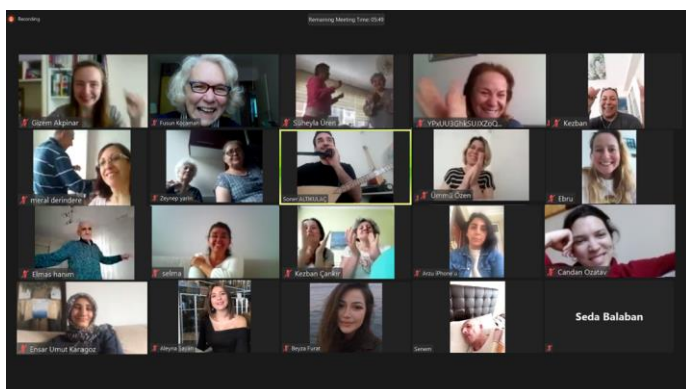
[https://survey.qualtrics.com/jfe/form/SV\\_9BLclicWrL47EdT](https://survey.qualtrics.com/jfe/form/SV_9BLclicWrL47EdT)

Documentation on the survey is available at:

[www.publichealth.ie/clic](http://www.publichealth.ie/clic) <<http://www.publichealth.ie/clic>

### **25 June: Turkish Alzheimer Society hosts digital tea parties during lockdown**

Wednesdays have been “ACTION” days since the first Day Care Centre in Turkey was initiated in 2011. On the first Wednesday of every month, a medical person presents information about the disease and the related care issues; while on the third Wednesday of the month, an expert psychologist offers a



group therapy session to caregivers. The second and fourth Wednesdays are “Fun Days” and people with dementia and their caregivers get together for a party with live music, at which they can enjoy singing and dancing all together, regardless of whether they are Day Care Centre members or not. These activities are called “Tea Parties”, because after each one the guests are served tea, cakes, cookies, etc.

Since the outbreak of the pandemic, the first measure taken by the Turkish Alzheimer Society was to shut down the Centre and start a help-line, as well as publishing printed texts and videos on its website and social media, all of which the Society did immediately, to ensure continuity of services inasmuch as it was possible. For the first weeks, this worked very well because, mainly, people needed information and reassurance. After the first month or so had passed, however, the Turkish Alzheimer Society became aware that both caregivers and people with dementia started longing for their Tea Parties, where they enjoyed socialising. Consequently, “Digital Tea Parties” were started, which are now being organised every Thursday afternoon, and at which all are welcome, unconditionally.

On Thursdays, an online meeting is also organised, that is announced on all the Society’s digital channels. For each meeting a guest speaker is invited, based on the theme for that week. Examples of guest participants so far, are: a nurse; a social worker; a music therapist (with all participants singing and dancing); a psychologist (a group therapy on caregivers’ self-care); a neurologist; and a physical trainer (with live exercising). On 25 June, “psychodrama” was the theme explored with people with dementia and their caregivers, and the next session, on 2 July 2020, will be “Art Therapy at Home”. In order to increase participation, information on how to participate in Zoom/Telco/Skype meetings is communicated via social media channels, using colourful “posters”.

It is clear, from feedback received from participants at these digital events, that this type of function needs to be continued, even after the current public health crisis, says the Turkish Alzheimer Society. First of all, because distance and location are no longer an issue, even if a participant, speaker or organiser is not in the same city or country, let alone the same building. Additionally, time limitations are overcome, since the links to the video recordings of the meetings are disseminated

instantly. Last but not the least, the meetings become public property and anyone can participate anonymously.

**26 June: Report shows that the impact of COVID-19 on care homes varies substantially between countries**



On 26 June, Dr Adelina Comas-Herrera and colleagues published an updated report on the mortality associated with COVID-19 outbreaks in care homes, summarising and contrasting international data on deaths in care homes due to COVID-19. The report, updated from an April version, with data from a larger number of countries, was published on the website of the International Long-Term Care Policy Network.

The COVID-19 pandemic has expanded rapidly across the globe, with over 10 million cases and 502,000 deaths reported to date. An increasing number of countries are now publishing data on the number of deaths among care home residents. With the caveat that direct data comparisons are difficult, due in part to inter-country differences in how “care homes” are defined and COVID-19 data are managed, the report aimed to evaluate the relative impact of COVID-19 on care home residents in different countries.

Summarising data from 26 countries across the world, including 13 EU countries, the report shows that, on average, 47% of COVID-19 deaths to date have occurred in the care home setting. The researchers observed some variation in proportion of COVID-19 deaths within care homes, ranging from 81% in Slovenia (85 of 105 total deaths) to 24% in Hungary (127 of 532 total deaths) and 0% (0 of 9 total deaths) in Malta. Similarly, high levels of variability were observed in the proportion of care home deaths attributed to COVID-19. For example, 0.2% of care home residents in Hungary are reported to have died due to COVID-19, while in Spain and in the UK almost 6.1% and 5.3% of care home residents may have died as a direct or indirect result of COVID-19. These figures are strongly correlated with the total number of COVID-19 deaths in the whole population.

The authors will continue to issue updates to the report as further data becomes available.

The report can be found here:

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

**29 June: “Library under the Treetops” opens in Ljubljana to help meet needs of people with dementia and carers during pandemic**

Spominčica - Alzheimer Slovenija has conducted a survey among people with dementia and their relatives, looking at

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## ALZHEIMER EUROPE

### 8 June: Alzheimer Europe Board holds online meeting

The Alzheimer Europe Board met online on 8 June 2020. The meeting agenda included various financial and operational matters, including preparations for the 30<sup>th</sup> Alzheimer Europe Conference, which will be a virtual event, taking place from 20 to 22 October 2020. The Board also discussed Alzheimer Europe’s 2020 and 2021 activities and meetings, new project applications and prepared for the 2020 Annual Meeting, taking place online, on 5 October. The next Board meeting will take place on 30 September, also online.

### 9 June: Alzheimer Europe hosts online Company Round Table meeting



On 9 June, Alzheimer Europe hosted an online Company Round Table meeting, attended by representatives from Abbvie, Biogen, Eisai, Essity, GE Healthcare, Grifols, Janssen, Lilly, Lundbeck, Nutricia, Roche and TauRX. Also in attendance, were: 7 members of the AE staff, including Executive Director Jean Georges; 25 representatives of AE member organisations from 17 different countries; and 1 representative of the European Working Group of People with Dementia (EWGPWD).

Jean Georges updated sponsors and other delegates on Alzheimer Europe’s activities during the COVID-19 pandemic.



their needs, problems encountered, and lack of services during the COVID19 lockdown.

The main thing that became clear, reports Spominčica, was the lack of and need for social interaction, as well as tips and advice to overcome day-to-day challenges. For this reason, the organisation decided to strengthen its telephone advice service. Each day Spominčica provides tips for caregivers online and has opened the “Library under the Treetops” in Ljubljana, in June 2020. The organisation is happy and encouraged to be able to socialise and be outdoors as much as possible, with this new initiative.

The library will be open every weekday between 10am and 2pm, with interesting and diverse workshops planned to take place on a weekly basis, with well-known Slovenian writers.

“We are transforming the shadows of cities into islands of free reading, places of inspiration and encounter!” says Spominčica.

In the small park outside the organisation’s office, everyone can find a good book and read it in peace. The opening event was enriched with music and welcome speeches were given by Štefanija L. Zlobec, president of Spominčica and Gaja Naje Rojec, the representative of the Divja Misel Institute, which coordinates the Library under the Treetops network.

### Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for its 2020 activities.

Read more about sponsorship opportunities here:

<http://bit.ly/sponsorAE>



Policy Officer Owen Miller shared some recent policy developments at the EU and national levels and Project Officer Cindy Birck gave an overview of recent developments with regards our Clinical Trials Watch database.

Two company representatives then addressed delegates with presentations related to COVID-19: Lennert Steukers from Janssen discussed the impact of the pandemic on the neurodegeneration portfolio of the Innovative Medicines Initiative (IMI), and Martin Traber from Roche shared experiences of some of the implications for clinical trials.

Finally, Gavin Terry highlighted the impact COVID-19 has had on the research programme of the Alzheimer’s Society (UK).

We would like to thank our sponsors for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting, on 8 December 2020.

**9 June: Dementia in Europe issue 33 published as an e-magazine**



Alzheimer Europe has published the 33<sup>rd</sup> edition of its “Dementia in Europe” policy magazine in an electronic format, for the first time - a decision that was taken earlier in 2020, in light of the uncertainties around COVID-19 and its impact on service-providers.

The first section of the magazine highlights some of our efforts to ensure dementia remains a European priority.

It includes coverage of our most recent lunch debate, organised together with the Neuronet project and focusing on research collaborations at a European level; some of the work being done by the European Working Group of People with Dementia (EWGPWD) in the area of Patient and Public Involvement (PPI) in research; and two new JPND-funded projects, EUROFINGERS and ADAIR.

The Policy Watch section presents the newly-launched national dementia strategy from Iceland, with input from Icelandic Minister of Health, Svandís Svavarsdóttir, as well as from Alzheimer Iceland; Spain’s recently-published strategy, with feedback from the Confederación Española de Alzheimer (CEAFA); a campaign for change run by The Alzheimer Society of Ireland, during the Irish General Election; interviews with new European Alzheimer’s Alliance (EAA) Office Bearers, MEPs Christophe Hansen, Hilde Vautmans and Sirpa Pietikäinen; and some of the key issues around continence care for people with dementia.

Our third section, Dementia in Society, covers Dementia Friends programmes across Europe and how they continue to

engage their networks. It also looks at living well with dementia, in an article written by Finnish member of the EWGPWD, Petri Lampinen, who shares his thoughts on the importance of exercise, diet and careful planning. Dutch film director Mischa Kamp then discusses her award-winning film about dementia, “Romy’s Salon”, which was released at the start of this year.

Alzheimer Europe is also pleased to present a special section, drawing attention to the impact of COVID-19 and how we and our members have been able to respond to it, to ensure we continue to support people with dementia and carers during this difficult period. We also spoke to Chris Roberts, Vice-Chairperson of the EWGPWD and his wife and supporter, Jayne Goodrick about how they have been coping during the pandemic.

The magazine is being e-mailed to all Alzheimer Europe’s usual magazine contacts, including every MEP. It is also being shared on our website and social media accounts.

You can view the magazine online, here:

<https://bit.ly/DementiaInEurope33Online>

You can download the PDF, here:

<https://bit.ly/DementiaInEurope33PDF>

The entire back catalogue of Dementia in Europe magazines is also now available in this new electronic format, on our website: <http://bit.ly/DementiaInEurope>

**10 June: Alzheimer Europe hosts online Public Affairs meeting**

On 10 June, Alzheimer Europe (AE) hosted an online Public Affairs meeting. 31 representatives from member associations and 8 Alzheimer Europe staff members were in attendance. AE Executive Director Jean Georges led the meeting. The agenda focused on:

- Dementia as a European public health priority – Alzheimer Europe policy report and European Dementia Monitor (Owen Miller)
- Lockdown exit strategies and implications for people with dementia and carers (Angela Bradshaw)
- Representatives from six member organisations attending the meeting also had the opportunity to present their country experiences of lockdown exit strategies.

Alzheimer Europe is looking forward to meeting with its national member organisations at the annual Alzheimer’s Association Academy on 8-9 December 2020.

**11 June: At virtual meeting, members of the European Working Group of People with Dementia confirm Chris Roberts as future Chairperson of the group**

Members of the EWGPWD met virtually on 11 June to elect the Chairperson for the next term of office of the group and to

start preparing for their special symposium at the virtual Alzheimer Europe Conference.

With regard to the election of the Chairperson of the EWGPWD, the Board of Alzheimer Europe had adopted a new procedure. In order to guarantee some continuity of the expertise and knowledge obtained by the current members of the EWGPWD, the Board decided to ask the group to elect the future Chairperson (2020-2022) from amongst its current members. The nomination for the other members of the EWGPWD has not changed and a call for candidates was issued on 30 June.

After a call for candidates, Chris Roberts put forward his candidature and members of the group present at the virtual meeting unanimously supported this. As a result of this vote of confidence, Chris will take up his position as chairperson of the EWGPWD in October after the virtual Alzheimer Europe Conference "Dementia in a changing world". Helen Rochford-Brennan, the current Chairperson, will continue in her role until then.

The group also discussed the format and title of the special symposium and also discussed the structure and format of the group's meetings during the COVID-19 pandemic until face-to-face meetings can resume. The group looked at different challenges linked to operating virtually and how to overcome them. This is also linked to the topic on dementia-inclusive meetings and venues that the group is working on this year. A report will be produced at the end of the year about their experience and conclusions.



*Pictured: Helen Rochford-Brennan and Chris Roberts at Alzheimer Europe lunch debate, December 2019.*

## 29 June: Alzheimer Europe finalises abstract selection for #30AEC



Alzheimer Europe would like to thank everyone who submitted abstracts for its 30<sup>th</sup> Annual Conference (#30AEC). The final selection was made during June 2020 and notifications have been sent to all applicants. The detailed programme can be found on our website:

<https://www.alzheimer-europe.org/Conferences/30AEC-2020/Detailed-programme-and-abstracts>

Keep an eye on <https://www.alzheimer-europe.org/Conferences> and on our social media accounts (Twitter, Facebook, LinkedIn) for more information about registrations, the virtual conference platform, and all other aspects of the conference.

#30AEC is organised under the banner "Dementia in a changing world" and will take place from 20-22 October 2020.

## 30 June: Aideen O'Brien is leaving the Alzheimer Europe team

On 30 June 2020, Aideen O'Brien left her position as Administrative Assistant at Alzheimer Europe. Aideen joined the team in April 2019. The whole team wishes her all the best for her next chapter.

*Pictured: Aideen O'Brien at the 29<sup>th</sup> Alzheimer Europe Conference #30AEC in The Hague, October 2019*



## Alzheimer Europe networking (online)

On 29 May, Owen attended a meeting of the Core Group of the EU4Health campaign.

On 2 June, Jean attended the meeting of the Patients' and Consumers' Working Party of the European Medicines Agency.

On 3 June, Jean, Dianne and Angela attended a meeting of the Neuronet Working Group on Patient Privacy & Ethics.

On 4 June, Angela participated in a tweet chat for the DataSavesLives Initiative.

On 4 June, Alzheimer Europe convened a meeting of the European Group of Governmental Experts on Dementia.

On 5 June, Ange and Jean attended the Scientific Coordination Board meeting of the Neuronet project.

- On 8 June, the Alzheimer Europe Board met.
- On 9 June, Alzheimer Europe organised a company round table meeting with corporate partners and AE members.
- On 9 June, Ana attended the ADAIR General Assembly.
- On 10 June, Alzheimer Europe organised a public affairs meeting with member organisations.
- On 10 June, Jean met with representatives from Biogen to discuss 2020 collaboration opportunities.
- On 11 June, Dianne and Ana participated in the meeting of the European Working Group of People with Dementia (EWGPWD).
- On 11 June, Jean attended a digital workshop organised by Roche.
- On 11 June, Owen attended an online engagement session hosted by Cristian Silviu Buşoi MEP in relation to the EU's proposed EU4Health programme.
- On 12 June, Cindy and Angela attended a meeting of the Neuronet Communications Experts' Community.
- On 15 and 16 June, Jean attended a workshop on brain health services organised by the University Hospital of Geneva.
- On 17 June, Jean attended a meeting of the European Alzheimer's Disease Consortium and the European Academy of Neurology.
- On 18 June, Jean participated in a Biogen webinar.
- On 19 June, Angela attended the General Assembly meeting of the RECOGNISED project.
- On 23 June, Dianne participated in the AD Detect and Prevent webinar "Enhancing the early detection of Alzheimer's disease through digital technologies".
- On 25 June, Ange and Jean participated in the IMI interim review of the Neuronet project.
- On 25 June, Owen attended an online meeting, jointly hosted by the Patient Access Partnership and DG SANTE, relaunching the MEP Interest Group on equitable access to healthcare.
- On 25 June, Ana and Kate participated in the PARADIGM Patient Engagement Open Forum (PEOF).
- On 26 June, Ana participated in the PARADIGM Patient Engagement Open Forum (PEOF).
- On 26 June, Owen attended an online briefing for Non-State Actors, provided by the World Health Organization, on their work programme for the European Region for 2020-2025.
- On 29 and 30 June, Cindy and Jean attended the General Assembly of the PRODEMOS project.
- On 30 June, Owen and Angela attended a Science | Business webconference on Real World Data and health.



## EU PROJECTS

### 18 May: NEURONET convenes a meeting of its Working Group on Sustainability



On 18 May, the NEURONET Coordination and Support Action (CSA) held an online meeting of

the Working Group (WG) on Sustainability. Chaired by Carlos Díaz of Synapse Research Management Partners, who co-leads NEURONET alongside Lennert Steukers of Janssen Pharmaceutica, the meeting was attended by WG representatives from Innovative Medicines Initiative (IMI) neurodegeneration projects such as ROADMAP and EMIF, as well as by members of the NEURONET consortium.

The aim of the Sustainability WG is to work collaboratively with experts within IMI neurodegeneration projects to support these projects to maximise their long-term sustainability. Among other aspects, the WG discusses common issues relating to sustainability beyond the IMI funding period, such

as IP, legal and financial issues. During the meeting, the sustainability plans and models of the EQIPD and AETIONOMY IMI projects were presented by their project leaders. Discussions centred around the complexities of ensuring the sustainability of different types of assets, in particular those that include sensitive personal data from patients and research participants. The next Sustainability WG will be held in the summer.

### 1 June: EPAD releases the baseline data from the first 1,500 research participants enrolled in its Longitudinal Cohort Study

The European Prevention of Alzheimer's Dementia (EPAD) project, a major Europe-wide initiative aiming to improve the understanding of the early stages of Alzheimer's disease, has announced the external release of its second wave of data including the baseline data from the first 1,500 research participants (V1500.0).

The previous V500.0 data release went into open access in November 2019. Data are provided via secure online tools in order to facilitate collaboration between people and teams with similar research aims. Academic researchers and



institutions from all over the world are invited to begin the application process. To access the data, you will need to make an online request by visiting the [EPAD LCS Research Access Process webpage](#), where you will find a variety of resources to support your research.

“This most recent and substantial data release from the EPAD cohort will undoubtedly have a major impact on our understanding of Alzheimer’s disease at very early stages of its development. Releasing this data to the global research community for free and rapid access marks a major milestone for EPAD and will hopefully set a standard for open data access that will ultimately benefit the millions of people worldwide at risk of developing Alzheimer’s dementia.”, said Craig Ritchie, EPAD Co-coordinator.

In the chosen nomenclature:

- V1500.0: V=version, “1500” is the number of sequentially recruited research participants in each dataset and ‘.0’ refers to the study visit the dataset includes up (visit 0 refers to the baseline data).
- V500.0: V=version, “500” is the number of sequentially recruited research participants in each dataset and ‘.0’ refers to the study visit the dataset includes up (visit 0 refers to the baseline data).

### 3 June: Neuronet convenes a meeting of its Patient Privacy and Ethics Working Group

On 3 June, the Patient Privacy and Ethics Working Group of the Neuronet project convened an online meeting. The Neuronet Working Groups (WGs) are cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration, providing Neuronet with expert advice on four identified areas of interest: data sharing, HTA/regulatory interactions, patient privacy and ethics, and sustainability. As such, the WGs make an important contribution to Neuronet’s goal of compiling and leveraging the expert knowledge that is presently scattered across the different neurodegeneration projects in the Innovative Medicines Initiative (IMI) portfolio.

The primary goal of the Neuronet Patient Privacy and Ethics WG is to compile and share learnings on patient privacy and ethics, including guidance on ethical standards and practices to ensure personal data is protected. The June WG meeting was attended by ethics and data protection experts working on the EPAD, AMYPAD, RADAR-AD, MOPEAD, EMIF and AETIONOMY projects, among others, and was focused on identifying key topics to be addressed by the WG over the next two years of Neuronet.

Potential topics that were discussed include the communication of risk to participants, consent clauses for data reuse, reidentification of participants, and public involvement in research. The WG meeting was chaired by Jean Georges, Executive Director of Alzheimer Europe. The next WG meeting will be held in July.

<https://www.imi-neuronet.org/>

### 4 June: First ever “Data Save Lives” tweet chat looks at how best to communicate about health data during COVID19 and beyond

On 4 June 2020, the Data Saves Lives (DSL) initiative held its first “tweet chat” on how patient groups can best communicate about health data during the COVID-19 pandemic and beyond.

Nearly 200 posts using the event hashtag #DSLChat drove the discussion around three central themes – public understanding of health data, examples of patient-centred health data activities, and initiatives to support better communication of responsible health data sharing. COVID-19 was seen to have played a key role in accelerating public awareness of health data and ongoing awareness raising activities were identified as important to advocate for responsible health data use and public involvement.

The event was hosted live online with four expert panellists - the Dutch Patient Federation; the International Niemann-Pick Disease Registry; Birgit Bauer, Patient Expert and Multiple Sclerosis advocate and Angela Bradshaw, Project Officer, Alzheimer Europe. The panellists answered questions submitted via direct tweets using the hashtag #DSLChat.

Missed the chat? You can read the full discussion as it happened, at: [bit.ly/30iBCjM](https://bit.ly/30iBCjM)

Data Saves Lives is a multi-stakeholder initiative which aims to promote greater awareness of how health data can be used in trustworthy ways to improve health and care, and establishing a trusted environment for dialogue about responsible use and good practices across Europe.

You can find out more about the Data Saves Lives initiative on the website at <https://datasaveslives.eu/>, and stay up to date with the latest activities, tweet chats and webinars via the twitter: [https://twitter.com/DataSaves\\_Lives](https://twitter.com/DataSaves_Lives)

### 5 June: Neuronet convenes an online meeting of its Scientific Coordination Board

On 5 June, Neuronet convened an online meeting of its Scientific Coordination Board (SCB). The Neuronet SCB is composed of 16 leaders from Innovative Medicines Initiative (IMI) projects on neurodegeneration, including EMIF, AMYPAD, ROADMAP, MOPEAD and EPAD among others. 10 IMI projects were represented at the SCB meeting, which was chaired by the project Coordinator, Carlos Díaz (SYNAPSE Research Management Partners) and the project Leader, Lennert Steukers (Janssen). The meeting was also attended by Neuronet consortium members from SYNAPSE, Janssen, Sanofi, NICE and Alzheimer Europe.

Neuronet, a coordination and support action (CSA) for the neurodegeneration (ND) projects of the IMI portfolio, aims to enhance collaboration and communication between projects,



multiplying the portfolio's impact and enhancing its visibility in Europe and beyond.

Nina Coll of SYNAPSE kicked off the SCB meeting by providing a brief overview of the tools and platforms developed by Neuronet to support IMI projects, including the Knowledge Base and Asset Map.

Next, Carlos Díaz chaired a discussion between project leaders, on the impact of COVID-19 on project activities. Several projects involving clinical studies have had to cease recruitment and study visits, while preclinical research has also been halted for certain projects due to the closure of laboratories. The SCB members expressed concern at the prospect of ND research being deprioritised, and also at the detrimental effects of the pandemic on early career researchers.

Carlos Díaz closed the meeting by summarising some of the key priorities for Neuronet over the next few months, including sustainability mechanisms for key assets and activities to support ECRs working on IMI ND projects. The next SCB meeting will be held in the autumn.

### 5 June: RADAR-AD project publishes parts 2 and 3 of "Behind-the-scenes" interviews with its researchers



To show the variety of work going on "behind-the-scenes" in RADAR-AD, the project is publishing a

series of interviews with its researchers, the first of which appeared on 19 May. Parts 2 and 3, from 26 May and 5 June 2020 are now available on the project's website.

Researchers share the work they do for the project, what excites and challenges them the most, especially at times of the present COVID-19 pandemic, and how they see the impact of the project for the wider field of Alzheimer's research.

Read part 2 and part 3 of these interview series here:

<https://www.radar-ad.org/newsroom>

### 9 June: ADAIR holds its first (virtual) General Assembly

ADAIR is a JPND-funded project looking at the effect of air pollutants on the brain in humans and possible biomarkers for air pollution and Alzheimer's disease risk-prediction. Alzheimer Europe is an external collaborator in this project.

On 9 June, the first ADAIR General Assembly (GA) took place. During the GA meeting, project partners received an update on the work carried out to date and on the work planned for coming months, including the impact of the COVID-19 pandemic on the different project tasks. Project Officer Ana Diaz attended this meeting.

The website of the project is also now live and there has already been some dissemination of the work of the project via Alzheimer Europe's "Dementia in Europe" magazine (pp.13-14), as well as via the organisation's newsletter.

You can read the ADAIR article on pp.13-14 of the Dementia in Europe magazine, either online:

<https://bit.ly/DementiaInEurope33Online>

or in the PDF: <https://bit.ly/DementiaInEurope33PDF>

The next GA of the project is planned for 2021, in Finland.

### 16 June: PARADIGM organises online Patient Engagement Open Forum

The IMI-funded project PARADIGM - Patients Active in Research and Dialogues for an Improved Generation of Medicines - is organising its Patient Engagement Open Forum (PEOF) as a series of virtual sessions, in view of the current climate. A total of 8 dates are scheduled across 5 months, starting on 25 June, with the closing session taking place on 23 November 2020.



Topics include:

- Patient Engagement tools
- PARADIGM Patient Engagement Toolbox
- How to engage patients in the early stages
- Patient Engagement Monitoring and Evaluation Framework
- How patient engagement can foster access through improved affordability
- personalised medicine.

You can find out more about the PEOF and register here:

<https://patientengagementopenforum.org>

Alzheimer Europe is a partner in PARADIGM, involved in all work packages, and Project Officer Ana Diaz will be moderating a number of the PEOF online sessions.

Find out more about the PARADIGM project here:

<http://imi-paradigm.eu/>

### 19 June: RECOGNISED convenes its General Assembly meeting online

On 19 June, the RECOGNISED project (Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia) held its General Assembly meeting online. Bringing together 21 project partners from academia, SMEs and patient organisations, RECOGNISED aims to evaluate whether non-invasive retinal tests could be used to identify people with type 2 diabetes (T2D) who are at a higher risk of developing mild cognitive impairment (MCI) and dementia.

Prof. Rafael Simo (Vall d'Hebron Research Institute/VHIR), coordinator of the RECOGNISED project, kicked off the General Assembly by welcoming all project collaborators. With Prof.

Noemi Lois (Queen’s University, Belfast) and Dr Pascal Kahlem (VHIR), Prof. Simo gave a status report on the project, emphasising that work is continuing in spite of the lockdown measures for COVID-19. Following on from the introductory session, two parallel sessions were held on the clinical and preclinical aspects of RECOGNISED, led by Prof. Lois and Prof. Alan Stitt, respectively.

During the clinical session, each clinical partner provided a brief overview on the progress of the cross-sectional and prospective clinical research studies that will form a key part of the RECOGNISED project. These studies will investigate the retina structure and cognitive status of older people with T2D, aiming to establish retinal biomarkers that could identify those at risk of developing cognitive impairment.

The preclinical session followed a similar structure, with participants discussing the -omics and *in vivo* strategies that will be employed to identify the key molecular mechanisms that cause retinal dysfunction associated with type 2 diabetes and cognitive impairment.

Next, leaders of the dissemination & exploitation work package (EATRIS and Genesis Biomed) discussed the commercial exploitation strategies for RECOGNISED results, including how intellectual property aspects will be managed. Following on from this presentation, Alzheimer Europe and International Diabetes Federation – Europe (IDF-E), representing people with dementia and diabetes, respectively, gave an overview of the communications activities for RECOGNISED. These include the creation of a website and Twitter account, development of press releases and project leaflets, and drafting of a communications plan. Prof. Simo then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Angela Bradshaw represented Alzheimer Europe at the RECOGNISED project kick-off meeting.

[www.recognised.eu](http://www.recognised.eu)



### EU project acknowledgements



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:

**EPAD-** grant agreement 115736

**RADAR-AD** - grant agreement 806999

**Neuronet-** grant agreement 821513

**RECOGNISED** - grant agreement 847749

**PARADIGM** - grant agreement 777450

## 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 Blinkevičiute (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 Estarás 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).



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## EU DEVELOPMENTS

### 4 June: Alzheimer Europe hosts meeting of Governmental Experts on Dementia



On 4 June, Alzheimer Europe hosted an online meeting of the European Group of Governmental Experts on Dementia, which is comprised of policy leads in charge of dementia policies from national health ministries.

The meeting was attended by 44 people, including representatives from Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Latvia, Malta, Netherlands, Norway, Poland, Portugal, Slovakia, Slovenia, Sweden, Switzerland and the United Kingdom (Department of Health and Social Care and Scottish Government). Representatives from the European Commission (DG RTD and DG SANTE) and from the World Health Organization (WHO) also attended.

The meeting was split into two main sections, with the first one focusing on relevant European and national developments with regard to dementia strategies and policies. The second one was dedicated to an exchange on initiatives and good practices to support people with dementia and their carers during the COVID-19 pandemic.

In the first section:

- Germany and the Netherlands presented their respective new national dementia strategies.
- France outlined the outcome of the evaluation of its neurodegenerative strategy.
- The European Commission provided an update on the new EU4Health programme and on the Commission activities on the impact of the COVID-19 pandemic on mental health.
- Alzheimer Europe provided an overview of the estimated prevalence of dementia in Europe based on its 2019 Dementia in Europe Yearbook.

In the second section, dedicated to the COVID-19 pandemic, the WHO introduced the discussions by presenting the United Nations (UN) framework for the immediate socio-economic response to COVID-19 and the policy considerations developed by the WHO European region on strengthening and adjusting public health measures throughout the COVID-19 transition phases.

This was followed by short presentations on lockdown exit strategies by health ministry officials from Austria, Finland, Ireland, Israel, Poland, Sweden, Switzerland and the United Kingdom. Overall, participants reported that their countries were beginning to ease lockdown measures, with a number of themes emerging, including:

- the gradual re-opening of services with adjusted measures (e.g. fewer people, social distancing etc.)
- the move of many services to online and digital formats to provide continuity of support for people with dementia and carers, e.g. digital consultations
- the challenges around lifting measures for care homes, including lifting restricted visiting rights for families and carers with examples provided of outdoor visits, time-limited visits and dedicated visiting rooms
- and the emergence of regional measures in countries with regional differences in infection rates.

The Group is expected to meet again in December 2020, in Brussels.

### 11 June: Fundamental Rights Agency publishes annual report

The Fundamental Rights Agency (FRA) has published the “Fundamental Rights Report 2020”, reflecting on the developments and shortfalls of human rights protection in the EU over the past year.

The report examines how the EU’s Fundamental Rights Charter has gained visibility and led to a new culture at EU level, whilst noting that nationally, awareness and use of the Charter continue to be limited, despite it being legally binding for 10 years.

The report identifies achievements and areas of concern, presenting the FRA’s opinions on developments, as well as a synopsis of the evidence underpinning the positions taken.



The report covers a broad range of thematic areas, including:

- the ethics and rights in relation to Artificial Intelligence (AI), as well as the role of independent supervisory bodies
- the implementation of policies related to information, privacy and data protection, including in relation to the General Data Protection Regulation (GDPR)
- and the implementation of the UN’s Convention on the Rights of Persons with Disabilities (UN CRPD).

You can read the draft report here:

<https://fra.europa.eu/en/news/2020/covid-19-underlines-importance-strong-fundamental-rights-protection>

**17 June: European Federation of Neurological Associations (EFNA) #BrainLifeGoals grants awarded for 2020**

**#brainlifegoals**

PROJECT GRANTS

The #BrainLifeGoals campaign is an EFNA initiative that aims to

raise awareness of the impact of neurological disorders.

In the framework of the campaign, EFNA provides grants to support work on a chosen advocacy theme. This year’s focus is on “Ensuring Equitable Access to Treatment, Services and Support for Neurology Patients and their Carers”.

10 grants of EUR 3,000 each have been awarded to the selected organisations, working to address this theme.

You can find out more and see the list of winners, here:

<https://mailchi.mp/e771dd2af294/brainlifegoalsgrants-4011456?e=20b55c4167>

**23 June: European Commission launches online stakeholder EU survey into the use and re-use of health data in the light of the GDPR**



The European Commission has initiated a study that aims to examine in which manners the processing of personal health data is governed across the European Union (EU) and how this might affect the cross-border exchange of health data in the EU in light of the Search Results General Data Protection Regulation (GDPR). The study is executed by the EU Health Support consortium.

As part of this study you are invited to participate in an online survey, aimed to collect the views of experts and organisations representing a wide range of stakeholders, including patients,

care providers, industry, public bodies and researchers. The results of the study will be used to identify possible future actions to be developed at EU level, such as new legislation or codes of conduct for health data sharing for research or policy purposes, also in light of the current COVID-19 pandemic. The survey takes about 10-15 minutes to complete and the closing date is 5 July 2020. Complete it, here:

[https://ec.europa.eu/eusurvey/runner/Health\\_Data\\_Survey\\_EUHealthSupport](https://ec.europa.eu/eusurvey/runner/Health_Data_Survey_EUHealthSupport)

**23 June: IMI launches final IMI2 Calls for proposals, including Call on neurodegenerative diseases research**

On 23 June 2020, the Innovative Medicines Initiative (IMI) launched the last Calls for



proposals under the IMI2 programme. The Calls cover six topic areas, including one on research into neurodegenerative diseases (NDs) such as Alzheimer’s and Parkinson’s diseases. The NDs Call aims to create a platform that will make it possible for researchers to see what samples and data are available and access them for further research. The hope is that by opening up these samples and data, researchers will be able to discover new biomarkers that will ultimately help to diagnose patients, monitor their disease, and select the most appropriate treatment.

Other topic areas relate to tackling cancer through artificial intelligence, antimicrobial resistance, rare disease diagnosis, the return of clinical trial data to participants, and patient adherence.

IMI will contribute a total of EUR 59 million to the projects funded under the Calls; these funds come from Horizon 2020 and will support the participation in the projects of organisations such as universities, small and medium-sized enterprises (SMEs), and patient groups. EFPIA companies and IMI Associated Partners will contribute EUR 47 million, mostly as “in kind” contributions.

Stage 1 submission deadline is 29 September 2020 (17.00 CET).

Read the full press release, here:

<https://www.imi.europa.eu/news-events/press-releases/imi-launches-final-imi2-calls-proposals>

The information about call topics and how to submit proposals can be found here:

<https://www.imi.europa.eu/apply-funding/open-calls/imi2-call-23>

**24 June: European REGIOSTARS Awards 2020 nominees include INDEED dementia project**

The initiative “Innovation for dementia in the Danube region” (INDEED) has been nominated for the European REGIOSTARS Awards 2020, in the “Inclusive growth Skills & Education for a digital Europe” category. Each year, the prize (no money) is awarded by the European Commission to EU-funded projects



which represent excellence and innovative solutions in regional development.

INDEED is a project supported by the European Union in the framework of the INTERREG-Danube Transnational Programme from 2018 to 2021 with funds from the European Regional Development Fund (ERDF) and the Instrument for Pre-Accession Assistance (IPA).

If you would like to vote, please visit <https://regiostarsawards.eu/>  
Find out more about INDEED:

<http://www.interreg-danube.eu/approved-projects/indeed>

## 24 June: Rapporteur publishes report on EU4Health programme



The Rapporteur for the European Union's EU4Health programme, Cristian-Silviu Busoi MEP, has published his draft report, responding to the European Commission's initial proposal for the programme.

In his report, Mr Busoi welcomed the Commission proposal for a stand-alone EU4Health programme, including the significantly increased budget.

He reiterated that only a separate and robust programme could ensure the EU had the capacity to respond to future pandemics and health threats, as well as ensuring that health systems are more resilient and able to address current weaknesses.

The report sets out a number of amendments and changes to the Commission's initial proposal for the EU4Health programme, including:

- a call for a greater focus on disease prevention and health promotion by addressing health risk factors
- support for the promotion of early diagnosis and screening for both communicable and non-communicable diseases, including neurodegenerative diseases

- and the identification of mental health and ageing as a particular challenge, particularly in light of the demographic challenges in Europe, including in the areas of early diagnosis, treatment, support and prevention, training of practitioners, etc.

You can read the draft report here:

[https://europarl.europa.eu/doceo/document/ENVI-PR-653803\\_EN.pdf](https://europarl.europa.eu/doceo/document/ENVI-PR-653803_EN.pdf)

## MEMBERS' NEWS

### 5 June: Irish Dementia Working Group hosts virtual launch of "Hear Our Voice!" guidelines



## Hear our voice!

Virtual Launch of *Hear Our Voice! Guidelines for involving people with dementia in policy, advisory, consultation and conference activities* on Friday June 5th at 11am - 12 noon

The Irish Dementia Working Group (IDWG) hosted a Virtual Launch of the document "Hear Our Voice! Guidelines for Involving People Living with Dementia in Policy, Advisory, Consultations and Conference activities". This project is a collaboration between the Centre for Economic and Social Research on Dementia, The Alzheimer Society of Ireland (ASI) and the IDWG.

The document provides practical guidance in a user-friendly format for individuals and organisations that wish to involve people with dementia in their work or gain their views in a formal way. This publication was co-produced by people living with dementia - written *by* them, not *for* them.

Senior Research Fellow, Centre for Economic and Social Research on Dementia at NUI Galway, Dr Fiona Keogh said:

"We have been working with the members of the Irish Dementia Working Group and The Alzheimer Society of Ireland for many years now and have learned so much about what works best in terms of involving people with dementia as equal partners in our work. Co-producing the guidelines was a wonderful opportunity to bring all of that learning and experience together so that it can be shared more widely to increase the ways in which people with dementia are involved in policy and providing advice and expertise to a wide range of other organisations."

Speaking at the launch, Pat McLoughlin, CEO of The ASI said:

"Authentic participation of people living with dementia does not just happen; it takes planning, capacity building and robust support. I know policy makers want to involve people living with dementia and I believe this document can support them to do so. I have learned so much from people living with

dementia during my time with The Alzheimer Society and if we listen to them they can support us to create a better and more inclusive network of dementia supports.”

Over 150 people attended the virtual launch. The interest within the dementia community to support involvement of people living with dementia was palpable. Vice Chair of the IDWG Kevin Quaid, commenting on this interest, reminded those in attendance of the benefits of involving people with dementia, in particular as we live through a pandemic:

“People with dementia, like myself, are experts by experience and our voice is critical in the planning of dementia supports and services. Covid19 has been such a devastating time for people with dementia and their family carers with so much anxiety, anguish and confusion. But this document has reminded me that there is hope for the future. Our voices can be heard loud once more. We will prevail. I hope you enjoy reading it and more importantly I hope you use it!”

The development of the document was funded through a Knowledge Exchange and Dissemination grant #KEDS-2018-017 from the Health Research Board in Ireland.

The document is available here:

<https://alzheimer.ie/wp-content/uploads/2020/06/FINAL-Hear-our-voice.pdf>

## 8-14 June: The Alzheimer Society of Ireland marks National Carers' Week 2020



The Alzheimer Society of Ireland (ASI) marked National Carers' Week 2020 (8-14 June) in early June. The ASI used the opportunity to recognise, support and respect family carers, because “they have been the hidden heroes throughout the Covid-19 pandemic”, it said.

Although all events were run virtually and using social media, The ASI marked Carers' Week 2020 by taking the opportunity to:

- highlight some of our key carer support services which have been adapted in recent times to support families caring for a loved one with dementia
- highlight the experiences and voices of family carers
- use media opportunities to discuss the invisibility of family carers during this pandemic and even before Covid-19
- hold a successful open online meeting for family carers with over 30 participants to mark the week.

The ASI is fully aware, through research and from new information from its Dementia Advisers, its new online Dementia Nurse Service and via calls to its National Helpline, that the pressure points on family carers of people with dementia is increasing and is reaching critical levels.

The Covid-19 health crisis has been a “perfect storm” for carers of people with dementia with the closure of The ASI's day centres in particular, along with social clubs, Alzheimer cafés, and face-to-face carer trainings. Many carers have nowhere to go and no respite from the relentless demands of caring and the work to keep their loved ones stimulated.

*Pictured: Members of the Dementia Carers Campaign Network (DCCN).*

## 22 June: German Alzheimer's Association shares new information about Chronic Traumatic Encephalopathy (CTE)

The German Alzheimer's Association, Deutsche Alzheimer Gesellschaft (DAIzG), has published information about CTE, which is also known as *Dementia Pugilistica*, Punch Drunk Syndrome or Boxer's Dementia.



The impetus to deal with this topic came from Erich Grau (pictured), former American football quarterback who has been showing typical CTE symptoms for 20 years.

There are no special treatment options for CTE, but various methods and therapies can make life with CTE easier.

"Psychoeducation or the avoidance of difficult situations help to deal with the beginning of dementia or aggression. Adequate sleep, healthy nutrition, sports training and concentration on the essential aspects of one's own life also provide a strong basis for the successful treatment of CTE," emphasises Erich Grau. You can find more information here (in German):

<https://www.deutsche-alzheimer.de/die-krankheit/andere-demenzformen/chronische-traumatische-enzephalopathie-cte.html>

### 23 June: Alzheimer Athens presents Super Lingo programme



Super Lingo is an innovative foreign language (English) programme for cognitive training aimed at people with Subjective Cognitive Complaints (SCD) in the absence of objective cognitive deficits, people with Mild Cognitive Impairment (MCI) and people in the early stage of dementia. The project is funded by Erasmus+ and involves five European partners (Lingo Flamingo - United Kingdom, Spominčica - Alzheimer Slovenija, Asociatia Habilitas Centru de Resurse si Formare Profesional – Romania, Marathon Group – Ireland, and Alzheimer Athens - Greece) who combine their expertise in language learning, developing and delivering online educational technology, designing and providing services for older adults at risk for cognitive impairment. Currently in development, it will be launched in February 2022.

Short English lessons, based on role-playing scenarios and memory games will be provided. It will be accessible to anyone with a device (e.g. tablet) and internet access, allowing for use by people with mobility issues and/or limited access to appropriate and engaging cognitive activities. Users will also have the possibility to interact with each other on the platform, allowing for a social aspect. Super Lingo also aims to inform health care professionals, older adults and the general public about prevention strategies.

To ensure it is easy to use, the activities are being designed by experts in collaboration with members of the target group from Greece, Romania and Slovenia.

The programme is being based on research which suggests that the process of learning a new language engages different pathways in the brain. Studies have suggested that language learning is more effective than other forms of cognitive training, promoting neurophysiological changes in the brain that improve cognition and possibly delay cognitive decline, writes Alzheimer Athens. The organisation also points out that it should be noted that it is the process of learning, and not the proficiency achieved, which is important. For more information, visit: [www.superlingo.eu](http://www.superlingo.eu)

### 23 June: Alzheimer Hellas reports on outcomes of 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. It began on 1

September 2017 and will end 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).

By implementing the results, the project has been able to contribute to the goals of dementia friendly environments all over Europe. Intergenerational contact was established through an innovative creative learning module that combined theatre, poetry and music, tapping into the long term memory of older people with dementia. A core aspect of the module was the transnational blended learning platform (open source - Moodle) that contains all the teaching materials and made it possible for students to exchange information, ideas and content; to plan their own activities and report on their results and experiences.

The final outputs are:

- A teachers’ manual, supporting teachers who are implementing the iConnect module “Creative interaction with people living with dementia”, and
- A students’ manual, informing students about the module.

Module website:

<https://www.iconnectdementia.eu/iconnect/module-variations>

Manuals:

<https://iconnectdementia.eu/courses/moodle-registration/2-uncategorised/94-useful-material>

Project website: <https://www.iconnectdementia.eu/>

### 24 June: Alzheimer Switzerland appoints new Chairperson



On 24 June, Alzheimer Switzerland announced it has a new chairperson, Catherine Gasser (pictured, right). Dr Gasser succeeds Dr Ulrich Gut (pictured, left), who has been Chairperson for the past 11 years and has strongly advocated for dementia to be on the political agenda in Switzerland and beyond.

Dr Gasser was previously a member of the executive board of Alzheimer Switzerland, for one year. She also has many years

of leadership experience including in the health and social sector. Read more about this new appointment and about other new board members, here (in German):

<https://www.alzheimer-schweiz.ch/de/medien/medienmitteilungen/>

## 29 June: Alzheimer’s Society has a new CEO



Kate Lee recently joined Alzheimer’s Society (UK), as its new Chief Executive Officer (CEO). She was previously Chief Executive Officer at CLIC Sargent - a children’s cancer charity – for 5 years and prior to that worked as the CEO of a Hospice Group as well as spending 12 years working for the British Red Cross.

She succeeds Jeremy Hughes, who was CEO at Alzheimer’s Society for a decade.




You can read a full profile of Kate Lee, here:

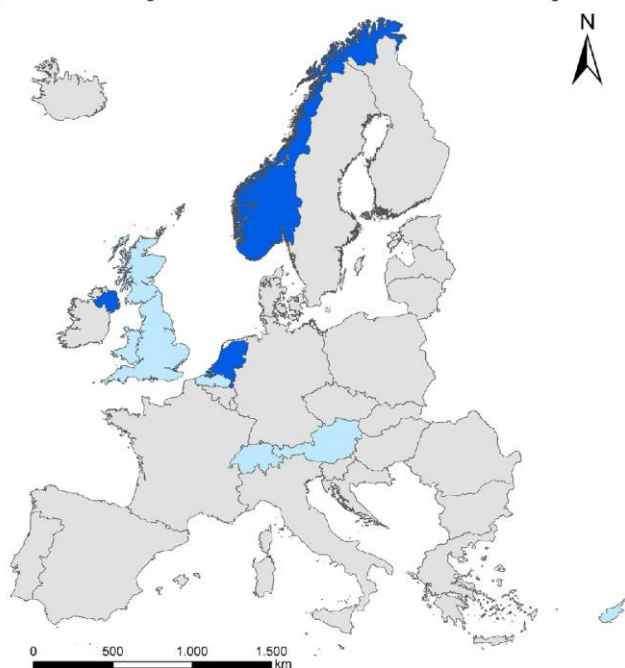
<https://www.thirdsector.co.uk/kate-lee-i-seen-innovation-last-month-entire-time-sector/management/article/1683522>

## POLICY WATCH

### 26 May: Is care for people with dementia from a migration background addressed in national dementia plans and strategies in Europe?

#### Migration-related National Dementia Plans in Europe

-  Countries without migration-related NDPs
-  Countries with migration-related NDPs
-  Countries with migration-related NDPs and available services for migrants



On 26 May, a study examining whether or not national dementia plans and strategies in Europe have a focus on care

for people with dementia from a migration background, was published in the journal BMC Public Health.

The study was carried out by a team of researchers at the German Centre for Neurodegenerative Diseases (DZNE), led by Tim Schmachtenberg. Their aim was to illustrate how European countries identify the dementia-related needs of people with migration backgrounds and to find out if specific healthcare services are provided for them, at the national level.

A qualitative analysis of national dementia plans of the EU and EFTA (European Free Trade Association) countries was carried out, and results showed that, of the 23 (out of 35) EU and EFTA countries which have national dementia plans in place, 10 of these made reference to migration.

Only one country (Austria) had a national dementia plan with a specific chapter on migration, while eight countries identified that people with migration backgrounds and dementia have specific needs. Dedicated actions to care for this population group were laid out in nine of the ten countries’ plans, but only the national dementia plans of Norway, Northern Ireland, and Netherlands referred to currently available healthcare services for people with migration backgrounds.

Overall, the study concludes that the topic of migration plays a “subordinate role” in the national dementia plans of European countries and that this lack of migrant-specific healthcare services in almost all European countries may lead to denying the right to appropriate care to what is a growing population.

The data analysed in this study are publically available via the website of Alzheimer Europe: <https://www.alzheimer-europe.org/Policy/National-Dementia-Strategies>

The study was carried out within the project “Atlas zu Prävalenz von dementiell erkrankten Menschen mit Zuwanderungsgeschichte in Europa” funded by the Robert Bosch Stiftung. Study link: <https://bit.ly/2YbThIJ>

### 16 June: Dementia included in the Irish Programme for Government

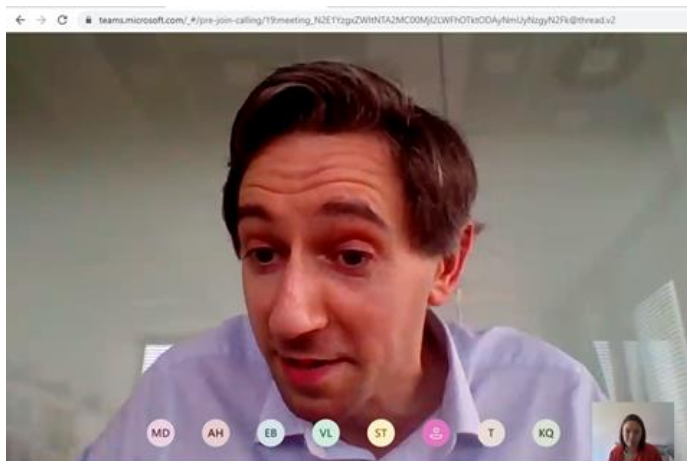
Government formation is still ongoing in the Republic of Ireland following a General Election in February of this year. In mid-June the prospective Government coalition published its Programme for Government. Two of the key asks from The Alzheimer Society of Ireland General Election campaign “Deliver on Dementia” were included in this. These were the implementation of the National Dementia Strategy and the introduction of a statutory home care scheme.

In fact, dementia got a section in itself where commitments were outlined to:

- Implement the National Dementia Strategy;
- Ensure that home support is adaptable and responsive to the needs of those with dementia;
- Increase the number of dementia advisers;
- Investigate the possibility of establishing a dementia village along the lines of Hogeweyk in the Netherlands;

- Finalise a code of practice on Advanced Healthcare Directives, allowing for full commencement of the legislative framework.

Other points of note included a commitment to deliver a “Carers’ Guarantee” proposal that will provide a core basket of services to carers across the country, regardless of where they live.



On 16 June, The Alzheimer Society of Ireland (ASI) also had a virtual online meeting with Minister for Health Simon Harris (pictured) to discuss the impact that Covid-19 has had on people with dementia. The Minister gave assurances that he would highlight the “invisibility” of dementia and in particular family carers in the road-maps being laid out to respond to Covid-19.

Although this is just the first step in a long journey, it is an essential one; without it, it would become very difficult for The ASI to lobby for action.

**18 June: WHO Europe publishes draft work programme for 2020-2025**



The World Health Organization Regional Office for Europe (WHO Europe) has published a draft of its European

Programme of Work (EPW) for 2020-2025, which is now open for consultation. The EPW is entitled “United Action for Better Health” and sets out future priorities for WHO Europe, building on the mandate of the Regional Director for Europe.

The EPW is designed to align with the WHO’s overarching Thirteenth General Programme of Work (GPW13) and is structured around four key areas: Behavioural insights; mental health; health; and immunisation.

WHO Europe is encouraging any stakeholders with an interest in health policy to contribute to the consultation, with a deadline for contributions of 18 July 2020.

The EPW will be put to ministers and representatives for health from the 53 Member States in the WHO European Region for their endorsement at the WHO’s annual governance meeting, the 70<sup>th</sup> session of the WHO Regional

Committee for Europe, in September this year. You can access the draft European Work Programme here:

<https://bit.ly/31xY4Gh>

**1 July: German Government approves national dementia strategy**

On 1 July 2020, it was announced that the German Government has adopted a National Dementia Strategy.



Die Bundesregierung

The Strategy was written by an alliance involving the Deutsche Alzheimer

Gesellschaft (DAIzG) – the German Alzheimer Society, the states and municipalities, healthcare associations, the social security institutions, civil society and the scientific community.

27 objectives were identified and around 160 actions were agreed upon, including:

- **On-site networks:** Local networks to provide advice and support for people living with dementia and their families.
- **Nursing care networks:** In addition, regional (dementia) networks to better connect the actors involved in nursing care will be increased and intensified. The funds earmarked for this purpose from long-term care insurance are to be significantly increased.
- **More focus on dementia:** In order to encourage more involvement in, and focus on, the area of dementia, a nationwide campaign will be run, as part of which people will be invited to become “dementia partners” (Germany’s Dementia Friends programme).
- **Post diagnostic support and counselling:** Professional and voluntary support, as well as counselling services are being expanded.
- **Care and employment networks:** Relatives of people with dementia face particular challenges in balancing care and work. Employers, municipalities and carers are therefore to develop strategies and establish networks. This will be supported at government level.
- **Promoting health for carers:** Health and prevention programmes for carers will be further established and improved. A new funding programme is being considered to support this.
- **Coordinated procedures in care:** Doctors, hospitals, nursing homes and other stakeholders are to cooperate and communicate with each other more clearly and efficiently through a developed “care pathway” interface.
- **Dementia-inclusive hospitals:** The needs of people with dementia are to be taken into account in the spatial design of hospitals and nursing homes and “dementia-inclusive” work processes and qualified staff will be put in place to better support people with dementia during hospital stays.

- **Dementia research:** Collaboration between different research institutions and areas will be promoted through the establishment of a national clinical dementia research network and a network for dementia care research. Access to data for research purposes will also be made easier.

In a joint statement, Minister for Family Affairs, Senior Citizens, Women and Youth Franziska Giffey, Minister of Health Jens Spahn and Minister of Education and Research Anja Karliczek stressed:

"Germany is ageing and more and more people are developing dementia. There are currently 1.6 million, and by 2050 the figure could be 2.8 million. We must prepare Germany for this, and that is what we are doing with the National Dementia Strategy. The condition concerns us all.

It is clear that this strategy will only be a success if everyone now joins in the implementation. We need a new awareness in all areas of life, social support networks on the ground, good medical care and first-class research. If everyone contributes, we will successfully implement the strategy."

The new strategy will take effect in September 2020, following which the implementation will begin, with an assessment planned for 2026.

The full press release can be read, here (in German):

[https://www.bmbf.de/files/2020-07-01\\_90%20PM%20BMG-BMFSFJ-BMBF%20Demenzstrategie\\_2.pdf](https://www.bmbf.de/files/2020-07-01_90%20PM%20BMG-BMFSFJ-BMBF%20Demenzstrategie_2.pdf)

The National Dementia Strategy in its entirety and further information can be found at:

<https://www.nationale-demenzstrategie.de/>



## SCIENCE WATCH

### 27 May: University of Pittsburgh will use USD 2.6 million NIH award to examine how biological factors affect brain disease

The University of Pittsburgh (US) has received a grant of USD 2.6 million from the National Institutes of Health (NIH) to study how biological factors such as sex differences contribute to cognitive impairment and dementia. Bistra Iordanova, assistant professor at the University of Pittsburgh will work on this project to see how sex differences influence the neural activity and changes in cerebral blood flow. She will also study how hormonal changes during ageing may affect the energy consumption of the brain.

"One reason it is difficult to understand the sex-based distinctions in dementia is because in a significant portion of the human studies, the gender is regressed out, and the data are pooled together to increase the effect size. Our approach will examine the gene expression of individual cells and use

brain imaging to determine the specific cell types that contribute to neurovascular resilience", said Bistra Iordanova.

[https://www.eurekalert.org/pub\\_releases/2020-05/uop-etn052820.php](https://www.eurekalert.org/pub_releases/2020-05/uop-etn052820.php)

### 28 May: Neurotrope launches a new long-term clinical trial of Bryostatatin-1 in Alzheimer's disease

On 28 May 2020, Neurotrope, a company focused on developing drugs to treat neurodegenerative diseases including Alzheimer's disease (AD), announced the launch of a Phase II clinical trial to investigate the long-term use of Bryostatatin-1 for the treatment of AD. The new study will be conducted in collaboration with the National Institutes of Health (NIH) under a USD 2.7 million grant. The company expects to enrol approximately 100 people with moderate and severe AD and to dose the first research participant later this year.

In September 2019, Neurotrope announced that the confirmatory Phase II clinical trial of Bryostatatin-1, in moderate to severe AD, failed to meet its primary endpoint of change from baseline to week 13 in the Severe Impairment Battery (SIB) total score. In January 2020, the company reported that the study showed improvement in cognitive function, following completion of data analysis.

"We are very excited to advance Bryostatatin-1 to its next phase of development. Given the high unmet need for new therapies to treat AD, recognised by the NIH and highlighted by their financial and scientific support, we plan to move this program forward as rapidly as possible, with the goal of demonstrating Bryostatatin-1's potential benefit in this setting. Many other AD studies have been longer in duration than the studies we previously conducted" stated Dr Daniel Alkon, President and Chief Scientific Officer of Neurotrope.

<https://prn.to/2ZrThnm>

### 29 May: New study reports that nilotinib, an FDA-approved drug for leukaemia, is safe and well-tolerated in AD Phase II trial

Nilotinib was approved by the US Food and Drug Administration (FDA) for chronic myeloid leukaemia in 2007. Nilotinib has been proposed for repurposing as a disease-modifying treatment for neurodegenerative diseases including Alzheimer's disease (AD). In 2017, the Georgetown University group started a Phase II clinical trial enrolling 37 people with mild to moderate AD (mean age 70.7 years old). The randomised, double-blind and placebo-controlled study investigated the safety and tolerability of nilotinib. Participants were given either a placebo or nilotinib daily for 12 months.

According to the data published online on 29 May 2020 in the journal *Annals of Neurology*, nilotinib was safe and well-tolerated, although more adverse events, particularly mood swings (agitation and irritation), were found at the higher dose. In addition, researchers reported that some AD

biomarkers were reduced at 6 and/or 12 months in the nilotinib group compared to the placebo. A multicentre and larger Phase III trial is planned, to evaluate the safety and efficacy of nilotinib in people with AD or mild cognitive impairment.

<https://onlinelibrary.wiley.com/doi/10.1002/ana.25775>

**4 June: Anavex Life Sciences receives regulatory approval to expand its Anavex 2-73 Phase II/III trial for AD in Canada and UK**



On 4 June, Anavex Life Sciences Corp - a clinical-stage biopharmaceutical company developing therapeutics for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD) - announced that it has received regulatory approval from Health Canada and Medicines and Healthcare

Products Regulatory Agency (MHRA) in the United Kingdom (UK) to expand its Phase II/III clinical trial for the treatment of AD into Canada and the UK.

The Phase II/III trial is a double-blind, randomised and placebo-controlled study currently underway in Australia, with more than 50% of the 450 research participants enrolled. It is aiming to evaluate the safety and efficacy of ANAVEX 2-73 in people with early AD.

<https://www.anavex.com/5927-2/>

**15 June: Amylyx Pharmaceuticals announces completion of enrolment of its PEGASUS Phase II trial for Alzheimer’s disease**

On 15 June, Amylyx Pharmaceuticals, a clinical-stage pharmaceutical company developing a novel therapeutic for Amyotrophic Lateral Sclerosis, Alzheimer’s disease (AD) and other neurodegenerative diseases, announced that it has completed the enrolment of its Phase II trial evaluating AMX0035 in people with AD. AMX0035 is a combination of existing compounds designed to prevent neuroinflammation and nerve cell death.

The PEGASUS Phase II trial is a 24-week randomised, double-blind, multi-site and placebo-controlled study evaluating the safety and tolerability of AMX0035 in people with late mild cognitive impairment or early dementia due to AD. The company announced that it has recruited 96 research participants and expects to share topline results of the PEGASUS trial in early 2021.

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



**17 June: Pooled study analysis shows how combinations of lifestyle factors may affect Alzheimer’s disease risk**



On 17 June, Dr Klodian Dhana and colleagues published an article in the journal *Neurology*, showing that people with several healthy lifestyle habits have a lower risk of developing Alzheimer’s disease.

The researchers analysed data from participants in two separate longitudinal studies: 1,845 participants in the Chicago Health and Ageing Project (CHAP) and 920 participants in the Rush Memory and Ageing Project (MAP). Both of these studies, which were funded by the US National Institutes of Health (NIH), collected information on diet, lifestyle factors, genetics and cognitive function, with an average follow-up of 5.8 and 6 years, respectively. A healthy lifestyle score was assigned to each participant based on their smoking status (non-smoking = 1 point), level of physical activity (>150 minutes of moderate or vigorous activity per week = 1 point), alcohol consumption (light to moderate = 1 point), quality of diet (healthy Mediterranean diet = 1 point) and engagement in late-life cognitive activities (1 point).

Statistical analyses showed that each additional healthy lifestyle factor conferred an average reduction in risk of Alzheimer’s disease (AD) of 27%. Compared to participants with 0 or 1 healthy lifestyle factor, those who had 2-3 healthy lifestyle factors had a 37% reduced risk of AD, increasing to a 60% reduced risk in those with 4-5 healthy lifestyle factors.

<https://n.neurology.org/content/early/2020/06/16/WNL.0000000000009816>

**17 June: AriBio announces the completion of enrolment of its Phase II trial with AR1001 for AD**

On 17 June, AriBio - a clinical-stage biopharmaceutical company developing innovative drugs for specific diseases including neurodegenerative and infectious diseases - announced the



completion of enrolment of its Phase II study of AR1001 for Alzheimer’s disease (AD).

The Phase II study is a double-blind, randomised and placebo-controlled trial evaluating the efficacy and safety of AR1001 in people with mild to moderate AD. A total of 210 US research participants received placebo or AR1001 orally, once daily over 26 weeks. The company is expecting to announce the topline results by early 2021 and to initiate another Phase II study for mixed dementia in 2021.

<https://www.businesswire.com/news/home/20200617005630/en>

**22 June: Study of postmortem brain samples shows striking differences in Tau between individuals, contributing to clinical heterogeneity in AD**



On 22 June, Dr Simon Dujardin and colleagues published an article in the journal *Nature Medicine*, describing striking differences in Tau biochemistry between individuals with Alzheimer’s disease (AD), and identifying particularly hazardous forms of soluble Tau that may be associated with a more rapid disease course.

The clinical course that AD follows is extremely heterogeneous, with wide-ranging rates of disease onset and cognitive decline. Tau, a microtubule-associated protein that accumulates in neurofibrillary tangles during the development of AD, also exists in soluble and hyperphosphorylated forms. Several lines of evidence have shown that soluble Tau oligomers are neurotoxic, causing degeneration and death of brain cells. In their paper, Dr Dujardin and colleagues set out to establish whether differences in Tau biochemistry could explain why some individuals experience a particularly rapid and severe AD course compared to others.

To investigate Tau biochemical diversity in AD, the researchers obtained *postmortem* brain samples from 32 participants in the Massachusetts Alzheimer’s Disease Research Center Longitudinal Cohort Study. Each of these participants had a confirmed AD diagnosis, with detailed information on their clinical progression over time. Using soluble extracts prepared from the brain samples, the researchers found substantial between-participant differences in the ability of Tau to propagate from cell to cell, seeding new Tau aggregates. They then performed biochemical assays to identify the Tau characteristics that drive higher versus lower

seeding; these analyses suggested that oligomeric, phosphorylated Tau forms had higher levels of seeding compared to other forms. More detailed analyses revealed specific Tau phosphorylation sites that correlated with higher or lower seeding ability, suggesting that Tau phosphorylation greatly impacts on its ability to seed.

Finally, they looked at whether the rate of clinical decline was linked to the biochemical properties of brain extract Tau. Interestingly, they found that higher rates of Tau seeding were associated with more rapid clinical decline, and younger age of AD onset. High seeding was particularly prevalent in participants who carried two ApoE4 alleles, pointing to a role for genetic risk factors in influencing Tau aggregation and seeding.

<https://www.nature.com/articles/s41591-020-0938-9#Abs1>

**23 June: Clinical study links obesity with dementia risk**

On 23 June, Dr Yixuan Ma and colleagues published an article in the *International Journal of Epidemiology*, reporting an increased risk of dementia in older individuals who are overweight or obese.



In the study, Dr Ma and colleagues evaluated over 6,500 participants in the English Longitudinal Study of Ageing (ELSA) who were aged >50 years at baseline. Participants were classified as obese or overweight based on their body mass index (BMI) and/or waist circumference, using established categories. Several clinical and lifestyle measures were also collected, including ApoE4 status, levels of smoking and physical activity, and whether they had hypertension or diabetes. Participants were followed up for an average of 11.4 years, and underwent cognitive assessments at 2-year intervals.

Statistical analyses showed that obese participants with a BMI of >30kg/m<sup>2</sup> at baseline had a 35% increased risk of dementia compared to participants with normal BMI. The association between obesity and dementia remained even after adjusting for ApoE4 status, hypertension, smoking status, education and marital status. When waist circumference, a measure of central obesity, was measured, the researchers detected a 39% increased risk of dementia in women, compared to women with no central obesity. When taking both measures of obesity into consideration, the association with dementia remained, with a 28% increased risk in participants with high BMI and greater waist circumference compared to those with a normal BMI (<25kg/m<sup>2</sup>) and waist circumference.

<https://academic.oup.com/ije/article/doi/10.1093/ije/dyaa099/5861491>

**24 June: Clinical study published in Neurology indicates that hormonal changes may contribute to the increased prevalence of Alzheimer’s disease in women**



On 24 June, Dr Aneela Rahman and colleagues published an article in the journal Neurology, identifying a correlation between menopausal status and Alzheimer’s disease (AD)-associated

changes in the brain.

The study involved 85 women and 36 men aged between 40 and 65 years, all of whom were cognitively normal. As well as assessing lifestyle and medical risk factors for Alzheimer’s Disease (AD), the study mapped their hormonal status and

performed MRI and PET imaging scans. In particular, these scans aimed to detect brain biomarkers of AD, such as amyloid-beta deposition (via PiB-PET) and neurodegenerative changes (via structural MRI and FDG-PET).

Although the male and female groups were comparable in terms of clinical and cognitive measures, the researchers observed higher levels of amyloid deposition and reduced grey and white matter volume in the female group, irrespective of age. For example, women had approx. 30% more amyloid plaques than men, while men had approx. 11% greater white matter volume. Second to female sex, menopausal status followed by hormone therapy were the strongest predictors of brain biomarker differences. To further confirm the results of this study, more large-scale and longitudinal studies are now required.

<https://n.neurology.org/content/early/2020/06/24/WNL.0000000000009781>

**LIVING WITH DEMENTIA**

**11 June: Open letter published in HRB Open Research reflects on Helen Rochford-Brennan’s experiences of the COVID-19 pandemic**



An open letter has been published on the online research platform of the Health Research Board (HRB), entitled “Giving voice to those directly affected by the COVID-19 pandemic – the experience and reflections of a person with dementia”. This letter takes the form of a reflective conversation with Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD).

Honouring the principles of public and patient involvement (PPI), it is an attempt to give voice to the experience of one of the many thousands of at-risk people during the COVID-19 pandemic. The letter was informed by a series of conversations between Helen Rochford Brennan and Fiona Keogh from the Centre for Economic and Social Research on Dementia at NUI Galway.

Helen reports heightened anxiety, stress and isolation. As well as having dementia, Helen is the carer for her husband and is finding this responsibility particularly stressful just now. She also emphasises the many positives in her life –not living alone, being able to get outside in her garden, and having a supportive network of family and neighbours. It is also helpful that she is adept at using computers and social media and has access to good broadband. These resources help her to stay active and to keep the isolation and anxiety at a more manageable level.

She suggests two practical supports, which she feels would really help people with dementia at this time. Firstly, human contact which is essential for reassurance and emotional support; and secondly, a simple information sheet specifically for people with dementia and their carers, sharing useful strategies and information.

The open letter identifies that years of neglect of community-based supports for people with dementia are more obvious now than ever. While formal health services are important, it states, people with dementia have long recognised the importance of a social model of support and the development of dementia friendly communities has played an important role in building community responses. It also stresses that there are some lessons to be learned from the current crisis, not least the need to have significant investment in home care services and supports, a need which is evident in Helen and her husband’s case. They receive no more than half an hour of home support between them, per week, despite both having medical conditions which, particularly during this crisis, mean they are considered “extremely medically vulnerable”.

Keeping people out of nursing homes and building a person-centric continuum of care, allowing people to live at home, in their communities, should be the legacy of this virus, Helen concludes. You can read the open letter, here:

<https://hrbopenresearch.org/articles/3-29>

## DEMENTIA IN SOCIETY

**9 June: Internationally acclaimed Australian short film about dementia is available to view online**



“Skewwhiff” is a short film about an older couple, Bill and Rae, who are dealing with the fact that Rae has dementia. In the film, she wants to get their car washed, but the windscreen is cracked, which poses a problem at the drive-through carwash. Bill is determined to grant her wish and the story unfolds as they wait for an answer, at the carwash reception.

The title “Skewwhiff” refers to the sense of things being not quite right; a little off-kilter, a feeling which permeates the entire film. Dialogue is kept to a minimum and much is expressed in the unspoken, mainly from the point of view of Bill as Rae’s primary caregiver and partner. There is frustration, sadness, anger, guilt, shame and fear, as well as a lot of love.

Writer-director Rob Summons, based in Melbourne, Australia, was delighted at the reaction to his film, which has garnered a number of international film festival awards. He wanted to make it available to as wide an audience as possible and has now made it available to view, online:

<https://vimeo.com/412546529>

You can find out more about “SkewWhiff” here:

<https://skewwhiffmovie.com/>

## NEW PUBLICATIONS & RESOURCES

**15 June: Activity and exercise programme video for people with early stage dementia is available online**



A video has been launched, aiming to help support people with early stage dementia, by demonstrating an activity

and exercise programme consisting of a combination of exercises, activities of daily living and memory strategies to help improve and maintain physical and mental health.

The video was co-produced by researchers and patients who took part in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) research programme at the University of Nottingham, United Kingdom.

Video link:

<https://www.youtube.com/watch?v=BXNHm9Nj1pk&feature=youtu.be>

**18 June: New book “Loud and Clear” charts 20 years of activism by people with dementia in Scotland**

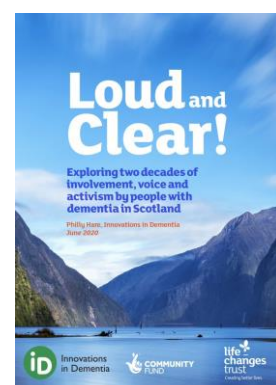
On 18 June 2020, a new book was published, telling the story of how a number of people living with dementia in Scotland have become activists and influencers in their own right over the last twenty years. “Loud and Clear” charts the history of and pays tribute to them.

The author, Philly Hare, tells the story largely through the eyes of the dementia activists themselves.

She said:

“I feel very privileged to have researched and written this book on behalf of Life Changes Trust. It has been wonderful to meet or re-meet so many remarkable people and to tell their story. Scotland has a lot to be proud of – and has built a strong foundation on which so much more can be done in the future.” Read the book here: <https://bit.ly/LoudandClearbook>

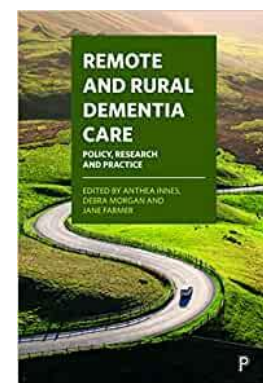
There is also a short film featuring some of the contributors to the book. Watch the film here: <https://bit.ly/LoudandClearfilm>



**25 June: New book on “Remote and Rural Dementia Care” is published**

Eamon O’Shea and Kieran Walsh of the National University of Ireland Galway (NUIG), who contributed to the book, which was published in May 2020, have written the following article introducing it:

The specific issue of rural ageing and dementia care has been neglected in many countries. As populations age, the need to provide services to an increasing number of older people with dementia living in rural areas will become more acute, even if the share of older people living in rural areas is likely to decline in the future, in Ireland and internationally. Concern for older people with dementia who continue to live in rural areas is based on a number of potential disadvantages arising from economic, social,



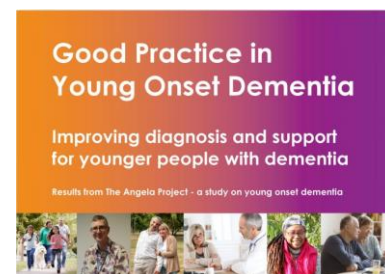
geographical, environmental and demographic sources. There is a tendency for cumulative cycles of decline to occur in rural areas; structural economic change and poor employment opportunities tend to lead to out-migration which in turn leads to population decline, unbalanced age structures and falling economic activity, which reinforces unemployment issues and further intensifies the out-migration of younger people. This is quickly followed by a reduction in health and social care provision, placing greater responsibility for care on people themselves and their shrinking networks and more dispersed families. Such circumstances can lead to a decline in well-being and lower quality of life for people with dementia living in rural areas. It can also lead to higher rates of admission to residential care than is necessary or desirable for people with dementia.

Our contribution to the book *Remote and Rural Dementia Care* edited by Anthea Innes, Debra Morgan and Jane Farmer, published by Policy Press, examines resource allocation and equity issues for older people with dementia living in rural areas in Ireland. It reframes the challenges people with dementia face in the context of social exclusion and its capacity to detract from full participation in society. People living with dementia in rural areas may, in effect, be subscribed into the position of lesser citizens, separated and disconnected from a level of engagement in economic and social life enjoyed by mainstream society. We use the analytical frame of social exclusion to help unpack complex and multiple challenges facing older people with dementia living in rural areas. We adopt a multifaceted policy approach to support full societal participation of people with dementia, drawing on secondary data from a small number of recent studies carried out by the National University of Ireland Galway. Our argument supports the recalibration of current dementia policy towards a broader social strategy for rural dwelling people with dementia. This will involve new investment and innovation in service infrastructure, service provision, new technologies, housing, transport and mobility and social relations, each of which, and in combination, can act positively as mediating factors for social exclusion.

A key element in the sustainability of rural communities generally is a broader vision of the regenerative nature of rural society. Development across Europe has, for too long, been narrowly defined in economic terms, while the social needs of people are relegated to a residual position, at best, or neglected entirely, at worst. This is catastrophic for people with dementia. People living in rural communities, experience life in economic terms certainly, but also in social and cultural terms. A vibrant social model that is place oriented and rights-based would enable people with dementia living in rural areas to fully realise their capabilities and latent potential, even when cognitive decline has taken hold. It would also take pressure off family carers who provide much of the day-to-day care and support of people with dementia living in rural areas.

**26 June: The Angela Project publishes its key findings in “Good Practice in Young Onset Dementia”**

The Angela Project was a three-year research study carried out by the universities of Bradford, Northampton, Surrey and University College London (UCL). It is the largest study of young onset dementia ever carried out in the UK, and was designed to look at how post-diagnostic support for people living with young onset dementia and the accuracy of diagnosis can be improved. Funding came from the Alzheimer’s Society, with Dementia UK and YoungDementia UK also partnering in the project.



During the study, views were gathered from professionals and over 230 people living with, or caring for, someone with young onset dementia. 500 sets of case notes were audited and the research team talked to commissioners and service providers to understand more about what helped and hindered them in providing young onset dementia services.

The survey also looked at good practice and needs met by good services, as well as examining the barriers and facilitators to good practice in post-diagnostic support for younger people.

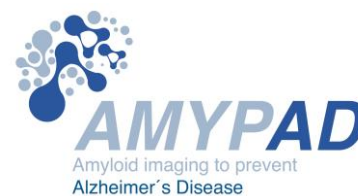
The findings of the study have been published in “Good Practice in Young Onset Dementia”. You can view the publication online or request hard copies, here:

<https://www.youngdementiauk.org/sites/default/files/TAP%20-%20Good%20Practice%20in%20YOD%20document%20FINAL.pdf>

**JOB OPPORTUNITIES**

**26 June: Clinical Trial Manager sought for AMYPAD project – temporary position**

Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) is a collaborative research initiative aiming to improve the understanding, diagnosis and management of Alzheimer’s disease (AD) through the use of  $\beta$ -amyloid PET imaging. At its VUmc site, the project seeks a maternity cover for a qualified Clinical Trial Manager to help ensure good conduct of the study across participating sites. The primary responsibility for the Clinical Trial Manager will be managing the study within the project consortium and in collaboration with AMYPAD’s industrial partners. They will be in charge of preparing sites for their local ethical and regulatory amendment submissions and liaising with the Clinical Research Organisation (CRO) for training sites and



resolving queries. Furthermore, they will serve as the main point of contact between researchers, academic sites, industrial partners, and the sponsor.

The position will be for 4 to 7 months (depending on contract hours) to cover Maternity leave period.

The desired start date is 1 August 2020. Interviews will take place in the week of 13 July. Applications close on 8 July 2020.

Find out more and apply:

<https://www.werkenbijvumc.nl/vacatures/clinical-trial-manager-for-a-european-alzheimer-study/>

**Contact Alzheimer Europe:**

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

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**AE CALENDAR**

Date	Meeting	AE representative
1 July	DataSavesLives webinar	Angela
1 July	COVID-19 Mental Health Support Stakeholder Network	Owen
7 July	Core Group meeting of the EU4Health campaign	Owen
7 July/10 July	European Working Group of People with Dementia (EWGPWD) meeting	Dianne and Ana
9 July	PARADIGM Patient Engagement Open Forum (PEOF)	Ana and Kate
15 July	MEP Alliance for Mental Health	Owen
16 July	Interim review meeting of VirtualBrainCloud project	Jean
21 July	International Alzheimer’s Disease Research Funders meeting	Jean
27-31 July	Alzheimer’s Association International Conference	Jean

**CONFERENCES**

Date	Meeting	Place
26-30 July	Alzheimer’s Association International Conference (AAIC), <a href="https://www.alz.org/">https://www.alz.org/</a>	Online
31 August-1 September	Conference “Dementia Care and Policies in extended Danube Region”, <a href="http://www.alzheimerbih.org">www.alzheimerbih.org</a>	Sarajevo, Bosnia & Herzegovina
2-5 October	The 14 <sup>th</sup> World Congress on controversies in neurology, <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a>	London, UK
20-22 October	30 <sup>th</sup> Alzheimer Europe Conference “Dementia in a changing world”	Virtual Conference
16-18 November	Second Krems Dementia Conference, <a href="http://www.donau-uni.ac.at/dementia-conference">www.donau-uni.ac.at/dementia-conference</a>	Krems, Austria
10-12 December	34 <sup>th</sup> International Conference of ADI "Hope in the age of dementia", <a href="https://adi2020.org/">https://adi2020.org/</a>	Singapore
9-14 March 2021	AD/PD 2021 – The 15 <sup>th</sup> International Conference on Alzheimer’s & Parkinson’s Diseases, <a href="http://lp.kenes.com/index.php/email/emailWebview">http://lp.kenes.com/index.php/email/emailWebview</a>	Barcelona, Spain
26-29 June 2021	Brain & Brain PET 2021, <a href="http://brain2021.scot/">http://brain2021.scot/</a>	Glasgow, UK
29 November - 1 December 2021	31 <sup>st</sup> Alzheimer Europe Conference	Bucharest, Romania
18-21 February 2021	12 <sup>th</sup> Panhellenic Conference of Alzheimer's Disease (PICAD) and the 4 <sup>th</sup> Mediterranean Conference on Neurodegenerative Diseases (MeCoND), <a href="http://www.alzheimer-conference.gr">www.alzheimer-conference.gr</a>	Thessaloniki, Greece

# 30<sup>th</sup> Alzheimer Europe Conference

## Dementia in a changing world

### Virtual Conference

### 20–22 October 2020

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