



**Alzheimer's Disease
International**

The global voice on dementia

July 2020
Volume 30, No. 2

Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.



ADI members respond to COVID-19

Since the beginning of 2020, the COVID-19 pandemic has upended and changed lives across the world as we know it. In response to the global health crisis, ADI wanted to use this issue of the

Global Perspective to bring attention to some of the innovative work and quick responses our members have taken to support people living with dementia across the world. Now more than ever, their work is imperative.

INSIDE Notes from ADI 2 • News 3-4 • Innovations from Members 5-6 • DAI 7 • ADI Webinars 8 • Webinars from Members 9
My Perspective 10 • Research and STRiDE Update 11 • Members and COVID-19 12



Alzheimer's Disease International

The global voice on dementia

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Send us your comments

If you have any comments about or items for the newsletter, please contact the Secretariat.

Want to contribute?

We welcome your contributions. Please get in touch to have your news and stories included in future issues.

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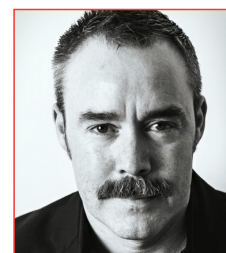
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Notes from ADI

“There has never been a better time to raise hope than now.”

This quote from ADI's Chief Executive, Paola Barbarino, in our new documentary film *'Hope in the Age of Dementia'* perfectly captures why now, during this global COVID-19 pandemic, we need hope, we need innovation, science, research, advocacy, support and care - to give us the energy, the momentum and the courage to ensure that dementia is not only retained as a global priority during the crisis but continues to be one as the world looks for a treatment and beyond.



Chris Lynch, Deputy Chief Executive of ADI

Age is the biggest risk factor for both dementia and for COVID-19 and we know, through **our series of open and member webinars** over the last 3 months, that people with dementia and their families are being disproportionately affected by the disease. Face to face support and services have been discontinued, the diagnosis pathway interrupted, research and clinical trials impacted, triage decision making called into question, and of course, people living with dementia and their carers are facing increased challenges at home, in the community, in care homes and hospital settings.

During the pandemic, as we have worked closely with our members and partners globally to respond, we re-scheduled a number of key events, publications and launches, including our global conference. Over the next month we feel the time is now right to introduce some of these, all now with added perspective around COVID-19 and all with added poignancy and urgency in relation to the preparedness of healthcare systems around the world.

Our report *'From plan to impact III: Maintaining dementia as a priority in unprecedented times'* was launched on 25 June with a virtual side event, replacing our planned World Health Assembly event in Geneva. The title says it all and the report findings reveal, that despite having a **Global action plan on dementia**, we must now re-double our advocacy efforts to ensure that governments do not waver from their commitments or re-prioritise dementia as a consequence of the pandemic.

On 30 June we were delighted to launch our new documentary film *'Hope in the Age of Dementia'*, showcasing some of the incredible and innovative work that is taking place, from research and drug development, to dementia friendly training for paramedics and emergency responders. Truly inspiring activity!

In the near future, we will also launch a key report with our partners Global Coalition on Aging and Lien Foundation – *'Dementia Innovation Readiness Index 2020: 30 Global Cities'*. This report, based on over 1,000 hours of research and interviews, looks at city level preparedness for dementia and how these urban centres are responding to strategy and commitment, diagnosis, access to care, community support and the business environment. The importance of innovation and preparedness has been thrown into sharp relief with COVID-19 and an extended foreword to the report sums up succinctly the importance of planning and of ***maintaining dementia as a priority in unprecedented times.***

News

ADI and ITN Productions launch 'Hope in the Age of Dementia'



ADI Chief Executive Paola Barbarino speaking with news anchor Sharon Thomas about the importance of hope in dementia research.

The end of June saw the highly anticipated release of **'Hope in the Age of Dementia'**, a collaborative news-style programme between ADI and ITN Productions. ADI and ITN previously worked together for 2018's documentary **'Every 3 Seconds'**, which looked to raise awareness around the global impact of dementia.

'Hope in the Age of Dementia' features a wide range of leading experts from the fields of neuroscience and drug discovery, to research and health care innovation, speaking about the latest innovations in dementia care, research and technology. The news-style programme also has a special focus on advancing and accelerating solutions for Alzheimer's disease around the world.

Elizabeth Fisher-Robins, Head of ITN Productions' Industry News, said: *"We're really excited by the opportunity to work with ADI to create an inspirational programme that showcases the amazing work being done to advance the dementia landscape. We hope the programme promotes a clearer understanding of the challenges faced and addresses how stigma and social exclusion are still major barriers for people living with Alzheimer's disease and other dementias."*

Dementia currently affects more than 50 million people worldwide, with this number projected to more than triple by 2050. While there is currently no cure available for Alzheimer's disease and other types of dementia, 'Hope in the Age of Dementia' explores the latest new ideas, potential therapies and other innovations around care, diagnostic, support and more.

ADI Chief Executive Paola Barbarino said: *"Now more than ever we need hope for those who live with dementia and their families. The global pandemic in 2020 has shown us how vulnerable our constituencies are and how unprepared governments are to help them cope with not just emergencies but daily life."*

Learn more about and watch **'Hope in the Age of Dementia'**.

Launching soon: Dementia Innovation Readiness Index 2020: 30 Global Cities



Dementia Innovation Readiness Index 2020: 30 Global Cities will launch later this year.

ADI has been working with the Global Coalition on Aging (GCOA) and the Lien Foundation on a new report 'Dementia Innovation Readiness Index 2020: 30 Global Cities'. The report, launching soon, evaluates dementia innovation readiness in 30 cities around the world—from Singapore to London to Buenos Aires. The Index is the third evaluation of dementia innovation readiness by GCOA and ADI and the first of its kind to focus on the unique opportunities and challenges of dementia innovation at the city level.

Chris Lynch, ADI's Deputy CEO and Policy, Communications and Publications Director, who led on ADI's side, said: *"Cities - which are home to more than half of people aged over 60 worldwide - are crucial in preparing for the innovations in treatment, risk reduction, care, and many of things that are decisive in people's dementia prognoses."*

Further details on the launch event to follow.

News

ADI releases 'From Plan To Impact III' report

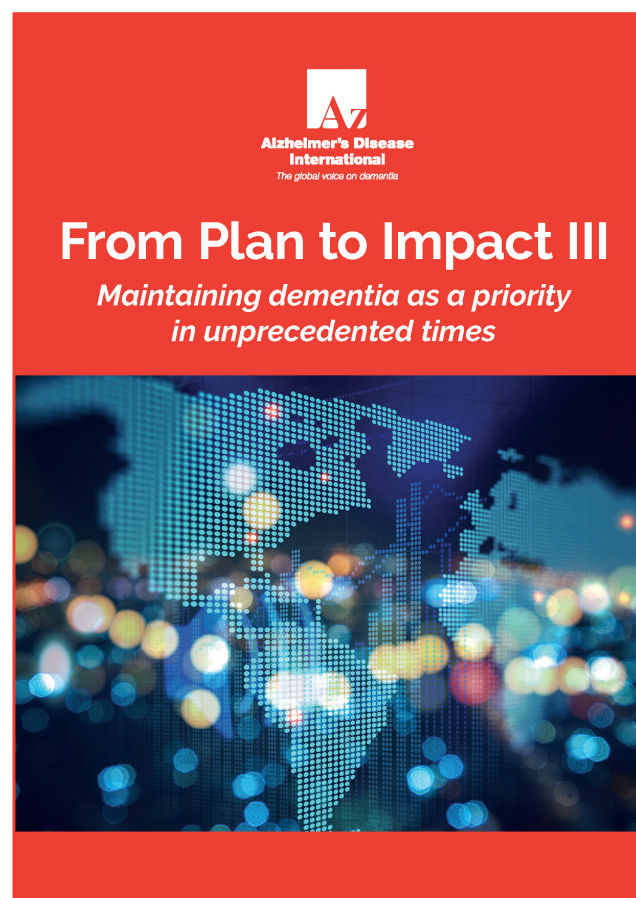
On 25 June, ADI launched the report **'From Plan to Impact III: Maintaining dementia as a priority in unprecedented times'**, which examines the World Health Organization's (WHO) progress on the **Global action plan on dementia**.

In response to the global health pandemic, ADI made the decision to coincide the launching of the report with a Virtual Side Event. The side event consisted of a 75-minute session with expert panellists from the WHO, Dementia Alliance International (DAI), the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) and governments, who discussed the additional challenges posed by COVID-19 and how progress towards the Global action plan can be maintained during unprecedented times.

During the virtual launch event, Dévora Kestel, WHO's Director of Mental Health & Substance Abuse, said: *"Three years into the implementation of the WHO global action plan, we can affirm that great progress has been made, but more work is needed. Collecting details and disaggregated data on dementia is essential for planning and delivering comprehensive services for people with dementia. We will continue to work with NGOs and Member States on this."*

ADI would like to give a special thanks to **IFPMA** for their support in the launch of our third 'From plan to impact' report.

Learn more about the report and watch the launch event [here](#).



Germany launches a national dementia strategy

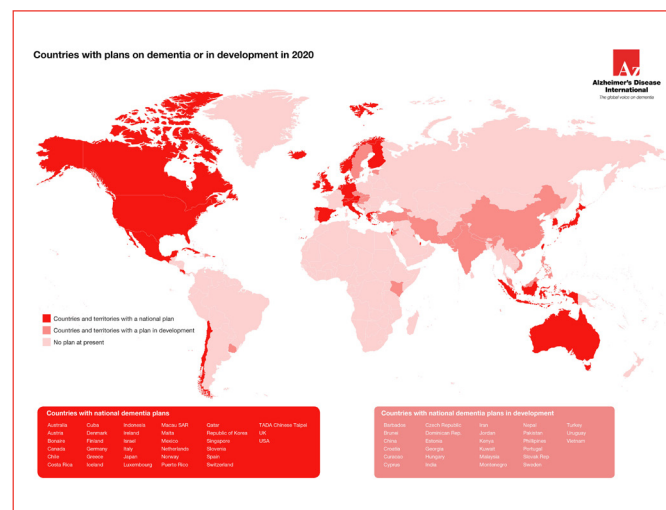
On 1 July, the German Government announced that a national dementia strategy had been officially adopted. The strategy was developed by the Federal Ministry for Family, Seniors, Women and Youth, the German Alzheimer Society or Deutsche Alzheimer Gesellschaft (DAIzG) and the Federal Ministry of Health, among other stakeholders from states and municipalities, healthcare associations and the scientific community. The plan is the 32nd to be adopted globally and will be implemented from September.

The Nationale Demenzstrategie will be a crucial support for the German population affected by dementia now and in the future. Around 1.6 million people are currently living with dementia in Germany, according to Deutsche Alzheimer Gesellschaft (DAIzG).

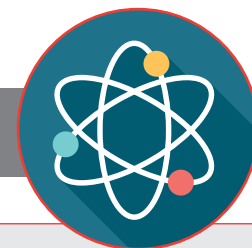
Sabine Jansen, Executive Director of ADI's member in Germany DAIzG said: *"We are happy that a National Dementia Strategy was also adopted in Germany last week. 1.6 million people with dementia live in Germany and also their families are affected by the disease. So,*

we need the combined efforts of all stakeholders in the field working together to improve the situation for them."

Read more about Germany's national plan [here](#).



Countries with plans on dementia or in development in 2020.



■ Innovations from our members

Since the start of the COVID-19 outbreak, organisations and associations around the world have had to find new ways of working by adapting and reinventing support services to align with social distancing measures. For ADI's members, this has been crucial. We asked some of our members about the innovative ways they have had to adapt, either in reinventing their existing services or responding to new problems caused by the pandemic itself.

Chinese Taipei – TADA

"TADA released the first edition of the COVID-19 epidemic prevention guide for professionals on 21 February 2020. It reminds professionals that people with dementia may have difficulties complying with some of the epidemic prevention.

On 25 February, TADA issued a press release to remind the public to actively help people with dementia to cooperate with the epidemic prevention measures and not to blame them if they were unable to comply. However, on 7 April, a person with dementia was sent to the police station because he failed to wear a mask on a public bus. In response, TADA released another press release to emphasise how to support and encourage people with dementia to wear facial masks.

TADA stressed that if people with dementia are able to show their disability certificate or certificate of diagnosis, they should have an exemption from penalty.

We are proud to say that this suggestion ended up being supported by the government."

Netherlands/Indonesia – Alzheimer Indonesia Netherlands

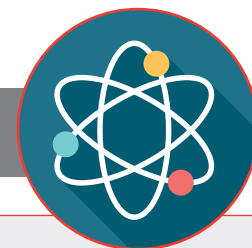
"From early on in the pandemic, we have been doing twice-weekly online activities which cover risk reduction, meaningful engagement and education. Our first step was collaborating with certain key stakeholders, such as voluntary instructors, musicians and supporters. We then looked at our participants, which covers people with dementia, caregivers, students, diaspora, health workers, private sector organisations and the public. Two of such online activities have included 'Inter-generational Karaoke & Singalong Sessions' and online colouring sessions.

The Inter-generational Karaoke & Singalong Online Sessions have been very cheerful and make everyone feel good. Younger generations play nostalgic songs, some of which are requested ahead of time, with their band. Sometimes they are live, sometimes they are pre-recorded. We open the sessions about music as a therapy and participants are given a list of songs to be played so they can follow along, as well as give carers the option to explain what to expect. To make it more fun, we have had sessions where participants dress up in costumes or vintage outfits.

The Online Colouring Sessions are relaxing and cosy for participants! Sessions begin with how colouring is a good therapeutic approach and are held with soft background music so participants can chat while colouring. One participant who is living with dementia, Oma Lalita, has continued with her colouring activities, completing more than 42 pictures and still going! The family has found out from these sessions that she likes the online activity."

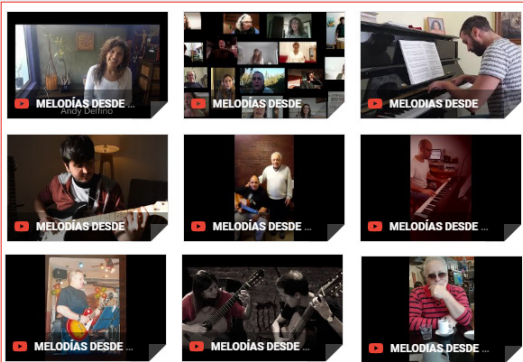


Oma Lalita shares some of her drawing from ALZI's online colouring sections.



Innovations from our members

Argentina – Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (A.L.M.A.)



Musicians record music and say hello for people connected to A.L.M.A.

“Our website, used for some years to publish news and reports, has exploded with online and virtual resources and services. We added a new section, **‘Cuarentena’** to bring activities to the homes of our participants and families when lockdown began.

We hold ‘Talleres de estimulación’ group sessions to stimulate brain functions for people living with dementia. They help with primary prevention, ‘memory activation’ and social gathering. Because of COVID-19, this had to change. Our psychologists, therapists, volunteers and staff teamed up to prepare short videos of 2-10 minutes with the tasks and exercises our group members are used to doing during face-to-face meetings. After we had an initial 53 videos approved, we began sharing one video per day by email or WhatsApp and eventually, on our social media networks for everyone to enjoy.

It has also not been possible to hold our ‘Café con A.L.M.A.’ in a real pub, bar or coffee house. Because of that, we have been asking musicians and performers to record a song or a piece of music and say ‘hello!’ to people connected with our Association. We began publishing these videos in a new section of our website, **Melodías desde el A.L.M.A.**”

Madagascar – Madagascar Alzheimer Masoandro Mody (ONG)

“In response to COVID-19, and among other actions, Madagascar Alzheimer’s association has chosen to disseminate messages and advice through short radio programmes, accessible to a wide audience. As a result, we received calls from families of people living with dementia, whose daily lives were significantly disrupted by the constraints of the lockdown. We were thus able to look for personalised advice and solutions together by phone. ***Being able to provide additional support to persons living with dementia and their families in these difficult times is crucial.***”

Iran – Iran Dementia & Alzheimer’s Association (IDAA)

“During the COVID-19 pandemic, Iran Dementia & Alzheimer’s Association raised awareness amongst its members by translating **ADI’s & WHO’s messages** into Farsi, producing videos and posting them on **IDAA’s website**, Instagram and the Telegram channel.

At the same time, a WhatsApp group was formed for 60 clients of the day centre to accommodate the needs of the carers to work with people with dementia, as well as maintaining care at home. IDAA’s initiation resulted in a dementia WhatsApp group formed by the Welfare Organization for its senior day centres staff across the country. The members of this group now have access to IDAA’s dementia posts, which they use for their online services.”



A graphic around COVID-19 advice for IDAA’s website and social channels.

■ Update from Dementia Alliance International (DAI)

Is there a positive side to the pandemic for people living with dementia?

From Kate Swaffer, Chair, CEO & co-founder

The novel coronavirus has exposed and highlighted more acutely than ever before the many breaches of human and legal rights faced by people with dementia and their families, which, sadly they have faced long before the pandemic.



Whilst States have the responsibilities under international law to respect and ensure the human rights of people with disabilities on an equal basis with others, which therefore includes the 50 million people currently living with dementia, society at large is also responsible. The vulnerabilities highlighted during this pandemic are a result of the structural discrimination, discriminatory legislation, and include practices of exclusion and violence both in communities and in health and social care settings. These vulnerabilities have increased during this pandemic.

During COVID-19, many people with disabilities and older people have been confined to their homes and will remain restricted for weeks and months after the rest of the community emerges from social isolation. People living in nursing homes have been isolated from their families due to further restrictions, and tragically, many have died alone. These lockdowns have resulted in strict limits on visits to all aged care residential facilities and have resulted in the suspension of many activities and therapies (for example, music or pet therapy), which would normally take the form of external visits, as well as limits on excursions. The increased experience of restraint has been intense, and the degree of isolation has placed additional stress upon individuals living in these institutions. For some, even having family and friends 'visit' through window visits has been extremely difficult, due to vision impairment and other conditions such as dementia. The people living in these institutions, many of whom who are frail and elderly, many also living with dementia and other co morbidities, have been further distressed because of the isolation, sometimes not fully understanding why they are not seeing family and friends.

People with dementia who live at home, and especially those who live alone, have been even more isolated than they were before the pandemic. The restrictions have negatively affected their access to food and other supplies as well as their access to socialisation. Many have also reported feeling as if their cognitive disabilities have increased, while, language and other communication disabilities have worsened greatly. These are just some of the additional challenges we face. Many people living with dementia, and those of us in DAI, used Zoom long before the pandemic. Many others are now using it and are recognising just how much fatigue online meetings can cause. Zoom does not make up for face to face contact. Suddenly it is everyone's problem, so people without dementia are talking about it!

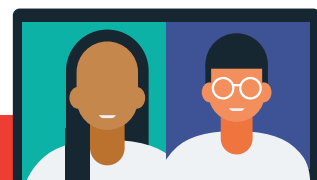
In saying that, the DAI **peer to peer support groups** which since the pandemic we host almost every day of the week for members around the globe, along with our cafes and **webinars**, have been a life saver to many of our **members** and their families.

Numerous international statements, as well as the WHO Coronavirus guidelines, have recognised from the outset of the pandemic that there are additional considerations for people with disabilities and older people, which go well beyond those applying to the general population. All marginalised groups, and people in low- and middle-income countries have also been worse affected.

My hope now is that the inequities and breaches of human rights, the stigma and discrimination, and the isolation people with dementia face on a daily basis, from the time of diagnosis, and that we have never had access to Universal Health Coverage, has now been exposed to the rest of the world. The pandemic may finally be the catalyst for things to actually change, and not just spoken about by the advocacy organisations including ADI and DAI. We must not be forgotten, and must not be left behind, and hopefully this may be the positive side to the pandemic.

For more information about DAI, please visit the [DAI website](#).





ADI Webinars

Since the beginning of March, ADI has worked to provide webinars for our members and the general public around dementia and the COVID-19 crisis. These webinars have focused on a wide range of subjects, including maintaining mental health support, how to support people living with dementia, future gazing and more. Our latest webinar, 'Innovating for the new normal: Experiences from around the world', took place on 15 July. Watch the recording [here](#).

Supporting people with dementia during COVID-19: experience and advice from around the world



On 22 April, ADI held its first public webinar addressing the vital issue of supporting people with dementia during the coronavirus pandemic. 'Supporting people with dementia during COVID-19: experience and advice from around the world' heard from several key speakers from some of ADI's member associations, who shared their experiences and processes for continuing support services for people with dementia and carers during the coronavirus crisis.

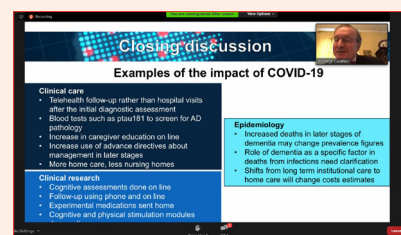
From the webinar:

Panelist Florence Mueni, based in Kenya and a carer for her mother with dementia, said: *"It is not easy being the caregiver for someone with Alzheimer's. I have to be strong for her – I am strong for her. I just feel a great sense of responsibility: everything that I do or decision I make at this time affects her."*

Watch the webinar [here](#).

Future gazing: COVID-19 and dementia

The second 90-minute webinar, 'Future gazing: COVID-19 and dementia', was held on 6 May. The session looked to address the future of potential outcomes of the COVID-19 crisis for people living with dementia, their families and carers. Subjects discussed included the impact of COVID-19 on dementia diagnosis and post-diagnostic support, disruption to clinical trials, political de-prioritisation of dementia and more.



Dr Serge Gauthier, member of ADI's Medical and Scientific Panel (MSAP), closes 'Future gazing: COVID-19 and dementia' with a discussion on the impact of COVID-19.

From the webinar:

Panelist David Jefferys, Chair of the International Federation of Pharmaceutical Manufacturer & Association (IFPMA)'s Regulatory & Scientific Committee said: *"I predict there will be more home care and less nursing home care in the later stages of dementia. This will shift costs and will mean more education for caregivers."*

Watch the webinar [here](#).

The hidden casualties of COVID-19: Revealing the emergency in care homes and the lessons learnt in day care

The third webinar addressed a sensitive topic that ADI has been closely following since the beginning of the pandemic. Held on 3 June, 'The hidden casualties of COVID-19: revealing the emergency in care homes and the lessons learnt from day care' hosted a widely varied panel who discussed how the COVID-19 crisis has brought to light some troubling issues surrounding ageism and policies on long-term care.

Why do we need to know about deaths of care home residents linked to COVID-19?

- In many countries, care homes not included in initial responses to COVID-19.
- Focus was on stopping transmission in the community and boosting hospital capacity, but situation was different in countries in Asia with SARS and MERS experience: strong Infection Prevention and Control systems in care homes.
- No data on number of people infected (and deceased) in care homes: risk that vital resources needed to tackle infections in care homes are not made available



Adelina Comas-Herrera speaks about care home resident mortality linked to COVID-19.

From the webinar:

Panelist Adelina Comas-Herrera from the Care Policy and Evaluation Centre at the London School of Economics and Political Science (LSE) and one of the co-founders of LTC-Covid said: *"It took quite a long time to have any data on what is happening in care homes in relation to COVID-19. Until April, we did not have any data but we had worrying reports from Italy, Spain and other countries about what was happening."*

Watch the webinar [here](#).



Webinars from our members

Mexico – Federación Mexicana de Alzheimer, A.C. (FEDMA)

“For FEDMA, everything that has been developed virtually is here to stay. Of our 22 associations that have the resources, 17 were able to quickly adapt to and create virtual resources to continue supporting people living with dementia and their families.

This has included recording physical therapy routines, cognitive stimulation exercises and interviews with specialists. We have also created a series of 21 videos, with some members of **Dementia Friends**, around COVID-19 and how to support and take care of yourself. **Tools like these have allowed us to reach more people than ever before and we hope this allows us to reach the more marginalised and poor areas where dementia has a presence.**”

Armenia – Alzheimer’s Care Armenia (ACA)

“Undeniably, this is a time of challenge and uncertainty in the shadow of COVID-19 which has profoundly impacted all of our lives.

To provide support, Alzheimer’s Care Armenia hosted a webinar for healthcare professionals in Armenia titled ‘Elder Abuse and COVID-19: Increased Vulnerabilities’. We discussed heightened risk factors of elder abuse - including social isolation and lack of support, along with steps professionals can take to mitigate these risks. Alzheimer’s Care Armenia also partnered with the Armenian American Mental Health Association and developed a series of webinars for healthcare professionals in Armenia. **Due to increasing need, ACA is now developing an elder abuse and dementia training program for healthcare professionals which will launch in early August.**”

ACA
ALZHEIMER'S CARE ARMENIA

**Elder Abuse and COVID-19
Increased Vulnerabilities**

LIVE Presentation by Gerontologists

Dr. Jane L. Mahakian
Dr. Anna Arabyan

June 3rd 9:00am Pacific Time
20:00pm Yerevan Time

ZOOM: <https://bit.ly/2WKLw1Y>
Meeting ID: 817 3166 6276 Password: 451469

Dr. Jane Mahakian is Gerontologist who has worked and advocated for 30 plus years in the "realm of forgetfulness." In 1997, she founded Aging Matters, Inc., a leading care management and consultation firm based in Orange County California that specializes in older adults with dementia and their families. She was previously an adjunct faculty member at the University of California San Francisco Institute for Health & Aging. Dr. Mahakian is the President of Alzheimer's Care Armenia, a 501(c) 3 in California and a registered NGO in Armenia whose mission is to create sustainable programs and services for people with memory loss and their families in Armenia. She serves as the Vice-President of the Alzheimer's Association of Armenia.

Dr. Anna Arabyan, Adjunct Professor at the USC School of Gerontology was born and raised in Los Angeles, California. She went to college at the University of Southern California (USC) where she studied gerontology. She went on to receive her Doctorate of Pharmacy degree from USC. Dr. Arabyan has a particular interest in Women's hormonal health and palliative care. She now serves as a faculty member at USC's Leonard Davis School of Gerontology where she teaches courses on health, aging and pain management. Dr. Arabyan serves on the Board of Directors of Alzheimer's Care Armenia.

A online promotional flyer advertising ACA's 'Elder Abuse and COVID-19: Increased Vulnerabilities' webinar.

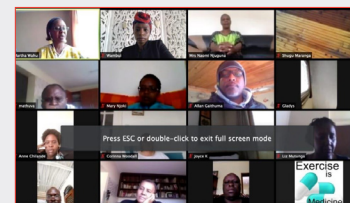
Kenya – Alzheimer’s & Dementia Organisation Kenya (ADOK)

“After the first case of COVID-19 was announced in Kenya, we were not able to hold monthly support group meetings due to the lockdown in the country.

Instead, we had to hold fortnightly virtual meetings to support carers of people living with dementia.

During those meetings, we have tackled topics such as: self-care through mental and physical exercise of caregivers, COVID-19 and dementia, family dynamics, the use of art and music therapy, nutrition and the stories on dementia from Scotland Pulmonary Health and COVID-19.

We have been able to reach more people when conducting virtual meetings. People are joining the webinars from all over Kenya and the world, such as the US, Scotland, South Africa and the UK to mention a few. The feedback we are receiving is that the topics covered have empowered carers to cope during this pandemic and as they care for loved ones, they are remembering to care for themselves too.”



ADOK holds one of its virtual meetings for carers.

United Arab Emirates – 4get-me-not

“When the outbreak of COVID-19 began, we were concerned about the stress and wellbeing of seniors. Even those who were not going out much before were having their routines affected. We decided that webinars would be the most effective way of staying connected.

While some of our older members are not tech-savvy, most were very eager to learn how platforms like Zoom and ToTok work in our first masterclass. Shortly after that, we began organising webinar activities such as ‘trips down memory lane’. Members were asked to tell a story from their life to an assigned volunteer. Not only did it allow them to speak about themselves but it also opened up the opportunity to make new friends.

Since we started webinars, we’ve done sessions on cooking activities, learning basic Arabic and talking about what our members would like to do once lockdown is done.”

My week living with dementia in a nursing home

'Lockdown has highlighted how it was before the pandemic'

My name is Lyn Rogers and I have been a permanent resident in a nursing home in the state of Victoria in Australia for over two years.

I have a diagnosis of dementia and live with other comorbidities, like most people over the age of 65. I moved to the facility from Queensland, therefore most of my family and friends are not living nearby, and although I use a crutch to walk, it is essential I maintain my regular exercise routine.

For many weeks during this pandemic, I was denied the right to walk, and had to write a formal letter of complaint, which was taken to management, the owners of the facility, and eventually ended up with the Minister of Health. Hence, although the week I have highlighted below says I have been walking every day, this was not the case for a long time during lockdown!

Whilst it is not my preferred place of residence, as I would prefer to live independently in my own home, I felt it was an important decision to make due to living alone, and not wanting to place the burden on my family as my dementia or other health issues progress. This is how life is for me and other residents, since the Coronavirus pandemic. Since the Coronavirus pandemic, I have been denied the right to maintain my regular exercise, which is walking daily in the Botanical Gardens nearby. Here is an example of my life in a nursing home during COVID-19.

Monday

It is Monday, and another week in lockdown begins. As usual, breakfast was at 7.30am. Straight after breakfast, and most days now, well, since I took my 'case' to the management, and the Minister, and am allowed to go walking again, I go walking daily in the Botanical Gardens nearby. I then have my regular physiotherapy for 15 minutes, and after that, join my online peer to peer support group, which is run by **Dementia Alliance International**. Engaging with my peers, who all live with dementia, has empowered me to live more positively, and to speak up for my human rights. On Mondays, we also have 'whiteboard games' which I love, and which are better than sitting staring out of the window.

Tuesday

Well, I got out of bed again today, and to be very honest, Tuesday it is no different to Monday. We

have no activities person on Tuesdays, so at times, residents are left sitting at the breakfast table until almost lunch time, which is infuriating for me to see. My worry, is although this is not happening to me today (or this week), will it be what happens when I can no longer advocate for myself? Before the pandemic we had an activities coordinator three days a week, since the coronavirus, it is four days a week. This is hardly enough, and I worry it will be dropped back to three days a week after the pandemic.

Wednesday

It is Wednesday, which is a better day than usual. Like every other day, I now walk in the Gardens, and we have singing and music after lunch, and since the coronavirus, we have another extra happy hour... Woo hoo! Yet again, a happy hour but with limits. 2 glasses of wine are all we can have, which is of course, a healthy limit, but cask wine is not very expensive, so it seems a bit mean! Carpet bowls is also on Wednesdays, but is not always a meaningful activity, as all I can do is score, and it highlights the other residents' frustrations!

Thursday

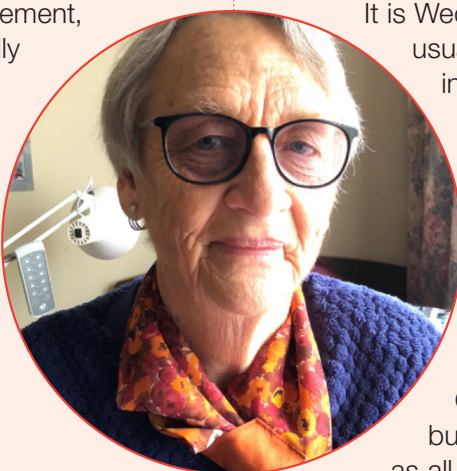
Thursday means it is one more day to get to the weekend. Which sadly is not anything to be excited about as it means the isolation of the week, is intensified as activities are switched off on weekends! Unfortunately, this is not an exaggeration! I do my washing, go for my walk, and watch the increase in the distress of the other residents - which are in fact, normal human responses' - and they are even more isolated and lonely than usual.

Friday

Fridays continue to be similar to all other days; breakfast, a walk in the gardens, physio, and another happy hour with a quiz, not dissimilar to reminiscing, but which I enjoy. I also have another peer to peer support group with DAI, which helps me keep sane. All days include dinner at 5pm, and supper at 7pm - if I was not living in a nursing home, I'd most likely eat dinner after 7pm, so this is a childlike timeline for adults!!!

And then I have to face dreaded Weekends!!!

Well, apart from an extra walk, and listening to more audio books, most of my weekends are very boring, and this one is no different!





Research and STRiDE Update

Thoughts on the impact of COVID-19 and dementia from ADI's Serge Gauthier

During the first wave of the COVID-19 pandemic, many countries such as Canada initiated task forces to answer the immediate needs of people living with dementia, such as access to intensive care if needed and they wanted it, regular contact with their health care practitioners by phone, email or Zoom.

Carers needs also increased because of social isolation. One surprise was the high death rate for older persons living in long-term care facilities, many of them having dementia, which may have been an important comorbidity to the COVID-19 infection. Lessons were learned and will improve some aspects of dementia management, taking into account both the needs of people living with dementia and their carers.

During the pandemic clinical research was not stopped but has had to adapt to social isolation: research participants have been called regularly and interviewed with new COVID-specific stress scales, and tested with neurocognitive tests validated for use using phone and/or tablet. Data already collected has been analysed and led to **the important finding** that high plasma levels of ptau181 in persons with MCI or early dementia indicate that they have both amyloid and tau pathology in their brain. This plasma biomarker may speed up enrolment in upcoming clinical trials with anti-amyloid and/or anti tau drugs, and future use of these drugs if found to be safe and effective. Watch out for new data on neuroinflammation as a triggering or accelerating factor in the brain where amyloid is already present.

Let's not give up hope for better diagnosis and management of Alzheimer's disease at all its stages!



Dr Serge Gauthier, member of ADI's Medical and Scientific Panel (MSAP).

STRiDE Update

Having reported in February's **Global Perspective** update that STRiDE fieldwork was in full swing, we found the very next month that the COVID-19 pandemic brought with it a change of plans. STRiDE has had to 'pause' all field work due to the pandemic, but country teams continue with data analysis, situational analysis desk reviews and research that can be done without face to face contact. Country teams are also continuing ongoing collaboration with national advisory groups and exploring how they may continue research interviews virtually, either by computer or telephone.

Each STRiDE country team also contributed country reports on the impact of COVID-19 on people living with dementia – specifically around long-term care – to the LTC-Covid website, which can be found **here**. STRiDE has also added two new work packages to the project: Work Package 11 will concentrate on collaborations developed and nurtured throughout the project and Work Package 12 will focus on COVID-19 research, responses, and lessons learned across the countries.



A special thanks to our funders & supporters

ADI would like to extend a special thanks to Biogen, Lundbeck, Roche, The Mary Oakley Foundation and all our supporters who have responded so generously to our emergency appeal. During these sometimes fraught periods, ADI deeply appreciates your support.



More inspiration from our members

The novel coronavirus has impacted every single country around the world. For some of us, we are familiar what happens when there is an outbreak of disease and we have the foundations to respond. For others, COVID-19 has presented a steep learning curve and we have found ourselves coming up with new ways to respond. We wanted to know how our members have been doing, in whatever way that may be.

New Zealand – Alzheimers New Zealand

“‘Together but apart’ has been our motto here – finding innovative ways to help, while keeping everyone safe and supported. But the Covid-19 lockdown has also highlighted the vulnerability of older New Zealanders, meaning our focus on getting the NZ Dementia Action Plan across the line is sharper than ever.”

India – Alzheimer’s & Related Disorders Society of India (ARDSI), Calcutta Chapter

“By nature and as dementia champions, we are dedicated to creativity and never waste a crisis. With COVID amongst us we need to be prepared to take on risk and deliver safe, secure care when, where, and how our dementia clients and their families want it. Until then we continue on our reassurance work!”

Argentina – Asociación Lucha contra el Mal de Alzheimer (A.L.M.A.)



A live group video session for people living with dementia in Argentina.

“We have recently started with telemedicine in the form of virtual neurological and psychiatric consultations. We are also currently in the process to implementing remote neurocognitive evaluations. Additionally, we’ve also began launching live group sessions for people who are living with dementia in Argentina. Doing all this work we found a way to improve the inside of our Association, knowing each other better, reaching more and more people, being close to them.”

El Salvador – Asociacion de Familiares Alzheimer de El Salvador

“Unfortunately, the location where our office is has been affected by COVID-19 and we cannot go there anymore. So, we’ve been responding through chat and video calls to help meet the needs of people. We’ve also been utilising the different useful webinars from **Alzheimer Iberoamérica** and affiliated organisations for our carers, which has been very helpful.”

Members of 4get-me-not, featured on page 9, with gift baskets and cakes sent from the association.

