

# Benefits of ADI membership



**Alzheimer's Disease  
International**

*The global voice on dementia*



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# Benefits of ADI membership

### A Global Membership Organisation

- A unique global network of 102 Alzheimer and dementia associations
- Be a stakeholder in our governance
- Newsletters, monthly updates, website



### International Events

- A global conference every 2 years
- Regional conferences & Member meetings
- Alzheimer Universities
- Regular webinars & online events
- World Alzheimer's Month - a global annual campaign



### A global voice on dementia

- International network with strong connections with WHO, G20 and other multilateral organisations
- Global influence - giving our members a voice on the global scene
- Renowned publications



### Dementia Research

- Involvement in international research projects
- Access to information around research projects on best practice care interventions for people affected by dementia
- Advising on patient experience in clinical trials
- Promoting the voice/experience of LMICs



## Engage with our global network now!



## ADI: A Global Membership Organisation

### Networking and Support

By joining ADI, you will become a part of a unique global network of 102 Alzheimer and dementia associations and gain support from the ADI team, based at sites in the United Kingdom, France and Indonesia. DY Suharya, located in Jakarta, is the Regional Director of the Asia Pacific Regional Office, focussing on capacity building, advocacy and outreach for the 20 member associations in the 4 sub-regions.

*“There is a real ‘ADI family’ culture of members helping other members in the Asia Pacific region - recent examples include TADA taking the initiative to send out 20,000 masks to a few LMICs during the COVID-19 pandemic, or Dementia Australia and Alzheimer NZ representatives supporting Tonga in organising their first ever dementia friendly communities workshop (funded by Asian Development Bank).”* **DY Suharya**

We work with a network of partners including Dementia Alliance International, as well as with NCD Alliance, King’s College London’s Global Observatory on Ageing and Dementia Care, Swedish Care International, the Global Brain Health Institute (GBHI), Alzheimer Europe and Alzheimer Iberoamerica. ADI is also a partner of the STRiDE project (Strengthening responses to dementia in developing countries), led by the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE).

### Governance and direction

As a member of ADI, you are a stakeholder in our governance: ADI has a Council made up of representatives from each full member association, which meets once a year - either online or during our global conference. The Council elects a Board of people from around the world, led by our Chair, Glenn Rees. Our

President is Princess Yasmin Aga Khan. Members can nominate people for Board and Committee positions.

ADI’s strategy is shaped by feedback from member consultations on the Strategic Plan as well as member surveys every 2 years. You can find our latest Strategic Plan 2019-2022 [here](#).

### Communications

- Regular email communications from ADI’s Membership Manager. If you are not receiving these emails, please notify the ADI team so we can add you to the right mailing lists.
- **Triannual Global Perspective newsletter** highlighting best practice and advances in care and scientific research.
- **Monthly Updates (e-newsletters)** sharing member activities and other news. Please send us your contributions (stories, pictures, videos, etc.)
- [ADI Website](#) (our new website will be available by the end of this year) & [Intranet /ADI blog](#)
- **Social media accounts:** We encourage our members to share best practice and exchange information as much as possible.

### Find us on social



**Twitter** @AlzDisInt



**Facebook** facebook.com/alzheimersdiseaseinternational



**LinkedIn** linkedin.com/company/alzdisint/



**Instagram** instagram.com/alzdisint



**Youtube** youtube.com/user/alzdisint



**Whatsapp/WeChat**

Join our regional member groups on WhatsApp

## ADI Events



### International Conference

We hold an international conference every two years, working with different member associations around the world. The conference is a unique opportunity to bring together everyone with an interest in dementia - staff and volunteers of Alzheimer associations, people living with dementia, family members, clinicians, care professionals and scientists - to share and learn from one another.

**Each member organisation benefits from one free registration.**

We also organise specific workshops for ADI members for further training during the conference: Fundraising, World Alzheimer's Month, Advocacy etc. Members are encouraged to share their experiences/success stories during these sessions.

Depending on the venue, members can also usually apply for a free tabletop stand at the conference. This is a wonderful opportunity for members to showcase the work they are doing to people from around the world.

### Regional Conferences & Member Meetings

During the years in which we do not hold an international conference, ADI organises regional member meetings and participates in regional conferences across the world in cooperation with local associations and sometimes takes the opportunity to coincide with WHO meetings.

### Alzheimer Universities

The Alzheimer University (AU) is a series of workshops for national Alzheimer association staff and volunteers to help them strengthen their associations. The aim of the AU is to give participants the tools to identify their association's aims, provide information, raise money and awareness, effectively govern their association and influence public policy.

**ADI financially supports invited participants to attend the Alzheimer University programmes and provides ongoing support after the course.**

An annual programme for emerging associations sees representatives from new and developing associations meeting to learn and discuss the best ways to establish their association. *"The AU made me realise that there is nothing more motivating than having clearly stated direction and measurable goals."* **Nilanjana Maulik, India.** These workshops are often led by representatives of developed Alzheimer associations.

Various Alzheimer University programmes also take place each year for member associations of various sizes and stages of development. These programmes deal with more advanced organisational issues and have a particular focus on one area, for example fundraising or advocacy. The Advocacy and Public Policy AU is strongly focussed on improving influence and working with national governments in the delivery of national plans and the WHO Global action plan.

We have also started to run virtual Alzheimer Universities.



## Regular webinars & online events

ADI organises regular **Member Update Webinars and Briefings** in English and Spanish (possibly French in the future) via Zoom to update members on our latest developments. The sessions are an excellent opportunity to engage with the ADI team and connect with the wider ADI community. Please contact Laura Dabas for recording links.

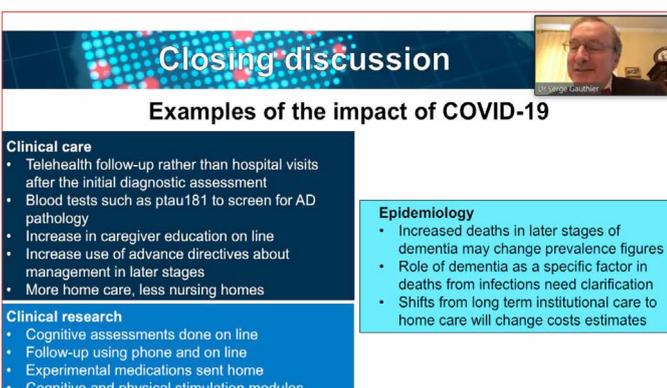
*“Thank you for this extraordinary experience this morning with your global webinar, which was so well organized, by the way. It reminded me of the importance of ADI and its role in empowering a worldwide network.”* **Peter Braun, USA**

We have also delivered a global webinar series on dementia research and clinical trials, titled **‘Let’s Talk About Dementia Research’**, as well as webinars in collaboration with [WHO](#) and [DAI](#), all open to the public.

**Members can apply for a bursary to print their own materials for World Alzheimer’s Month.**

Working closely with experts and carefully selected partners, ADI also delivers **a series of online masterclasses** on different topics (Principles of Advocacy, WHO, Fundraising Strategy and Sponsorship Packs, Presentation/Public Speaking skills, etc). These 45-minute webinars are recorded and available for ADI members only.

For the past two years, our partners Edelman and Mana Communications have also delivered pro-bono **Media and Social Media Training Webinars** to members around World Alzheimer’s Month.



**Closing discussion**

**Examples of the impact of COVID-19**

<b>Clinical care</b> <ul style="list-style-type: none"><li>• Telehealth follow-up rather than hospital visits after the initial diagnostic assessment</li><li>• Blood tests such as ptau181 to screen for AD pathology</li><li>• Increase in caregiver education on line</li><li>• Increase use of advance directives about management in later stages</li><li>• More home care, less nursing homes</li></ul>	<b>Epidemiology</b> <ul style="list-style-type: none"><li>• Increased deaths in later stages of dementia may change prevalence figures</li><li>• Role of dementia as a specific factor in deaths from infections need clarification</li><li>• Shifts from long term institutional care to home care will change costs estimates</li></ul>
<b>Clinical research</b> <ul style="list-style-type: none"><li>• Cognitive assessments done on line</li><li>• Follow-up using phone and on line</li><li>• Experimental medications sent home</li><li>• Cognitive and physical stimulation modules</li></ul>	



## Twinning

This year, ADI will be launching a new Twinning programme. The Twinning will be more project-focussed and time-bound (short-term) - for instance ‘Creating a Newsletter’, ‘Setting up a Helpline’, ‘Developing an Online Event’, ‘Setting up a Fundraising Strategy’, ‘Organising a Memory Walk’, etc.

## Global Annual Campaign: World Alzheimer’s Month

September is World Alzheimer’s Month, an international campaign coordinated by ADI to raise dementia awareness and challenge stigma. During this month, Alzheimer associations from around the world unite to organise advocacy and information provision events, as well as Memory Walks and fundraising days.

Each year, ADI develops campaign materials in 3 languages (English, Spanish and French): key messages, toolkits, campaign guides, bulletins, posters, social media banners, graphics, etc. Alzheimer associations, groups and individuals around the world are encouraged to use the yearly theme and materials to focus their messages and campaigns on advocacy and public awareness, but ADI encourages adapting to suit national and local contexts.

In 2019 ADI worked closely with PAHO and the Country Offices on a regional extension to the annual WAM campaign reaching out through associations and using a bespoke set of campaign materials.

ADI is also keen to showcase all the hard work members are doing for World Alzheimer’s Month all around the world, and lists all the main events on the World Alzheimer’s Month website:

[www.worldalzmonth.org](http://www.worldalzmonth.org)

## ADI: 'The Global Voice on Dementia'

- ADI is in official relations with the **World Health Organisation (WHO)**. One of ADI's biggest achievements is the adoption of the WHO Global action plan in May 2017, following comprehensive engagement with ADI and others on its concepts, vision and measurements. ADI had been advocating for a global response to dementia for over a decade. We maintain a strong relationship with the Mental Health & Substance Abuse department and deliver a statement each year during the World Health Assembly (WHA). ADI members can get access to the Palais des Nations.
- In 2019, ADI in coordination with its members in G20 countries, sent letters to each Minister of Health, calling for strong leadership to ensure that the commitments to dementia made in the G20 Osaka summit declaration were delivered. Dementia indeed featured heavily in the **Okayama Declaration of the G20 Health Ministers**, displaying an ongoing commitment of the G20 to addressing the greatest health and social care crisis of the 21st century. ADI is working closely with Civil Society partners and G20 Health Development Partnership to maintain momentum under the Saudi Arabia presidency in 2020, and is already engaged with the Italian Sherpas in preparation for their presidency in 2021.
- ADI is in regular contact with multilateral organisations, such as **G7, ASEAN, OECD**, etc.
- ADI has a **Global Ambassadors Programme**, which currently includes Queen Sofia of Spain, Queen Silvia of Sweden, ex-President of Costa Rica, Luis Guillermo Solís Rivera.
- In 2019, Pope Francis called attention to World Alzheimer's Day during one of his Wednesday General Audience addresses in the Vatican, following a meeting between Paola Barbarino and representatives of the Holy See earlier that year.
- Members can use ADI representatives as spokespeople at events / meetings with government (where possible).
- Members can receive letters of support for advocacy work, as well as guidance on developing and funding national dementia plans.
- ADI offers occasional bursaries to attend regional WHO meetings.

## ADI: A Publications Organisation

ADI is the publisher of the World Alzheimer Report and over the last decade has published leading reports on the global prevalence, cost, healthcare systems, research, etc. In 2019, "Attitudes to dementia" which was produced with strong collaboration with our members, enabling the survey of 70,000 people to be translated into 32 languages, resulted in vital insights into awareness levels and stigma globally.

- World Alzheimer Reports:  
[www.alz.co.uk/research/world-report](http://www.alz.co.uk/research/world-report)  
(Our members find the 2015 report with prevalence statistics particularly useful).
- From Plan to Impact annual reports, monitoring progress against the WHO Global action plan on dementia. Members feed into this report, supplying details on activity for all 7-action areas of the Global plan
- Dementia in Humanitarian Settings report
- Reports and policy briefs:  
[www.alz.co.uk/reports](http://www.alz.co.uk/reports)
- Publications / Information booklets and factsheets on dementia care and research and development of an organization:  
[www.alz.co.uk/publications](http://www.alz.co.uk/publications)
- *Please note that all ADI materials can be translated by members.*





## ADI: Involvement in Dementia Research

### **STRiDE project:**

*London School of Economics and Political Science (LSE)*

Working across 12 countries with 12 key work packages (WP).

The aim is to build research capacity, develop research evidence into what interventions work, create a better understanding of the impact and cost of dementia. ADI leads WP 8, using evidence to support the development of national dementia plans.



### **DISTINCT Project:**

The aim is to develop a multi-disciplinary, multi-professional education and training research framework for Europe aimed at improving technology and care for people with dementia and their carers. ADI offers expertise in areas of community-based practice and national policies through participating in training and education of the early stage researchers (ESRs), facilitate INTERDEM Academy to take place during the ADI biannual international conferences, and facilitate secondments through ADI national members.



### **COGNISANCE Project:**

*EU Joint Programme for Neurodegenerative Disease Research*

(JPND) - 3-year project working in 5 countries, led by Henry Brodaty in Australia, with partners in Australia, Canada, Netherlands, UK, and Poland. COGNISANCE is a loose acronym for 'Co-designing dementia diagnosis and post-diagnostic care' and is a partnership across seven universities and funded by JPND Research. ADI is an external collaborator.



- Co-designing dementia diagnosis and post diagnostic care.
- Toolkit to be disseminated internationally so this may be an opportunity for ADI members to be involved.
- Set of standards to ensure the diagnostic and post-diagnostic process and care are as positive an experience as possible.

### **CST International:**

*UCL Brazil, India, and Tanzania*

Three-year project in four phases. ADI sits on the Advisory Board.



The project will develop, test, refine and disseminate implementation strategies for CST for people with dementia in three diverse parts of the world – increase quality of life and cognition for people with dementia, increase awareness and skills in the detection and management of dementia.



## COVID-19 Response

In response to the global COVID-19 outbreak, we have been adapting our work and working closely with members to best support the millions of people affected by dementia globally, who are particularly at risk during this time.

*"I am amazed by all the good work that is happening to support those living with Alzheimer's and dementia in different countries and touched by some of the stories from the other participants. Being part of the Member Webinar today showed the wealth of knowledge that can be shared by listening to what others are doing and what they have managed to achieve. The platform is a great resource that has brought together people from different countries at a time when everyone is talking of social distancing and self-isolation."*

**Carol Ocama, Uganda**

- [Resources webpage](#) to which our members and other organisations contributed throughout the crisis.
- Professor Huali Wang's [presentation on the lessons learned from China in supporting people with dementia during COVID-19](#)
- The Lancet article on '[Dementia care during COVID-19](#)' by Huali Wang, Paola Barbarino, Serge Gauthier et al.
- A position paper on [COVID-19 and dementia and difficult decisions about hospital admission and triage](#)

- A thought piece on [age, dementia and the allocation of health resources during and beyond COVID-19](#)
- Member Webinars on Maintaining services during a crisis: How to continue supporting people with dementia and their carers; Mental Health and Wellbeing during self-isolation; Dis-crimination against Elders; Positivity Forum; Webinar in collaboration with United for Global Mental Health; Who decides what life is worth? Dementia and advocacy in a post COVID world.
- [Open Webinars](#) on Supporting people with dementia during COVID-19: experiences and advice from around the world; Future gazing: COVID-19 and dementia; The hidden casualties of COVID-19: revealing the emergency in care homes and the lessons learnt in day care
- A special series of online masterclasses (soon available).

With COVID-19 dominating the narrative in all facets of policy and decision-making everywhere, there is a justifiable concern that progress made under the [Global plan](#) will be reversed, nationally and internationally.

**As the global voice on dementia, ADI will continue advocating, more than ever, to ensure that dementia stay a priority everywhere.**