



2019  
Annual  
Report



11  
09:45-11:00  
**DESA/DISD: COSP12-  
Dementia-The Leading  
Cause of Disability**  
11:30-12:45  
DESA/DISD: COSP12 - Children and Young People with Disabilities  
Organized by Secretariat Services and Conference Management





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Kate Swaffer, presenting at the CoSP, New York 2019



## Welcome

Welcome and thank you for supporting Dementia Alliance International. As we ended another very busy year of advocacy and activism by DAI members, and many others living with dementia globally, we are collectively or individually working towards positively improving the lives of all people living with dementia and our families.

I would like to thank the current board members for their work and commitment this year, including those who had to step down for health or personal reasons. We especially thank Mike Belleville, Jerry Wylie, Agnes Houston and Maria Turner for their time, expertise, work for DAI, and ongoing friendship and support to both the board and our members.

I'd also like to thank the action group members, past and present, and members of our subcommittees, as well as Sarah Yeates, who has volunteered for DAI for many years, and Tamara Claunch, who commenced volunteering for us in 2019.

Special mention to Board member James McKillop from Scotland, who has just celebrated 20 years of advocacy. We are honoured to have him on our board.

One other member I wish to thank is Graeme Atkins from Australia, who in spite of some very serious health conditions this year, continues to attend meetings and to compose songs about dementia, and about DAI. For example, he wrote and performed our 5th birthday song, available on our award-winning YouTube channel.

DAI continues to grow, and the dreams of our eight founding members are being realised and are something we can all be proud of. Working as a team, our past and current Board members, Action group and sub committees members and our peer to peer support group hosts continue to engage and strengthen our resolve to empower current and new members to live more positively with dementia, and to become self-advocates, as well as to advocate for the human rights of our members and their families.

It is wonderful that DAI continues to grow, and to welcome new members; the growth of our peer to peer support groups is a unique free global service actively supporting and empowering our members to live with a better quality of life.

My sincere thanks to everyone for their continuing dedication to improving the lives of people with dementia and our families, and I look forward to working with the new board in 2020.

I'm very much looking forward to working with the incoming 2020 board and teams next year, and to collaborating with others as we continue this important work.

Best wishes,

**Kate Swaffer**  
Chair, CEO & Co founder  
Dementia Alliance International

# 2019 Board



Chair and CEO: Kate Swaffer, AU



Vice Chair: Alister Robertson, NZ



Treasurer: John Sandblom, USA



Eileen Taylor, AU



Wally Cox, USA



Christine Thelker, Canada



Bobby Redman, Australia



James McKillop, Scotland



Bill Turner, Australia

## Volunteers

Secretary, Sarah Yeates, Australia and Finance Officer, Tamara Claunch USA

# The Richard Taylor Advocates Award



It was thrilling to announce that DAI Board member James McKillop MBE from Scotland, was awarded the 2019 Richard Taylor Memorial Advocates Award, on World Alzheimer's Day, September 21, 2019. James has been a Pioneer dementia advocate, having been diagnosed himself with dementia in the last Century, and DAI is honoured and privileged to work with, and walk beside him; our members find him a constant source of inspiration.

James motivates many DAI members to keep going and is always a source of great wisdom and wonderful Scottish humour. Since joining DAI, James has continued his work locally and nationally, as well as being a very active DAI member on occasions representing us internationally, travelling with his dear wife, Maureen. James became a DAI board member some years ago and continues to co-host the UK peer to peer support group on a Monday morning, which now also meets on Thursdays. Congratulations from us all James.



## *The Richard Taylor Memorial Award 2019*

*James McKillop*

*For Outstanding Contribution to DAI's  
Global Advocacy and Mission*



*Kate Swaffer*  
Chair,  
Dementia Alliance International



# Human Rights Update

DAI continues to advocate at the WHO and UN for our access to the CRPD, and myself, and others have attended a number of high-level events on rights.



DAI attended the 12th Session of the Conference Of State Parties (CoSP12) on the Convention on the Rights of Persons with Disabilities (CRPD) which we hope will have far reaching benefits for all people with dementia, now and into the future.

DAI hosted the first Side Event to be dedicated specifically to dementia in the history of the CoSP, which was seeing dementia as a disability. The recording of the DAI Side Event is available on our YouTube channel. – add link

It is imperative we all work towards ensuring that dementia is recognised by all as a condition causing acquired cognitive and other disabilities, and therefore one that people diagnosed with dementia must be provided with full and equal access to the CRPD and other Conventions, and to Universal Health Care.

The United Nations and the World Health Organisation supported our event, and we acknowledge our co-sponsors, the Australian Government, the International Disability Alliance, Alzheimer's Disease International, Human Rights Watch, the Global Rehabilitation Alliance and the World Hospice and Palliative Care Alliance. We also thank our two sponsors, Alzheimer's Disease International and Boehringer Ingelheim.

DAI was honoured that Ms Catalina Devandas Aguilar, the UN Special Rapporteur on the rights of persons with disabilities made time to be available to provide the opening remarks for our Side Event, and thanks all other speakers. It was a rich discussion on dementia as a disability, on people with dementia as rights bearers, and of the rights of all, including people with dementia to rehabilitation and other services, and to full and equal access to the CRPD.



Mrs. Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities opens the DAI side event, CoSP 2019.

The overarching theme was social inclusion and health, two determinants of well-being, both of which are being systematically denied to people with dementia all around the world. Dementia had never been represented formally in a Side Event ever before at the COSP, hence why DAI felt it was so important.

Our disabilities may be more invisible than many others, but we are still, even in 2019, being stigmatised and discriminated against on a daily basis, and we hope this event will be the start of change for the more than 50 million people currently living with dementia, and every person being newly diagnosed every 3.2 seconds.

As an organisation DAI intends to continue to work towards others joining our campaign that dementia is a condition causing acquired cognitive and other disabilities, and for full and equal access to the CRPD and other Conventions, so that no one is left behind, including people with dementia. Rehabilitation, and all other health and disability services and support are essential for maintaining independence and dignity, for longer, and whilst dementia is a terminal condition, we should not all be 'dying at diagnosis'.

A number of blogs were published during and after this event, including the statements made by myself and Christine Thelker. We have also had an opportunity this year to provide feedback via the International Disability Alliance on potential themes for 2020. DAI continues to make submissions to governments on our rights, on dementia plans, on access to the CRPD, and on other matters, as they arise.





Civil Society Statement presented at the Conference of State Parties (CoSP) on the Rights of Persons with Disabilities (CRPD), on June 13, 2019, by DAI Chair, Kate Swaffer.

*“Distinguished Chairs, speakers and delegates.*

*Thank you for the opportunity to make this statement on behalf of Dementia Alliance International, a registered charity providing advocacy and support for people with dementia. We are also celebrating its 5th birthday.*

*Started in 2014 by 8 people with dementia including me, it has become the global voice of dementia. We started with a dream, specifically for full and equal inclusion, and to be respected and valued as members of society. We also advocate for equal access to universal health care.*

*This has become our dream for the more than 50 million people with dementia, and each person newly diagnosed every 3 seconds. That is also why DAI has organised a Side Event, taking place on Thursday morning.*

*No one and no organisation has ever represented people with dementia in this way, at this conference before.*

*Being diagnosed myself with dementia aged 49 taught me what the late Dr Martin Luther King Jnr. called ‘that sense of otherness’.*

*I had not been stigmatised or discriminated against, except as a woman.*

*I had not come from a deeply marginalised group. However as one of the 50 million people currently living with dementia who’s life was thrown in the bin at the time of my diagnosis, and still experiencing stigmas and discrimination.*

*Dementia is a significant global issue; it is the 5th cause of death globally, the 5th cause of death in America, and the 2nd cause of death in Australia.*

*However, after a diagnosis, we do not receive access to universal health care.*

*We do not receive post diagnosis rehabilitation or most other allied health services to support our independence or social inclusion.*

*We are segregated from others when we require assisted living.*

*We are institutionalised.*

*We are restrained physically and chemically, with no consideration of our rights.*

*In society, clinical practice is only provided, when supported by strong evidence-based research. However, the use of the concept Behavioural and Psychological Symptoms of Dementia (BPSD) was implemented, with no evidence-based research was implemented.*

*This has led to further chemical and physical restraint.*

*Secure dementia units, also a breach of many of our rights, including our right to freedom, are evolving into dementia villages, again with no evidence based research for their value.*

*Disease or disability specific villages are little different to ghettoization of groups of people. They are not a solution to those people with dementia who do need assisted living.*

*We are daily and systemically being denied our human rights. Unfortunately, people with dementia who decide to manage their symptoms as disabilities and proactively seek disability support, are also often demonised for daring to live positively.*

*Approximately 5 years ago the Dementia Envoy for the World Dementia Council Dr Gillings said people with dementia may need to take to the streets and march on the steps of parliaments. This is the beginning of that march, so that people with dementia are not left behind in the 2030 Agenda.*

*Thank you”*

**Kate Swaffer**  
Chair, CEO & co-founder  
Dementia Alliance International

# Capacity Building Workshop and Advocacy Resources

In 2019 DAI focused on building capacity of its leaders, through a two day workshop, and working with on a joint project with the Alzheimer's Society UK and the 3 Nations Dementia Working Group to collate advocacy resources and create a video about advocacy, which we are proud to highlight here.

## Capacity Building Workshop

Dementia Alliance International (DAI) is an organisation run by, and specifically for people with dementia, that is also regularly asked to support external organisations with advocacy, advice and direct support. It also provides global education to members, as well as the dementia industry and research community through free regular online webinars, providing presentations from international experts and speakers. It is imperative therefore that its leaders receive training and support.

Beyond the leadership level of DAI, and its direct services to members and the wider dementia community, members of DAI are regularly asked to be involved as advocates for external organisations such as Alzheimer's Disease International and national organisations, such as Alzheimer's Society UK and Dementia Australia. They are also asked to provide advice and feedback to the World Health Organisation, United Nations and other organisations including Pharmaceutical companies. Many are also asked to work with researchers as advisors or collaborators, and most grant funding regularly depends on this involvement.

Dementia Alliance International (DAI) received a generous grant from Boehringer Ingelheim to be used specifically in 2019, with a portion being used for Capacity Building. DAI held a capacity building and leadership training workshops for DAI board members, volunteers and leaders from within our growing organization.

Due to the amount of the grant, we were restricted to how many members we could invite, and reserved the training for the board and leaders who are actively engaged in key positions and activities. This training workshop was the first step in efforts to increase competence and professionalism in DAI leadership, to ensure DAI

continues to serve its members effectively, and to ensure DAI has a transition plan for new leaders and board members.

It was the first of a proposed two; we planned to hold a similar 2-day training session for board and other active members in Australia and New Zealand in 2020, if funding was available.

In July 2019, seven leaders of Dementia Alliance International (DAI) met in Los Angeles for a two-day capacity building workshop. Even with the restricted grant for this training, it was only possible because Kate Swaffer was funded to be there in her role with the World Dementia Council, and our facilitator led the workshop without a fee.

Goals of the workshop included the following:

1. Enhancing DAI members leadership and management skills.
2. Enhancing members ability and capacity to perform board and leadership roles within DAI, and beyond.
3. Explore ways in which DAI can navigate the growth and success it is experiencing since it was launched on 1 January 2014, in a way that mitigates risk.
4. Establish a stronger foundation for the future that also ensures the core mission and vision of the organization are realized.

On day 1 of the workshop, DAI leaders participated in three sessions: essentials of nonprofit board & leadership service; leadership skills & expertise; and nonprofit board lifecycle stages. Prior to the workshop, participants had been asked to complete a survey aimed these various topics. The workshop facilitator reviewed these results at the outset of each session and opened the floor for discussion.

Most participants in the workshop had little to no previous experience serving on a nonprofit board. Several were DAI members not serving on the Board, but perhaps considering this for the future. Therefore, a portion of the first session



was dedicated to the basics of board service where participants learned about the main roles of nonprofit boards as well as the ethical and legal responsibilities of individual board members.

Another segment was dedicated to exploring the human-to-human challenges that arise when there is too much work and too few people to do it, no paid staff and very limited funding. Participants discussed the differences between friction and tension, and the complexities arising from varying leadership styles in the group. DAI leaders then went through a board skills mapping exercise to identify which skills the board has today, and which ones will add value to the organization in the future.

For the first five years of its existence, founding board members have been handling the vast majority of DAI's operational tasks and duties. But as the organization grows and changes, so must the duties and responsibilities of the board. The process of transitioning from a founding board to one that governs was a key topic of discussion during the workshop. In this, participants learned most of their challenges relate directly to the organizational lifecycle, rather than to their individual capacities and capabilities. By establishing a common understanding of what it means to become a board that governs, participants gained insight into opportunities the change process presents. Then they engaged in a roundtable discussion on DAI's need for improved systems, clearer definitions of board and staff roles and more "business-like" practices.

DAI leaders then engaged in a session on performance management, with the goal of addressing operational efficiency and effectiveness gaps highlighted in the pre-workshop survey. Navigating growth calls for close attention to be paid to measuring the efficiency and effectiveness of DAI's strategic plan, fundraising activities, key programs and service deliveries. The fact that DAI members and leaders are all living with acquired cognitive disabilities lends additional complexity to "normal" organizational growing pains. Therefore, the group focused discussions on employing technological and procedural to act as cognitive ramps that will enable their long-term success as individuals and teams.

While the first day of the workshop focused on establishing a common nonprofit and organizational change management baseline understanding, the second day aimed to launch the group towards the future of DAI. Beginning with a session on fundraising, participants learned tools and techniques to increase their capacity and skills in this area. For many, living with dementia and its associated discrimination and stigma increases the complexity and anxiety around fundraising. To enable the team's success in this key area, participants worked to design a basic fundraising toolkit to be used by individual members. They also broke into small groups to craft and share their personal stories of why they are involved with DAI and the importance of the work that DAI does. While most participants surveyed indicated that they felt comfortable and excited talking about the organization with others, many indicated that they were not actively engaging in ongoing fundraising efforts. In the course of the workshop, DAI leaders transitioned from viewing fundraising as transaction-based to a perspective based more on relationships, sharing a common vision and achieving a higher purpose.

The final workshop session was entitled "Planning for Transformation". Pre-workshop surveys indicated the group was well-aware of imbalances in workload and responsibilities between members. In this segment, DAI leaders learned about common growing pains for founding or organizing boards and essentials for effective governance, as well as common nonprofit organizational committee structures. They then discussed difference opportunities for improvement in organizational structure as well as workload balancing.



# Capacity Building Workshop and Advocacy Resources

Overall, the two-day capacity building workshop brought great value to the participants and Dementia Alliance International as an organization. The group succeeded in establishing baseline competency around key topics such as nonprofit leadership and board service basics, organizational development and change management, as well as fundraising strategy and tactics. Group discussions and break-out sessions generated energy, engagement and individual empowerment. In the workshop, DAI leadership created a comprehensive overview of all services delivered to members, care partners/family and the general public, including academics and researchers. They also laid out key performance indicators designed to measure and monitor the health of the organization as well as how effectively and efficiently services are delivered to consumers.

Their capacity for fundraising as individuals and as a team was increased, tailored to their own lived experiences and in the context of working together towards a world where all people are valued and included. Perhaps most importantly of all, participants developed a common vision of where the organization is going and how to get there.

Several specific improvement opportunities were suggested during the workshop, and the majority of these are currently being implemented. Many were procedural in nature, such as surveying active/inactive members or improving the new member onboarding process. Other improvements coming out of the workshop were harder to define but nonetheless strengthened the capacity and capabilities of the team. A renewed sense of being a team and increased awareness of workload imbalances led to greater burden sharing and improved delegation of responsibility. In short, the outcome was that team members were all better-positioned to be successful in their individual roles within the organization and the leadership team as a whole is well-positioned to successfully navigate its duties more effectively, during a period of significant growth and change.



Members	Family Carepartners	General Public Academics/Research
P2P		
Support groups	BrainHealthHub	BHtH
-Livvy/Alche	Cafe LeBrain	Webinars
-Aphasia	Webinars	Christmas Party
-BHtH	Christmas Party	YouTube
-International	YouTube	WRAD
-General	WRAD	FB page
Cafe LeBrain	FB page	FB BHtH page
Webinars	FB BHtH page	Focus groups
Christmas Party	Advocacy	Advocacy
YouTube	Resources (in website)	Resources (in website)
1-on-1 Building		
WRAD		
FB page		
FB support group		
FB BHtH group		
Advocacy		
Resources (in website)		



## Supporting Dementia Self Advocates: A Directory of Resources





## The Global Voices of Dementia: Resources for Self-advocacy

Dementia Alliance International (DAI), the Alzheimer’s Society UK, and the 3 Nations Dementia Working Group (3NDWG) have worked in partnership to develop two resources to educate, inspire and empower more dementia self-advocates.

The inspiration for this project evolved from conversations between Kate Swaffer from Dementia Alliance International (DAI) and Amy Little from The Global Alzheimer’s & Dementia Action Alliance (GADAA), after conversations on how to better support capacity and abilities of DAI members, all people diagnosed with dementia, who have increasing disabilities. With the appropriate support, it is very evident people with dementia can still, and do still live very meaningful lives, for much longer than they are told to expect, especially if diagnosed in the earlier stages of dementia.

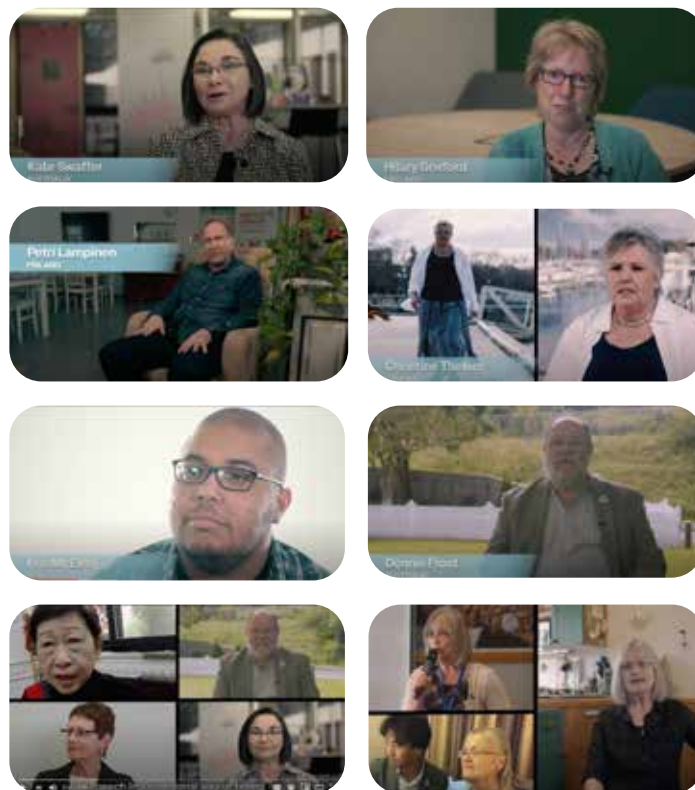
This project was initiated, to support others with dementia to not only be inspired, but to develop some of the skills to become self-advocates. The project partners consulted with dementia working groups and individuals who are already active dementia advocates in different countries. This was done to identify the barriers to self-advocacy, which can include: confidence, accessibility, discriminatory language, stigma and lack of engagement from others. The project also identified existing resources to support dementia self-advocates and highlighted some of the gaps that exist.

Self-advocacy is about having a voice, and being able to represent yourself and express your views and needs. Self-advocacy supports the human rights of people affected by dementia and gives our movement a more powerful and united voice.

As part of the project two resources were created:

1. Supporting Dementia Self-Advocates – a Directory of Resources, which collates relevant online resources to support inclusive working and self-advocacy.

2. The Many Voices of Dementia Advocacy, a short film with seven people living with dementia in different countries, talking about their experiences of self-advocating, their motivation and top tips.



For more information or support, or to get involved with local or global advocacy, contact the project partners for more information:

1. [Dementia Alliance International](#)
2. [Join Dementia Alliance International](#)
3. [Join the 3 Nations Dementia Working Group.](#)
4. Or contact your national Alzheimer association

**By working together,  
the impact of  
self advocacy makes a  
bigger difference.**

# World Alzheimer's Month 2019

This year, we once again ran a #Hello my name is blog series, and many members were involved in conferences and WAM events around the world. Members all around the world were very involved with events for DAI or with their local or national Alzheimer's advocacy organisations. They can be found by going to our regular blogs, published in September 2019.

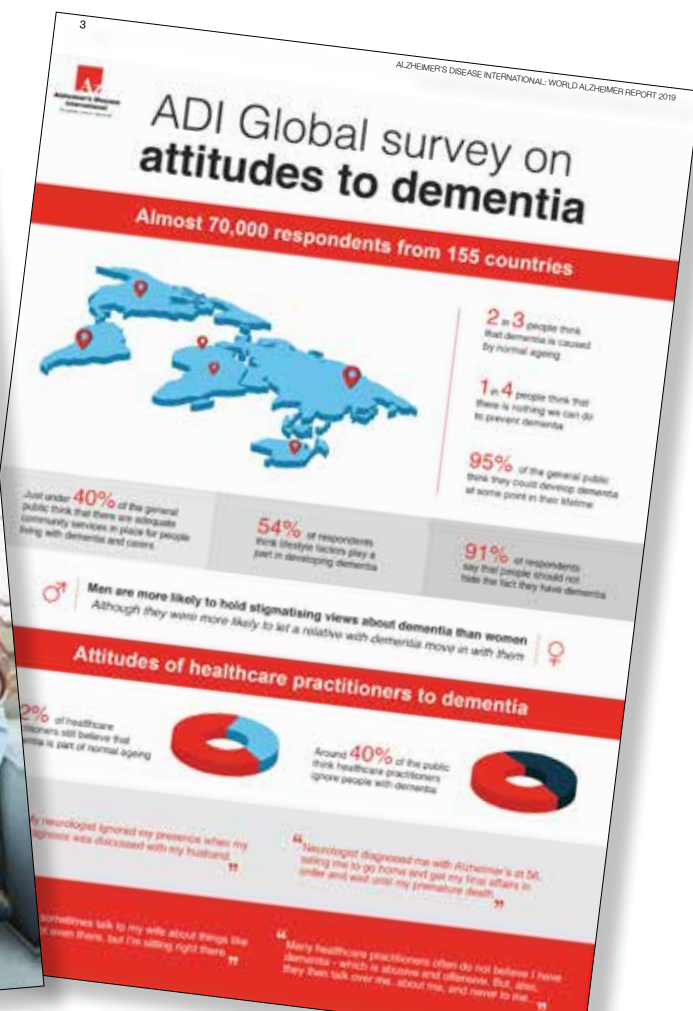
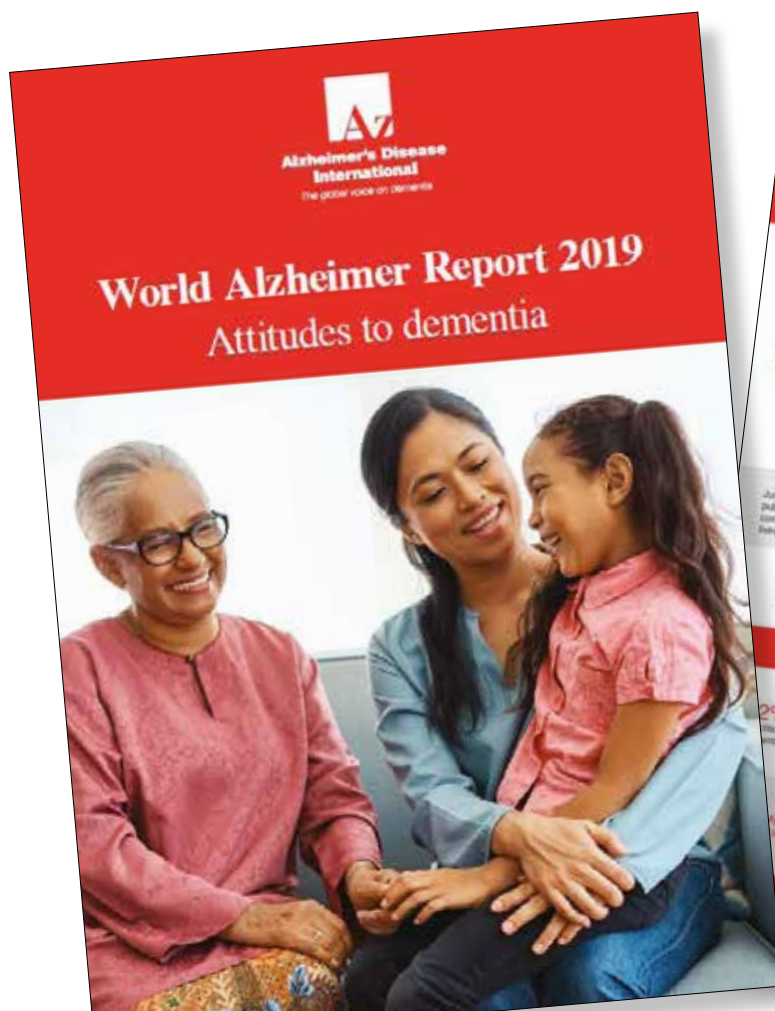


DAI also supported Alzheimer's Disease International, including for the launch of their 2019 World Alzheimer's Report, Attitudes to dementia, which analyzed the results of a global survey on attitudes to dementia, supplemented by 40 expert essays and case studies. The report revealed the results of the largest attitudes to dementia survey ever undertaken, with almost 70,000 people across 155 countries and territories completing

the survey. It spans four demographic groups: people living with dementia, carers, healthcare practitioners and the general public. Analysis of the study, which collected responses from, was carried out by the London School of Economics and Political Science (LSE).

Some of the key findings of the report include:

- Almost 80% of the general public are concerned about developing dementia at some point and 1 in 4 people think that there is nothing we can do to prevent dementia
- 35% of carers across the world said that they have hidden the diagnosis of dementia of a family member
- Over 50% of carers globally say their health has suffered as a result of their caring responsibilities even whilst expressing positive sentiments about their role
- Almost 62% of healthcare providers worldwide think that dementia is part of normal ageing
- 40% of the general public think doctors and nurses ignore people with dementia





# Webinars, Conferences and other online events

DAI continues to host Webinars, and this year, speakers have included Jerry Wylie and myself, a special online event to celebrate our 5th birthday, Dr Laura Booi, a Fellow at Trinity College in Dublin from the World Young Dementia Leaders, Jerry Wylie who hosted the WRAD event, Drs Jacki Little & Theresa Scott, Dr Daniel Potts, Liz Smith & Alister Robertson, Christine Thelker, Dr Noelannah Neubauer, Professor Yun-hee Jeon, Professor Keith McVilly and Phil Hazel, and tomorrow, Dr Al Power.

We will end the year with two celebrations, one a non-denominational spiritual service, and the other, a celebration of the festive season and year behind us. We will kick off 2020 with a birthday party in January, and a speaker on clowning and humour in February.

DAI members have also attended many other events, conferences and meetings around the globe, again

including the World Health Assembly, the CoSP, the second Rehabilitation 2030 conference and the Mental Health Forum in Geneva at the WHO.

Dr Jennifer Bute, a longtime member in the UK continue to support ADI as a speaker at their Alzheimer's University, and we thank her for her commitment to this on behalf of DAI, and for her other advocacy work.



A DAI WEBINAR  
**"Collaboration Across Disciplines and Countries Among the Next Generation of Dementia Leaders"**  
 Dr Laura Booi, World Young Leader in Dementia (WYLD)  
 27/28 February, 2019  
 WYLD NETWORK DEMENTIA ALLIANCE INTERNATIONAL



A DAI Meeting Of The Minds Webinar  
**"Step Up for Dementia Research"**  
 Yun-Hee Jeon, RN, PhD  
 25/26 September, 2019  
 Step Up! THE UNIVERSITY OF SYDNEY DAI 5



A DAI WEBINAR  
**"Dementia as a Disability"**  
 Christine Thelker  
 July 24/25, 2019  
 DEMENTIA ALLIANCE INTERNATIONAL 5th ANNIVERSARY



A DAI WEBINAR  
**"Learnings from patients and family"**  
 Daniel C. Potts, MD, FAAN  
 May 29/30, 2019  
 DEMENTIA ALLIANCE INTERNATIONAL



A DAI WEBINAR  
**"Staying engaged without driving"**  
 Dr Jacki Little (OT, Research Fellow, PhD, DOT 9 level)  
 Dr Theresa Scott (NH&MRC Dementia Research Development Fellow and a Psychologist)  
 April 23/24, 2019  
 THE UNIVERSITY OF QUEENSLAND AUSTRALIA DEMENTIA ALLIANCE INTERNATIONAL



A DAI Meeting Of The Minds Webinar  
**"Dementia & Wayfinding"**  
 Noelannah Neubauer  
 PhD, MSc., WYLD  
 28/29 August, 2019  
 WYLD NETWORK DAI 5



A DAI Meeting Of The Minds Webinar  
**"Assistance Dogs for people with dementia"**  
 Keith McVilly PhD, Professor of Disability & Inclusion, The University of Melbourne  
 Phil Hazel, Chair, Dementia Australia Dementia Advisory Committee  
 23/24 October, 2019  
 THE UNIVERSITY OF MELBOURNE DAI 5

# Services for members

## Membership guidelines

There has been some confusion about DAI membership guidelines, which currently remains exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world, although we are aware of some people with MCI who have joined as members. As reported at the AGM in 2018, the clinical and research community continue to 'revise' the guidelines between dementia and Mild Cognitive Impairment (MCI), and we acknowledge everyone need support, and therefore if MCI is to be considered early or pre-dementia, DAI will consider adjusting membership guidelines to include people with MCI.

## Member Services

### DAI Brain Health Hub

Our Facebook Brain Health Hub page continues to grow, and we have modified our meeting to suit different time zones, hosting two per month for everyone. The Brain Health Hub was set up to support members wanting to manage dementia (either themselves, or with the support of their own doctor) with a lifestyle approach to dementia such as the Bredesen Protocol. These groups are not exclusive to DAI members, and anyone interested in brain health is welcome to join the meetings and the Facebook page.



## Living Alone Social Support Groups

DAI has commenced a number of additional services or events for its members, including a weekly Online Social Support Group held every Sunday at a time zone suitable to members in Europe, the UK, Scotland, the USA and Canada, hosted by Julie Hayden from the UK, and David Paulson in the USA. We also now hold a fortnightly Living Alone Social Support group for members in Australia, New Zealand and Asia, hosted by Bobby Redman and Jo Browne. As membership increases, so does the demand for peer to peer support groups; hence we will also aim to be hosting more in different regions in 2020.



## Peer to Peer Support Groups

DAI members facilitate and provide online peer-to-peer support groups and social groups for people with dementia through Facebook and Zoom (online video conferencing), for our members, and which are free; you can join here. Online support groups are ideal for those who cannot drive to their local "in person" support group or who live in isolated areas with limited access to services. Many of our members also like to join more than our DAI support groups, and may also belong to a number of other groups run by different organisations or individuals, either online or in person if they have them available in their local areas.

Peer to Peer support groups continue to grow in numbers and time zones, and anyone with dementia can join for free, by becoming a member of DAI. Listed here are our current support groups:

Contact us at [info@nfodai.org](mailto:info@nfodai.org) for more information.



## Peer to Peer Support Groups

### Weekly Peer to Peer Support Groups

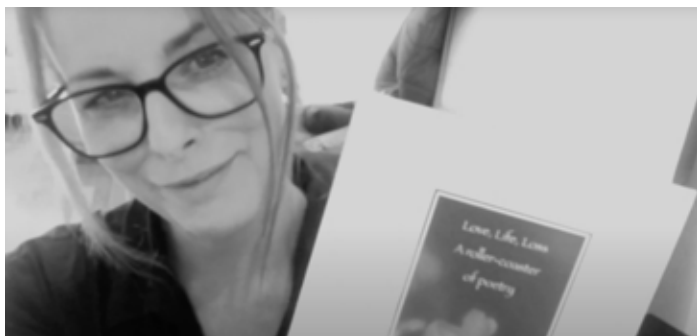
Countries	Day & Time	Co-hosts
 Australia, New Zealand and Singapore	Mondays 10:00 AM ACST	Eileen Taylor & Kate Swaffer
 United Kingdom, Europe, South Africa and Australia	Mondays 9:00 AM GMT	James McKillop & Dennis Frost
 Australia, New Zealand and Singapore	Wednesdays 1:30 PM ACST	Bobby Redman and Kate Swaffer
 USA and Canada	Thursdays 1:00 PM CDT	John Sandblom & Wally Cox,
 USA, Canada, Australia	Thursdays 3:00 PM CDT	Kate Swaffer, Sid Yidowitch, Dallas Dixon,
 USA and Canada	Fridays 2:30 PM CDT	Christine Thelker & Diana Blackwelder
<b>Living Alone Social Support Groups</b>		
 USA, Canada and United Kingdom	Sundays 5 PM GMT	David Paulson & Julie Hayden
 Australia and New Zealand	Sundays 5 PM AEST	Bobby Redman & Jo Browne (fortnightly)
<b>Monthly Social Support Group</b>		
 Japan, Scotland, Canada, USA & Australia	Tuesdays as members are available	Christine Thelker & Kate Swaffer

# Services for members

## World Rocks Against Dementia (WRAD) 2019

Dementia Alliance International hosted their second World Rocks Against Dementia (WRAD) online event in March, and together, we 'Rocked the World Against Dementia"! Graeme Atkins regularly highlights his ongoing love of music, and we thank him for agreeing once again to open and close our WRAD event with two live performances, albeit via zoom!

The 2019 WRAD event was hosted by our Vice Chair Jerry Wylie from the USA, and Board member Christine Thelker from Canada, who did a fantastic job, and also made sure we have fun. Mike Belleville from the USA, also a board member was once again our producer. We thank them all for their hard work to put this event on.





### DAI's FINAL WRAD 2019 PROGRAMME

We commenced with one minute of silence for our brothers and sisters in New Zealand, following the recent shootings there

Live performance by Graeme Atkins, Australia: Living Well With Dementia

Dr Al Power, USA: Happy Wanderer\*

Chris Madsen & Jenny Garbutt, Canada: In the Stillness

Veda Meneghetti, Australia: Living beyond my diagnosis of dementia

Chris Madsen & Jenny Garbutt, Canada: It shall always be

Vince Zangaro, USA: Better Man

Raukatauri Music Therapy Centre, New Zealand: Mahana

Residents living Care Centre, Levin, New Zealand: Edelweiss

Shoutsister Choir, Canada: Stand by Me

Dementia Drumming Group, Day Care Respite Centre, Australia: Mind to Beat, Beat to Mind -five Fives and We Will Rock You

Bay Samba, Australia: Mangueria

Daniella Greenwood, Australia: Something For Kate

Kate Swaffer, The World: Sadness

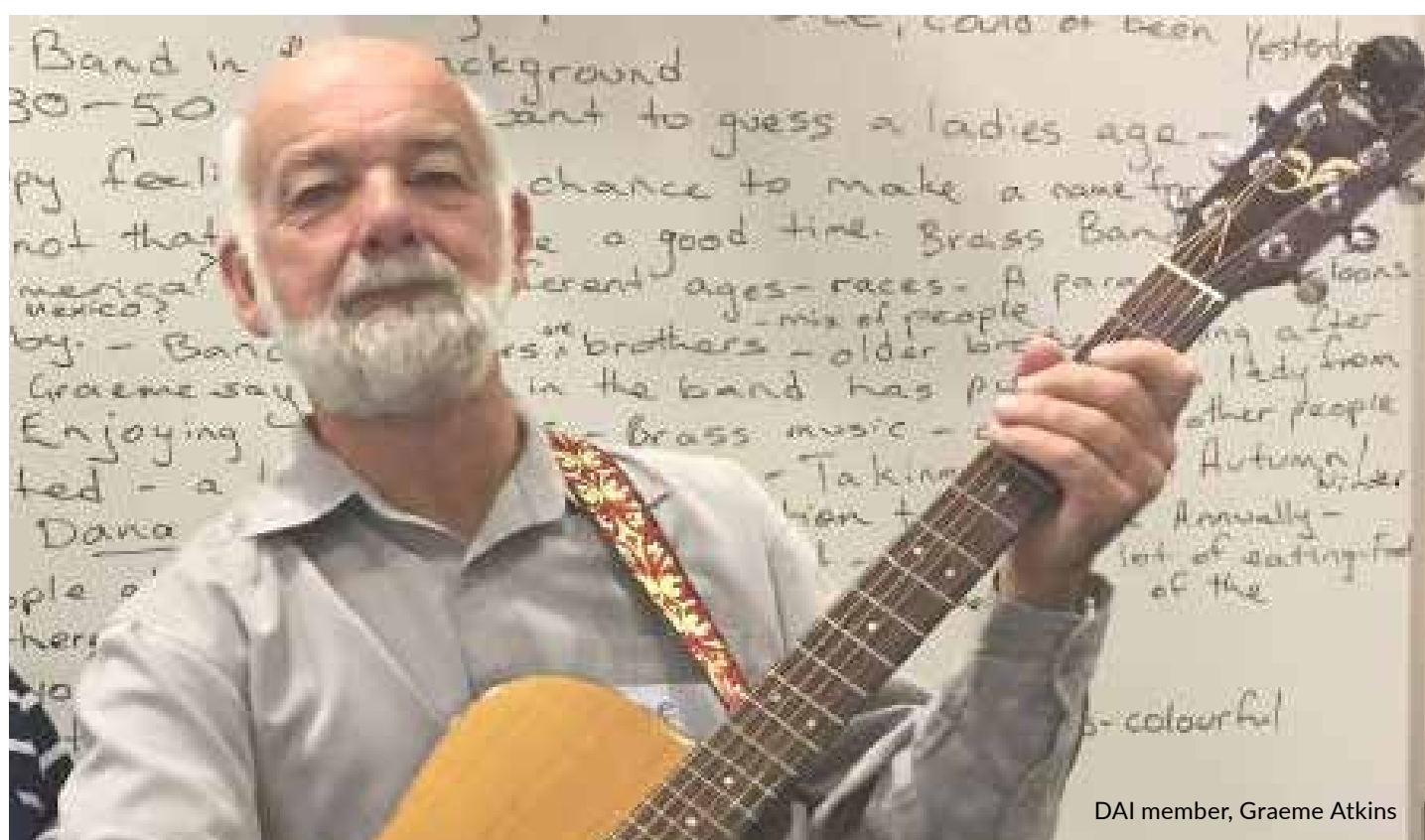
Kate Swaffer, The World: Happiness

Paul Hitchmouth, USA: Invisible

Live performance by Graeme Atkins: The Minimal Mental Test

Graeme Atkins (pre recorded): Happy 5th Birthday to DAI

*\*The Happy Wanderer was performed by Al Power, with new lyrics relating to people with dementia, and is available to watch on our YouTube channel.*



DAI member, Graeme Atkins

# Global Partners or Relationships



**StepUp 4 Dementia Research:** DAI is invited to become an Organizational Champion for this newly established research organisation in Australia. The aim is to partner researchers with people with dementia and care partners or families.



**World Dementia Council:** Two DAI members are full members of the WDC; Kate Swaffer stepped down this year, and members with dementia include Hilary Doxford from the UK, and new member Maryna Maritz, from South Africa.



**World Health Organisation:** DAI first applied in July 2018 to be accepted into Official Relations with the WHO, although our application was unsuccessful. Reapplying is to be reviewed early 2020. We have had many opportunities to provide feedback to the WHO, on documents such as the DFI Toolkit.



**LEAD Coalition:** DAI continues to work with this organisation in the USA; John Sandblom and Diana Blackwelder represent DAI at their monthly meetings



**United Nations:** DAI applied for ECOSOC Status with the UN, and although the application was unsuccessful in June 2019, our full ECOSOS membership will be reconsidered at the Executive Board meeting in 2020.



**GADAA:** This alliance is no longer active, although the website remains open as a repository for the work DAI and many other have contributed to.



**NCD Alliance:** DAI continues to work with the NCD Alliance, alongside ADI towards a better representation of Dementia at the UN High-Level Meetings in New York, and other important events and meetings.



**Convention of the State Parties on the CRPD:** DAI still has DPO status with the CoSP



**Global rehabilitation Alliance:** Launched in May 2018, DAI is one of the Founding member organisations; however, there is some doubt about whether this alliance will continue beyond 2019.



**International Disability Alliance:** We have retained Observer status membership of this organisation, which is proposed to be reviewed formally in 2020.



In 2019 ADI continued with a key focus of supporting members to encourage their governments to develop funded national dementia plans. ADI believes that national plans are the best tool available to

comprehensively tackle this challenge. Progress towards the national plans target of the Global action plan on the public health response to dementia 2017-2025 has been slow, with only 3 plans or strategies being adopted in 2019 in Canada, Spain and Gibraltar. 28 countries or territories are in the process of developing plans (many, encouragingly, in low- and middle- income countries). At the World Health Assembly in May 2019, on the second anniversary of the Global plan, ADI hosted a panel of government experts to discuss progress; a panel including Kate Swaffer representing DAI. In 2020 we will follow this up and also launch the third edition of the 'From plan to impact' report, monitoring progress during the plan's first interim reporting cycle.

In 2019 ADI successfully advocated for dementia to be a public health priority at the level of the G20. With the dedicated support of Noriyo Washizu, Alzheimer's Association Japan, Chris Lynch, Deputy CEO engaged with the Civil Society 20 (C20) global health working group, meeting key Japan Government Departments and cross parliamentary groups and undertaking media opportunities in the build-up to the G20 Summit. ADI's Chief Executive Paola Barbarino then wrote directly to each G20 Health Minister ahead of the follow-on Health Ministers Meeting, asking them to demonstrate strong leadership to the global health community to deliver a unified, strategic and sustainable response to dementia. These engagements reaped significant results, with the Okayama Declaration from the Health Ministers Meeting in October contained six major commitments to dementia: developing and implementing national dementia action plans; addressing risk factors and enhancing early detection, diagnosis, and interventions, including development of care pathways and strengthening primary health care; raising awareness and overcoming stigma by developing age-friendly and dementia-inclusive environments; promoting research and development; mutual knowledge exchange of initiative for active and healthy ageing. Maintaining momentum is now vital and looking to 2020 and 2021 DI is already engaging with the process for the next two presidencies of the G20, Saudi Arabia and Italy.

ADI's World Alzheimer's Month 2019 was the most effective campaign to date, with events being held in over 94 countries. ADI developed a larger set of materials for the campaign, under the theme of 'Let's talk about dementia'. A regional variation on the campaign was delivered with the Pan American Health Organisation, focussing mainly on middle and southern America and the Caribbean. Throughout the month global

monuments were illuminated purple and on 18 September at the Vatican, Pope Francis highlighted World Alzheimer's Day during his Wednesday General Audience address to an audience of around 10,000 people. ADI will continue to keep growing World Alzheimer's Month and create awareness campaigns for other regions of the world.

2019 also saw a global scale piece of research come into fruition: the World Alzheimer Report 2019: Attitudes to dementia. The report aimed to understand the extent of stigma surrounding dementia globally and to create a baseline from which to monitor behavioural and attitudinal change – both among the general public and within the health and social care systems. The report analysed results of the world's largest global survey on attitudes around dementia, with 70,000 respondents from 155 countries, speaking 32 languages. It was truly a collaborative effort by ADI staff, DAI, members, the London School of Economics and many other partners. The report was well received, achieving a large amount of media attention globally. ADI also published a report with Alzheimer's Pakistan and Global Alzheimer's & Dementia Action Alliance *Forgotten in a crisis: Addressing dementia in humanitarian response*.

Throughout the year, three ADI Alzheimer Universities were held in London, South Africa, Lebanon and Jamaica, accompanied by the sharing of knowledge and resources at ADI regional meetings in Asia Pacific, Latin America, the Middle East and Europe. ADI welcomed seven new members in 2018, with 17 associations on our Membership Development Programme. ADI took the opportunity to award their Majesties Queen Sofia of Spain and Queen Silvia of Sweden in formal recognition of their roles as Global Ambassadors.

From the research perspective ADI will continue to develop the STRiDE project, with DAI and the London School of Economics and Political Science (LSE); and the COGNISANCE project with DAI. The global webinar series on dementia research and trials continued with success into 2019. ADI will hold a joint webinar with DAI on dementia and rights in 2020. ADI is working closely with Alzheimer's Disease Association (Singapore) ahead of the next ADI International Conference in March 2020, having received more abstracts than ever before and expecting more delegates than ever before.

**Paola Barbarino**  
CEO, Alzheimer's Disease International

**Chris Lynch**  
Deputy CEO & Director of Policy, Communications & Publications, Alzheimer's Disease International

# Global Partners or Relationships



## Consumer engagement

Dementia Australia's national Consumer Engagement team

works together with Dementia Advocates (people living with dementia and their care partners) to raise awareness of dementia, to tackle stigma and discrimination, and to influence decision-makers across government and industry. The Dementia Advocates Program supports people living with dementia, current and former care partners, to be involved in advocacy activities.

### Key achievements over the last 12 months

#### Quality Dementia Care Initiative

A key strategic priority for Dementia Australia is to work collaboratively to define standards of quality dementia care. This work commenced with a round of national consultations about what quality dementia care looks like and means to people living with dementia, their families and care partners, and culminated in June with a Quality Dementia Care Consumer Summit in Canberra.

The Summit was attended by 47 Dementia Advocates, from every state and territory across metropolitan, regional and remote Australia, including Kate Swaffer, CEO, Dementia Alliance International, several industry leaders and the Department of Health. The representative group ratified a set of recommendations against each of the eight Aged Care Quality Standards that were presented by Advocates Dennis Frost and Maggie Jones to Senator the Hon Richard Colbeck, Minister for Aged Care and Senior Australians in a Communique, Our Solution: Quality Care for people living with dementia.

To further this work, a Roundtable was held to discuss the critical issues around quality dementia care, with industry and government representatives, and the Aged Care Quality and Safety Commissioner, Janet Anderson. Advocates Ann Pietsch, Tara McDonald and Phil Hazell set the intent of the day by explaining the importance of quality dementia care and the difference this makes.

To achieve quality in dementia care, a working group, with representatives from the Roundtable, is currently investigating how to implement within the current system an holistic and person-centred approach that is supported by a knowledgeable workforce.

#### Dementia Action Week

Dementia Action Week's Dementia doesn't discriminate. Do you?, commenced with a successful event at the Sydney Opera House, Discrimination and dementia the health issue of our time, which was attended by more than 100 people, and watched by 222 people via livestream. Phil Hazell, Chair of Dementia Australia Advisory Committee, representing the Dementia Advocates on the panel discussion, was inspirational.

The event was punctuated by moving clips of Dementia Advocates Tara McDonald, Danijela Hlis, Ann and Geoff Fairhall, Jodie Freeman and Ian Gladstone, who generously shared their personal experiences of dementia and discrimination.

#### Royal Commission into Safety and Quality of Aged Care.

Dementia Advocates have been instrumental in ensuring quality of dementia care is a key consideration of the Royal Commission into Aged Care Quality and Safety. During the past 12 months many Advocates have provided witness statements and shared powerful stories at the hearings, roundtables and community forums. Dementia Australia is very grateful for the contribution made by Advocates and the difference this makes in raising awareness, shaping policy and informing decision making more broadly.

Dementia Australia has a formal memorandum of understanding with Dementia Alliance International, which means the two organisations can collaborate across key issues impacting people with dementia.

**Maree McCabe**  
CEO, Dementia Australia





**World Dementia  
Council** Leading the Global Action  
Against Dementia

The WDC is pleased to update the DAI on our work over the past year. The WDC

was established by the G8 at the 2013 London summit and our role is to challenge and support the international community to deliver on the 2025 commitments. There are 24 full members including scientists working to find a cure, academics, representatives of civil society, individuals working in care, industry, and finance. In addition, the council has two members who are living with dementia. Alongside our 24 full members, the council has associate members: individuals representing national governments or international institutions like the WHO and OECD. Through international advocacy, international leadership and building global networks, we help keep dementia on the international agenda.

Full council members serve for fixed terms, and every year as members' terms come to an end, new members join the council. In 2019 we were delighted to announce new members Maryna Lehmann, a member of Dementia Alliance International (DAI), and living with dementia in South Africa, Philip Scheltens of the University Medical Center Amsterdam, Huali Wang of Peking University, Shekar Saxena of Harvard University and Paola Barbarino of ADI would be joining the council. At the end of their terms, we also thanked Kiki Edwards, Raj Long, Ron Petersen, and DY Suharya for their service, as well as the DAI's Kate Swaffer for her dedicated commitment to the WDC over the years.

At the beginning of the last decade, in the summer of 2010, the trial for Semagacestat was ended without success. It was the story of the decade, but there are good reasons to hope that it will not be the story of this decade. We are making significant advances. From the understanding of the basic science through to the development of new diagnostic tools and treatments, we are moving forward. We are advancing our understanding of the development of the disease and the potential for lifestyle intervention. But today, for many people, care remains a huge challenge. And even the visibility of dementia in many countries is low.

For all the challenges, the decade ahead will be one of progress. In an era of global fragmentation, the international dementia community has collaborated more closely to advance research, improve care and increase awareness.

The WDC with partners from around the world, has been investigating the evidence that underpins dementia friendly initiatives. One bit of the story, often overlooked, is how initiatives have been shared, copied and adapted from country to country as everything from governments to local activists seek to respond to the dementia challenge. Our international summit in Tokyo last year, ahead of the G20 Health Ministers meeting, convened international dementia leaders from government, academia, industry, and civil society, with a focus on accelerating progress.

For us, the year ahead begins with the publication of the report on dementia friendly initiatives this spring. The WDC will hold its council meeting this July at Alzheimer's Association's International Conference in Amsterdam, the Netherlands. The WDC will be holding a conference this autumn. And throughout the year we will hold a series of stakeholder meetings to help inform a report for publication in early 2021, at the start of the UK's presidency of the G7, that will review progress made since the UK last hosted the G8 dementia summit in 2013 and set the 2025 global dementia ambitions. Key policy areas for focus include data sharing, diagnosis, care research and the cost of dementia.

At the beginning of 2010s there were 35 million people living with dementia worldwide. At the end of this decade it will be something like 75 million. It is a daunting number and a huge societal challenge, but we begin the decade with reasons to hope.

We would like to congratulate the DAI for what it has achieved over the past year. We look forward to continuing our work with organizations from across the international dementia community and wish you all a successful 2020.

**Harry Johns**  
Chair, World Dementia Council

**Lenny Shallcross**  
Executive Director, World Dementia Council

# Global Partners or Relationships



Late in 2019, the leadership from the House and Senate appropriations

committees released two comprehensive FY 2020 appropriations packages containing all 12 appropriations measures. For links to details on those 12 bills, see item 3 below. The legislation is expected to be passed by Congress this week and then signed into law before the end of the month.

## Dementia-Specific and Dementia Relevant Highlights

Thanks to advocacy from the LEAD Coalition community, other stakeholder organizations, grassroots activists across the country, and the courageous leadership from our congressional allies, vital work will be maintained and expanded by federal agencies to accelerate science and improve quality of life among people living with dementia and their carers. NIH's overall budget will be increased by another \$2.6 billion to \$41.68 billion (38.6% growth since FY 2016) and Alzheimer's/dementia research will be increased by \$350 million to an astonishing \$2.818 billion annually (NIH invested \$631 million in dementia research in FY 2015, so the FY 2020 level will be roughly 447% higher). Because all NIH institutes will receive an increase in their base funding apart from the \$350 million increase targeted to NIA for dementia research, NIA likely will have total resources above \$2.82 billion available for dementia research. FY 2020 funding for the BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies Initiative) will increase \$71 million to \$500 million. A wide variety of aging services and support programs also are slated to receive increase funding in FY 2020, including a number of programs particularly important to the dementia community including the Alzheimer's disease demonstration grants, respite care, home delivered and congregate meals, and SHIP. See the NCOA aging program funding chart for a thorough breakdown of FY 2020 levels. The appropriations package also will triple CDC's resources its public health approach to brain health and dementia by adding \$10 million to begin implementation of the BOLD Infrastructure for Alzheimer's Act.

In addition to funding, the legislative package includes appropriations language expressing congressional intent to federal agencies. Here are a handful of examples of dementia-specific or dementia relevant appropriations language:

- Detecting Cognitive Impairment
- Further, the agreement urges NIDDK to work with NIA to explore the relationship between diabetes and neurocognitive conditions, such as dementia and Alzheimer's disease.
- Diversity of Clinical Trials
- National Alzheimer's Disease Plan
- Frontotemporal Degeneration Research-

## What's Next

Once these appropriations have been signed into law, the responsible federal agencies will be able to expend up to the legislated levels; in some cases, this will involve public comment and/or grant opportunities and the LEAD Coalition will endeavor to share information as it becomes available. Because the fiscal year began October 1 (2019) and will end on September 30 (2020), the roughly three month delay in passing the appropriations legislation compresses the time down to nine months in which funds must be utilized; thankfully, a number of key agencies (including NIH) have planning well underway and should be able to hit the ground running. That said, the FY 2021 appropriations process will begin in earnest in late winter, so please do not hesitate to engage me in your thinking about potential FY 2021 appropriations priorities (both dollars and language).

Best wishes and many thanks!

Ian

**Ian N. Kremer**

Executive Director

Leaders Engaged on Alzheimer's Disease (LEAD Coalition)



### Background:

The World Young Leaders in Dementia (WYLD) Network is an international network of passionate, young

professionals working across disciplines and borders to develop innovative dementia solutions. Our membership covers over 400 individuals from 30 countries across six continents, all of whom are young professionals in research, business, art and advocacy; all focused-on dementia-related careers.

The mission of the network is to build capacity and capability in the global research and care workforce, making dementia a public health priority, giving emerging leaders in dementia a voice in the global policy space, as well as bringing the value of diversity in tackling the challenges of dementia. Find out more and support our work at [wyldementia.org](http://wyldementia.org).

### Engagement:

On the local level, WYLD works to help our members plan and realise dementia inclusive initiatives, raise awareness of dementia and social inequalities in dementia. We facilitate professional careers through identifying and promoting training and mentorship opportunities as well as conducting stimulating networking and knowledge exchange between young professionals. We arrange seminars and conference workshops with experts on progressive topics. In our newsletter, we circulate advocacy endeavours, job postings, funding and development opportunities to our members. WYLD also connect and facilitate the engagement of our members with guidance from patient advocacy groups, such as Dementia Alliance International and the 3 Nations Dementia Working Group.

On a global level, WYLD supports policy efforts across all fields of research, cure, and care. We are open and collaborative with both our research and the facilitation of new entrepreneurial ventures amongst our members. WYLD regularly contributes to international scientific and policy efforts by reviewing/consulting on draft dementia strategies and publications developed by international health or care organisations, governments, academic groups and others (e.g. Alzheimer's Disease International, World Health Organization, the United Nations, World Federation of Science Journalists, etc.).

### Highlights of 2019:

- Several international presentations including the Engaged Dementia Conference (Dublin, April 2019); and AAIC Satellite Symposium (Sao Paulo, April 2019);
- Two invited presentations at Dementia Alliance International 'Meeting of the Minds' events one from Dr Laura Booi on her work co-founding WYLD (May 2019) and one from Dr Noelannah Neubauer about her work co-founding the International Consortium on Dementia and Wayfinding (August 2019);
- Social media video campaign to support the WHO Global Action Plan on Dementia (May 2019);
- Invited symposium on technology innovations in dementia diagnoses and care at Alzheimer's Europe, over 50 people attended; (The Hague, October 2019);
- Invited participation to the Copenhagen Summit on Cognitive Reserve, (Copenhagen, October 2019);
- Invited participation to the North East Dementia Alliance meeting (Newcastle, December 2019);
- Online membership engagement:
  - Membership online survey, in total 43 WYLD members responded (June 2019);
  - Volunteer contributors call, in total 22 WYLD members reached out to help the network (November 2019);
  - Leadership and sustainability call, in total 17 WYLD members participated (December 2019).

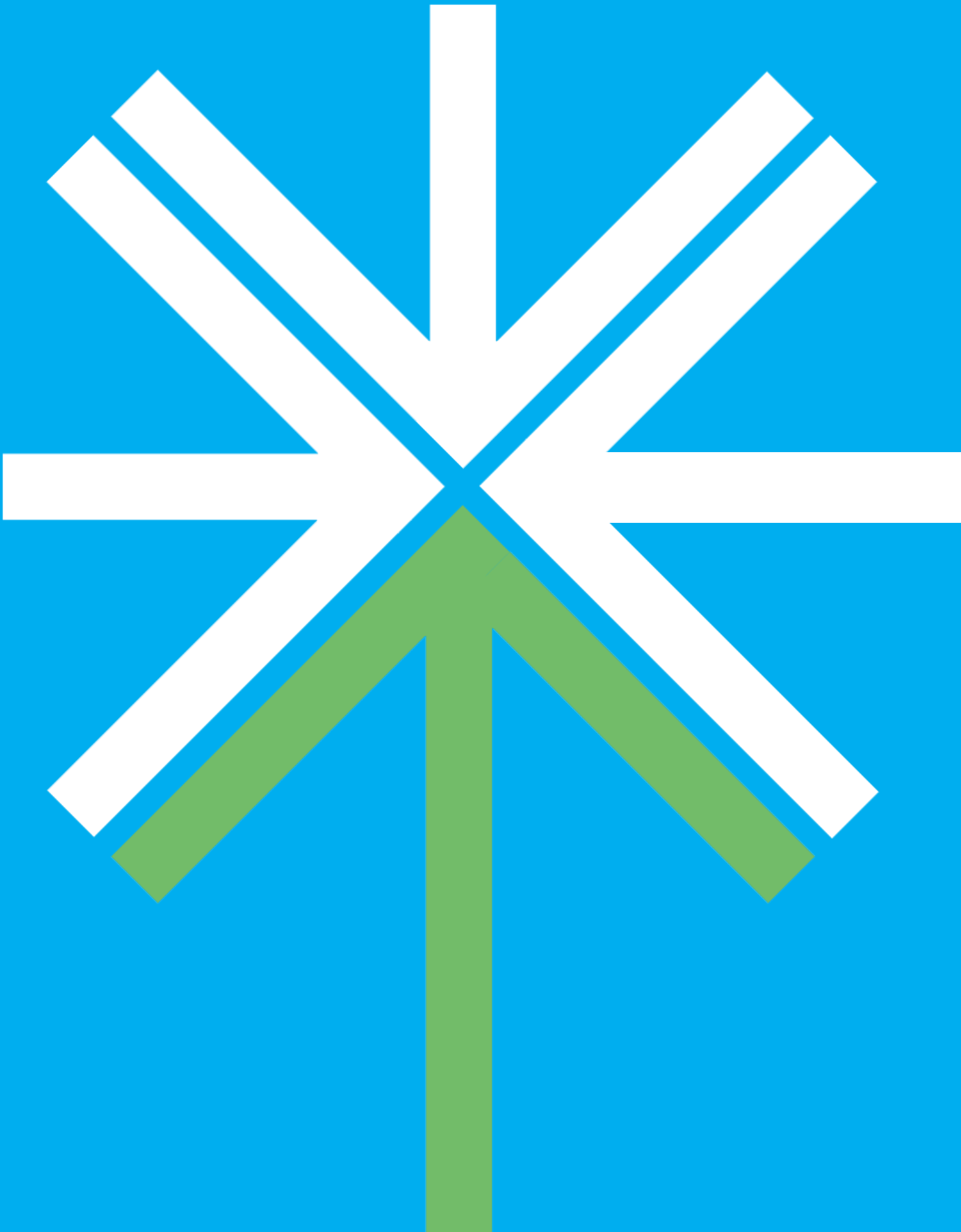
### Exciting developments for 2020:

- Develop a full-day event in focusing on dementia innovation in practice and design methods (Singapore, March 2020);
- Presentation at the AAIC Satellite Symposium (Athens, April 2020);
- Re-ignite the Virtual Seminars for WYLD members;
- Develop a symposium for Alzheimer's Europe (Bucharest, October 2020);
- We are also looking forward to working closely with DAI in 2020!

We are grateful for this opportunity to share the work of the WYLD network to members of DAI.

**Laura Booi PhD,**

Co-founder and WYLD Steering Group member



Research  
Projects

# Research Projects



## Safe and Just Futures for people living in Residential Aged Care 2019 Summary

This project investigated the impact of restrictive design in residential aged care facilities (RACFs) on the quality of life of people with dementia, and the project team presented its findings later in 2019 in a written submission to the Royal Commission into Aged Care in Australia, a bid to ensure the Commission considers the effects of the built environment.

The Safe and Just Futures for People Living with Dementia in Residential Aged Care research project will explore a range of questions including:

- Why do we house people living with dementia in large numbers separate to the rest of the community and most often separate to residents without dementia?
- Why do we have buildings that lock up people living with dementia and prevent them from accessing the community?
- What impact does this have on people living with dementia and the overall diversity and vibrancy of our communities as a whole?

Dr Linda Steele from the University of Technology Sydney was the Chief Investigator leading the project, working alongside Professor Richard Fleming and Dr Lyn Phillipson from the University of Wollongong and Kate Swaffer from Dementia Alliance International and the University of South Australia.

We all know that in most RACFs, people living with dementia are separated in locked facilities with limited access to outdoor spaces and the wider community, and there has been a growing demand for this to change, so that people with dementia are supported to live with their rights being upheld.

The project used the United Nations Convention on the Rights of Persons with Disabilities as a framework through which to view the restrictive environment of aged care facilities' segregation as an injustice to residents with dementia. Ms Swaffer, an international dementia rights advocate and person living with dementia, says most care providers restrict people with dementia's personal movement and access to all areas of society, and further segregate them from the rest of the community, including other residents.

The project team held forums in Wollongong and Sydney in May 2019 to bring together people living with dementia, care partners, aged care facility residents and employees, dementia advocates and lawyers, and aged care regulators for focus group discussions. Other focus groups and interviews were held throughout the project.

The aim was to seek people's views on buildings and other aspects of indoor and outdoor environments in RACFs, and to explore the extent to which residents with dementia have freedom to move through environments, including having community access that supports their quality of life. These forums also explored human rights perspectives on community access. A final Summit was held in Sydney later in 2019.

The project lead, Dr Linda Steele can be contacted by email [Linda.Steele@uts.edu.au](mailto:Linda.Steele@uts.edu.au) if you have any queries.



The first publication (1/5) published as part of this project:

Steele, L, Swaffer, K, Fleming, R & Phillipson, L. (2019). Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes, Laws, 8(3), 18; <https://doi.org/10.3390/laws8030018>.

Image source: Devon Bunce. Produced as part of the Summit: Human Rights for People Living with Dementia



**COGNISANCE: Co-designing a better experience of dementia diagnosis and support after diagnosis**

Many countries around the world have clinical dementia guidelines that set out the way in which a diagnosis of dementia should be made and communicated. Guidelines also contain information about support that should be available following diagnosis. Despite this, people diagnosed with dementia and their families are often dissatisfied with the experience and receive limited post diagnostic support.

To improve the experience of diagnosis and post diagnostic support, a new approach is being tried by the Co-designing dementia diagnosis and post-diagnostic care (COGNISANCE) project. COGNISANCE is a project led by Australia and involves four other countries - UK, Netherlands, Poland and Canada.

COGNISANCE is using 'co-design' methods. Co-design means there is an equal partnership between people who have lived experience (people with dementia and care partners, people 'at risk' of dementia, people who work in the health and social support systems and researchers).

Our aims are to produce provide a new, internationally adaptable sets of recommendations and toolkits for persons

living with dementia, their care partners and health and social care practitioners on how to make the diagnostic process and post diagnostic care as positive an experience as possible.

Once toolkits are developed, they will be promoted through social marketing campaigns – using for example, local papers, radio, social media and maybe even billboards, in selected localities of each participating country to get people asking for and service providers delivering more timely diagnosis and better ongoing support.

The study is led by Professor Henry Brodaty (UNSW Sydney), Associate Professor Lee-Fay Low (University of Sydney), Professor Isabelle Vedel (McGill University), Frans Verhey (Maastricht University), Joanna Rymaszewska (Wroclaw Medical University), Professor Greta Rait and Professor Dame Louise Robinson (University College London and Newcastle University).

Partners include Kate Swaffer (Dementia Alliance International), Dr Katrin Seeher (World Health Organisation), Wendy Weidner (Alzheimer's Disease International), Dr Lyn Phillipson (University of Wollongong), Carrie McAiney (University of Waterloo), and Shelly Doucet (New Brunswick University).

This project was awarded by the EU Joint Program – Neurodegenerative Diseases Research Program (JPND) and is funded by national funding bodies.

For further please see the study website, or contact the study co-ordinator, Dr Meredith Gresham at [cognisance@unsw.edu.au](mailto:cognisance@unsw.edu.au).



COGNISANCE full team meeting in The Hague, Oct 2019

# Research Projects



**A good life: developing a new quality of life instrument with older Australians for economic evaluation in aged care.**

This project seeks to develop a suite of quality of life measures that can be used for quality assessment and economic evaluation in aged care across community and residential aged care settings. In order to be used for economic evaluation, the measures must be preference-based. That means the identified quality of life domains will be weighted according to the importance of those domains to older people.

Unlike other quality of life measures, these measures will be developed from their inception with older people. We have also sought to be inclusive in our recruitment, including people with cognitive impairment and dementia if they are able to provide informed consent to participate. Initial eligibility is determined by providers and final eligibility by the research team. Participants are not required to undertake any cognitive testing as part of eligibility determination or for data collection.

Throughout 2019 we conducted qualitative interviews with 40 older people in the community receiving Home Care packages and 40 older people in residential aged care. These people were recruited through our industry partners as well as two affiliate organisations: Kalyra Communities and Willochra House in South Australia. Interviews were conducted in four states (SA, VIC, NSW, TAS) and included rural and metro communities.

The research team has completed qualitative analysis of the community data and identified five key quality of life

domains. Draft items and response categories have now been developed and will be tested for practicality and face validity in 2020 on a further 40 older people receiving Home Care packages. Some of our previous participants have indicated a willingness to be involved in the research again and we will also be talking to some people who have not previously been involved. Later in the year, the refined list of questions and response categories will be subject to more rigorous psychometric testing with older people using online and interviewer-facilitated modes of administration.

Qualitative analysis of the residential data is underway, and it is expected that the residential care quality of life measure will have some similarities to the community care quality of life measure as well as some differences. Development of questions and response categories and the subsequent refinement of those working in partnership with older people in residential care will occur later in 2020. In late 2019 the project launched its website which will be updated regularly.

Chief Investigator organisations: Flinders University, University of Sydney, Australia National University, Dementia Alliance International.

Industry Partner Organisations: Helping Hand, ECH, Uniting Agewell, Uniting NSW ACT, Presbyterian Aged Care.

Project Lead: Professor Julie Ratcliffe Timeframe: 2019-2021

Publications in 2019 included:

Ratcliffe, J., Cameron, I., Lancsar, E., Walker, R., Milte, R., Hutchinson, C., Swaffer, K. & Parker, S. (2019). Developing a new quality of life instrument with older people for economic evaluations in aged care: study protocol, *BMJ Open*, 9,e028647, doi: 10.1136/bmjopen-2018-028647 <https://bmjopen.bmj.com/content/9/5/e028647.abstract>

Cleland, J., Hutchinson, C., Milte, R., Khadka, J. & Ratcliffe, J. (2019). A review of the development and application of preference-based instruments with the older population, *Applied Health Economics and Health Policy*, first published online 13 September 2019, doi: 10.1007/s40258-019-00512-4. <https://link.springer.com/article/10.1007/s40258-019-00512-4>



Researchers Professor Julie Ratcliffe, Dr Claire Hutchinson, Dr Rachel Milte and PhD candidate Jenny Louise, Health Economics Group at Flinders University.





**STRiDE 2019 Summary**  
**(STrengthening Responses to dementia in DEveloping countries):**

Dementia affects more people in low- and middle-income countries than it does in the UK or other high-income countries, yet few countries are prepared for the challenges of the growing number of people with dementia. This project is examining current practice, both at a national level and for individual families, both to help people living with dementia to live well, and to ensure that family and other carers do not face excessive costs that could impoverish them or compromise their own health. One of the core activities is to understand the impacts of dementia in various cultural, social and economic contexts in order to support development, financing, planning, implementation and evaluation of National Dementia Plans.

The research is led by the Care Policy and Evaluation Centre at the LSE, in partnership with the Universities of Sussex and Cape Town, Alzheimer's Disease International and Dementia Alliance International. Funding by UK Research and Innovation through its Global Research Challenges Fund. You can find more information on their website

**Publications in 2019 included:**

Breuer E, Comas-Herrera A, Docrat S, Freeman E, Schneider M and the STRiDE team (2019) STRiDE Theory of Change Workshops: Guidance and Resources. STRiDE Research Tool No.1 (version 2), Care Policy and Evaluation Centre at LSE, London.

Ferri C, Mateus E, Oliveira D, da Mata F (2019) Stigma in Brazil: The narrative of a person with young-onset dementia, in Alzheimer's Disease International, World Alzheimer Report 2019: Attitudes to Dementia, ADI, London, pp 116.

Musyimi C, Mutunga E, Ndeti D (2019) Stigma and dementia care in Kenya; Strengthening Responses to Dementia in Developing Countries (STRiDE) Project, in Alzheimer's Disease International, World Alzheimer Report 2019: Attitudes to Dementia, ADI, London, pp 121-122.

Salcher-Konrad M, Naci H, McDaid D, Alladi S, Oliveira D, Fry A, Hussein S, Knapp M, Musyimi CW, Ndeti DM, Lopez-Ortega M, Comas-Herrera A (2019) Effectiveness of interventions for dementia in low-and middle-income countries: protocol for a systematic review, pairwise and network meta-analysis, *BMJ Open*, 9, 6, e027851.



Theory of Change workshop participants.



Dementia  
Working  
Groups

Dementia Alliance International works with many ADI Members around the world, supporting them to empower and train self advocates. We do this to ensure the voices of people with dementia are not only heard, but that policies and programs reflect the needs of people with dementia and their families in each country or region.

# Dementia Advocacy Canada 2019

## It all started over a beer!

Dementia Advocacy Canada (DAC), formed in January 2019, is a grassroots group of people living with dementia and care partners from across Canada who want to live in balanced partnership in the community and to influence policy, inform program development and improve access to supports and services across Canada.

DAC emerged as an extension of conversations began at Canada's National Dementia Conference held in Ottawa, Ontario in May 2018. There was a strong desire to foster the connections made with others across the country and to build on the growing momentum.

The conversations moved online, and the group continued to grow. Several months were spent debating and co-creating a vision, a mission, values and a name. An executive team consisting of (4) people living with dementia and (1) care partner was elected. Then, there was more discussion and debate to determine DAC's advocacy priorities, followed by a survey to confirm consensus on the top three. With stigma and human rights as crosscutting issues the top three priorities are:

1. Rehabilitation for people living with dementia immediately upon diagnosis
2. A single point of contact to navigate the healthcare system upon diagnosis through end of life
3. National education and training standards for the dementia workforce

DAC strives to collaborate as much as possible with existing groups to amplify the voice of lived experience and make a positive difference for people impacted by dementia. This includes social support organizations like the national

and provincial Alzheimer Societies, advocacy groups, technology accelerators and international groups like Dementia Alliance International.

Many DAC members are actively engaged as participants and speakers in local, national and international dementia-related events and conferences, including Christine Thelker's presentation at the 2019 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) held in New York city.

DAC hosts monthly webinars on a variety of dementia-related topics ranging from reducing the risk of getting lost to medical assistance in death (MAiD) to culturally appropriate dementia care to the value of rehabilitation for people living with dementia.

Leading up to Canada's federal election in October 2019, DAC organized a letter writing campaign from DAC members across Canada to the candidates in their ridings. and hosted a very successful online federal forum on dementia that included a candidate from each the four main politician parties presenting their party's dementia platform, how they would implement the newly released National Dementia Strategy and answering questions from the audience.

DAC's objectives for 2020 are to raise awareness about dementia through an advocacy campaign targeting politicians called "MP CANKnow Dementia" to garner their support to fully fund and implement the National Dementia Strategy, which was launched in June 2019.



Lisa Poole  
Co chair Dementia Advocacy Canada



Mary Beth Wighton  
Co chair Dementia Advocacy Canada



In Singapore, the Alzheimer's Disease Association is highly inspired with the work done by Dementia Alliance International (DAI). We are at the early stage of reaching out to families and persons with dementia to encourage them to share their inspiring stories through a new programme "Voices for Hope".

In 2018, during World Alzheimer's Month in Singapore, ADA invited DAI member Dennis Frost, his wife Tina and Nick Guggisberg, the Manager of Community Development for the Kiama Municipal Council, to share their experiences and insights on creating a Dementia Friendly Kiama.

Several Singaporeans also shared their personal stories – a first collaboration between international advocates, a local person with dementia and carer. With more persons with dementia exchanging their personal stories and hopes, it may accelerate initiatives as Singapore steers towards a dementia inclusive society.

We hope to continue working closely with DAI and share more good news in the months to come!

Thank you,

Francis Wong and Qian Ru Kong



ADA Singapore



# Alzheimers NZ Advisory Group 2019

The purpose of the Advisory Group is to provide Alzheimers NZ with insight into the experience, needs and expectations of people living with dementia, so that Alzheimers NZ's activities are focused on areas that will make a real difference for people living with dementia.

Members of the Advisory Group are made up of those with a diagnosis of dementia and those who provide support for a person with dementia.

With the goal of supporting people with dementia to live well, we were proud to launch NZ's first Dementia Declaration. The Declaration was written by New Zealanders actually living with dementia and outlines clearly what we need to live a meaningful life. It's a very compelling statement of which we should all take heed.

We were also proud to be part of Alzheimers NZ's research project This is our story as advisors, participants and monitors. This project features the lived experiences of 49 New Zealanders who either have dementia or are the care partner for someone living with the condition.

It is one of the first times we have had a first-hand account of what it's like to live with dementia in 21st century New Zealand. The research is being widely used and is based on the words of people living with dementia which makes it a powerful vehicle for strengthening the voice of the dementia community.

While this was happening, we were very busy on the government relations and advocacy front, meeting with Health Minister David Clark and Associate Health Minister Jenny Salesa, who seems to be warming to our cause, and various other politicians and officials, all of whom have an interest in, or responsibility for, healthy aging. We are hopeful we can make more progress in this area in the coming year.

Closely aligned to this work was the involvement of one of our members together with other members of the dementia sector in drafting the key steps needed in a Dementia Action Plan for NZ. We hope that this draft would then start a series of discussions within all the parts of our sector. The plan will be largely based on the WHO's suggested priorities for national action plans.

The Advisory Group took the opportunity to provide input into submissions on Carers Strategy Action Plan 2019-2023, Budget and input on NZ's performance in implementing the UN Convention on Rights of Persons with Disabilities. The group also has member(s) on Alzheimers NZ Education Advisory Group and Alzheimers NZ Board.





The Dementia Australia Advisory Committee provides a national platform for people living with dementia to advocate alongside Dementia Australia on matters important to them.

The group, previously known as the Alzheimer's Australia Dementia Advisory Committee, was founded in 2013. It was established in response to people with dementia around Australia who wanted to be involved in advocating for the needs of people with dementia and their families.

Committee members come from a wide range of professional backgrounds and use their skills, lived experience and connections as community leaders to represent people living with dementia.

As a formal group, the committee provides strategic advice to Dementia Australia and other stakeholders on shaping dementia services, programs, policy development and advocacy goals. The committee aims to be a catalyst of change, working towards an inclusive future, where people living with dementia are valued and respected.

Members meet monthly via video conference with one or two face to face meetings a year. For more information please visit <https://www.dementia.org.au/about-us/advisory-groups/dementia-advisory-committee> or if you would like to get in touch with the committee please email [DAAC@dementia.org.au](mailto:DAAC@dementia.org.au)



# International Advisory Group

DAI has implemented an International Advisory Group (IAG), which was set up to provide professional support, and as required, advice. Members review publication drafts of publication or other DAI documentation, get involved in research projects, or get involved with, or provide assistance or support with DAI projects. Historically, national or local organizations advocating for people with dementia and/or their families invite people with dementia and care partners to join their advisory groups.

DAI has upturned this concept for the purpose of ensuring we have a depth of expertise and knowledge to draw on, and we include people with and without dementia. We are very grateful to the members of this group, and understand they contribute as they are available to, or when they have an interest in a specific project or topic. If you are also interested in becoming involved, please contact us at [info@infodai.org](mailto:info@infodai.org)

<b>DAI members of the IAG</b>
Cheryl Day, Australia
Bonnie Erickson, USA
Diana Blackwelder, USA
James McKillop, Scotland
Julie Hayden, UK
Bobby Redman, Australia
Val Schache, Australia
Alister Robertson, New Zealand
Walter Cox, USA
Bill Turner, Australia
Dennis Frost, Australia
David Paulson, USA
Paul Lea, Canada
Agnes Houston, Scotland
Jane Washburn, USA
Lynda Henderson, Australia
Mary Beth Wighton, Canada
Eileen Taylor, Australia
Ian Gladstone, Australia
Emily Tan Tan Ong, Singapore

<b>Professionals of the IAG</b>
Ian Kremer, EO, LEAD Coalition, USA
Daniella Greenwood, Dementia Consultant, Australia
Bill Hillstrom, CPA, USA
Chris Lynch, Deputy CEO, ADI, UK
Sarah Yeates. CEO, Caladenia, Australia
Denise Craig, Psychologist and PhD Candidate, Australia
Dr Kenny Chui, Hong Kong
Associate Professor Lyn Phillipson, Australia
Associate Professor Lee-Fay Low, Australia
Sonya Barsness, USA
Susan Macauley, Canada
Lisa Poole, Canada
Leah Bisiani, Dementia Consultant, Australia
Al Power, MD, USA
Teepa Snow, Dementia Consultant, USA
Tamara Claunch, Wellness coach, USA
Dr Ellen Skladzien, CEO, Downs Syndrome Australia, Australia
Dr Daniel C. Potts, USA
Dr Louise Heuzenroeder, Australia
Dr Sue Jarrad, Australia





In 2019 DAI commenced a major review of its services, and overall operational performance and governance. The following flowchart outlines our working structure.

Discussions were held, board and member surveys have been completed, and reviews will be completed early 2020. A review of the CEO performance will also be undertaken by the board members. Many of the operational tasks have, to date, been completed by the board, and we are working towards our sub committees and volunteers taking over much of this work, and the board moving towards governance. We are also keen to hear from you, on matters like this, as well as member services, and are actively engaging with members of the Action group and emerging sub committees to ensure members are being best served, and we are fully IRS compliant.

DAI has and will continue to review the By Laws and Strategic Plan, has developed a new travel policy, and reviewed other Governance documents in depth. This is a normal and required business practice. In 2019 we had two issues which required legal attention, and subsequently were advised to update the member criteria section to enable us to exclude membership to people who are, for example, convicted felons.

Two formal non-member (and non-voting) volunteer positions are also being considered, one as Secretariat, and the other as a Finance Officer, to support the Finance and Fundraising committee. Our Finance Committee has also been working with an online financial reporting programme called QuickBooks, to improve and ensure consistent and ongoing transparency of our finances. Like all new tasks or online platforms, it has been a complicated learning curve but has progressed well.

Members of our Action Groups, Membership Team and Finance Committee continue to provide sage advice which reflects good governance, organizational growth, and positive members experiences. We thank them for their hard work, commitment to DAI and to our members.





# Financial Reporting

This year, DAI has retained the services of Mr. Bill Kerr, from Hillstrom, Kerr and Company Incorporated in the US to complete our monthly financial reports, and we will publish our fourth Annual Report in 2020. John will present the Financial statements following this report; however, I present this very brief update on fundraising and the grants from our sponsors.



Hillstrom, Kerr & Company, Inc.  
1114 Longdraw Drive  
Katy, TX 77494  
(832) 436-4200  
www.hillkerr.com

January 14, 2020

To the Board of Directors  
Dementia Alliance International, Inc.  
Ankeny, Iowa

Management is responsible for the accompanying financial statements of Dementia Alliance International, Inc. (a Texas not-for-profit corporation) which comprise the statements of assets, liabilities and fund balance—tax basis for the year ended December 31, 2019, and the related statements of revenue and expenses—tax-basis, and changes to fund balance—tax-basis in accordance with the tax-basis of accounting for the year ended December 31, 2019, and for determining that the tax-basis of accounting is an acceptable financial reporting framework. We have performed compilation engagements in accordance with Statements on Standards for Accounting and Review Services promulgated by the Accounting and Review Services Committee of the AICPA. We did not audit or review the financial statements nor were we required to perform any procedures to verify the accuracy or completeness of the information provided by management. Accordingly, we do not express an opinion, a conclusion, nor provide any form of assurance on these financial statements.

The financial statements are prepared in accordance with the tax-basis of accounting, which is a basis of accounting other than accounting principles generally accepted in the United States of America.

The owners have elected to omit substantially all of the disclosures and the statement of cash flows ordinarily included in financial statements prepared in accordance with the tax-basis of accounting. If the omitted disclosures and statement of cash flows were included in the financial statements, they might influence the user's conclusions about the Company's financial position, results of operations, and cash flows. Accordingly, these financial statements are not designed for those who are not informed about such matters.

Sincerely,

A handwritten signature in blue ink that reads "Hillstrom, Kerr &amp; Company, Inc." in a cursive script.

Hillstrom, Kerr & Company, Inc.



DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019

STATEMENT OF REVENUE AND EXPENSES

Through December 31, 2019

REVENUE

DONATIONS, GRANTS and REIMBURSEMENTS \$ 53,454.54

EXPENSES

SOFTWARE EXPENSES \$ 2,957.93

BANK CHARGES \$ 352.00

POSTAGE \$ 103.60

LODGING

EQUIPMENT PURCHASE \$ -

SALES TAX \$ 12.60

ADVERTISING \$ -

PAYPAL FEES \$ 126.26

ACCOUNTING SOFTWARE FEE \$ 175.00

PROFESSIONAL FEES \$ 880.00

REIMBURSED EXPENSES \$ 1,615.43

MISCELLANEOUS EXPENSES \$ 977.40

TRAVEL AND CONVENTION EXPENSES \$ 46,422.98

\$ 53,623.20

\$ 53,623.20

\$ (168.66)

# Financials

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019

## STATEMENTS OF ASSETS AND LIABILITIES AS OF DECEMBER 31, 2019

### ASSETS

BANK BALANCE WEST BANK	\$ 70,906.58
PAYPAL BALANCES	<u>\$ 4,567.81</u>
TOTAL ASSETS	\$ 75,474.39

### LIABILITIES AND FUND BALANCE

LIABILITIES	\$ -
FUND BALANCE	<u>\$ 75,474.39</u>
TOTAL LIABILITIES & FUND BALANCE	\$ 75,474.39



DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019  
DECEMBER 31, 2019

CHANGES IN FUND BALANCE

BEGINNING BALANCE JANUARY 1, 2019		\$ 75,643.05
DONATIONS	\$ 53,454.54	
TRANSFERS		
EXPENSES	\$ 53,623.20	
		<u>\$ (168.66)</u>
ENDING BALANCE DECEMBER 31, 2019		\$ 75,474.39

# Financials

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019

STATEMENTS OF CHANGES IN RESTRICTED FUNDS  
AS OF December 31, 2019

## ADI GRANT

GRANT AMOUNT	\$ 65,000.00
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## DAI TRAVEL EXPENSES

January	\$ 1,580.03
February	\$ -
March	\$ -
April	\$ 1,716.93
May	\$ -
June	\$ 20,377.15
July	\$ 10,750.75
August	\$ 295.25
September	\$ 35.40
October	\$ 6,195.55
November	\$ 2,500.00
December	\$ 3,035.35

\$ 46,486.41

Net funding remaining	\$ 18,513.59
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DEMENTIA ALLIANCE INTERNATIONAL, INC.  
 COMPILATION REPORT 2018  
 FOR THE YEAR ENDED DECEMBER 31, 2019

	INDIVIDUALS	CORP SPONSORS	GRANTS	EVENTBRITE WEBINARS CONSULTING	MISC	TOTALS
January						
	WestBank	\$ 271.78	\$ -	\$ -		\$ 271.78
	PayPal	\$ 5.74				\$ 280.15
February						
	WestBank	\$ 597.12		\$ 540.00	\$ 4,990.00	\$ 6,127.12
	PayPal	\$ 0.76				\$ 370.76
March						
	WestBank	\$ 211.40		\$ 713.00		\$ 1,064.40
	PayPal	\$ 0.15				\$ 120.15
April						
	WestBank	\$ 311.01	\$ 20,000.00	\$ 100.00	\$ 3,939.20	\$ 24,350.21
	PayPal	\$ 0.52				\$ 120.52
May						
	WestBank	\$ 638.54			\$ 186.20	\$ 824.74
	PayPal	\$ 1.11				\$ 1,121.11
June						
	WestBank	\$ 710.86			\$ 150.00	\$ 943.32
	PayPal	\$ 6.32				\$ 126.32
July						
	WestBank	\$ 77.90		\$ 10.00	\$ 44.73	\$ 132.63
	PayPal	\$ 2.63				\$ 224.70
August						
	WestBank	\$ 259.25				\$ 259.25
	PayPal	\$ 0.40				\$ 160.40
September						
	WestBank	\$ 292.67		\$ 45.00		\$ 337.67
	PayPal	\$ 2.09				\$ 122.09
October						
	WestBank	\$ 51.00		\$ 120.00		\$ 171.00
	PayPal	\$ 111.74				\$ 111.74
November						
	WestBank	\$ 233.04	\$ 15,000.00			\$ 15,233.04
	PayPal	\$ 611.00				\$ 611.00
December						
	WestBank	\$ 245.44		\$ 125.00		\$ 125.00
	PayPal					\$ 245.44
		\$ 2,848.94	\$ 35,000.00	\$ 1,653.00	\$ 9,310.13	\$ 53,454.54

# Financials

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019

## STATEMENT OF REVENUE AND EXPENSES DEC 2019

### REVENUE

DONATIONS		\$	370.44
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### EXPENSES

SOFTWARE EXPENSES	\$	282.22	
BANK CHARGES	\$	40.00	
POSTAGE	\$	-	
LODGING & TRAVEL			
ACCOUNTING SOFTWARE FEES	\$	70.00	
EQUIPMENT PURCHASE			
SALES TAX	\$	2.80	
ADVERTISING	\$	-	
PAYPAL FEES	\$	6.98	
PROFESSIONAL FEES	\$	-	
REIMBURSED EXPENSES	\$	-	
MISCELLANEOUS EXPENSES	\$	-	
TRAVEL AND CONVENTION EXPENSES	\$	3,035.35	
	\$	3,437.35	
		<u>\$</u>	<u>3,437.35</u>
		\$	(3,066.91)



DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2019  
FOR THE YEAR ENDED DECEMBER 31, 2019

STATEMENT OF REVENUE AND EXPENSES  
CHECKING ACCOUNT WEST BANK  
BEGINNING BALANCE DECEMBER 1, 2019

\$ 74,086.99

REVENUE

Eventbrite, Inc.  
Wire Transfer  
Wire Transfer  
Network for Good Payment  
Eventbrite, Inc.  
Eventbrite, Inc.  
Wire Transfer  
Wire Transfer

\$ 125.00

\$ 125.00

EXPENSES

ADVERTISING  
CHECK PRINTING  
EQUIPMENT PURCHASE  
WEBSITE  
DEBIT CARD FEE  
PROFESSIONAL FEES  
POSTAGE  
TRAVEL REIMBURSEMENT  
CONVENTION EXPENSE  
WIRE TRANSFER FEE  
SALES TAX  
ACCOUNTING SOFTWARE FEE

\$ 157.26

\$ 3,035.35

\$ 40.00

\$ 2.80

\$ 70.00

\$ 3,305.41

ENDING BALANCE DECEMBER 31, 2019

\$ 70,906.58

# Fundraising

Fundraising continues to grow modestly, and I wish to officially and personally thank every single person who has donated to DAI. Whether is it \$5 or \$500, every amount helps. We have to make the small funds we have stretch a long way, and also must keep funds in reserve for our future. Our fundraising team, also part of the Action Group are getting organised for campaigning to get as many members to Singapore for the ADI conference in March next year as possible.

## Grants, Donors and Strategic partnerships update

**Alzheimer's Disease International:** Our Strategic partnership with ADI has been signed off to continue into 2020, and we continue to work collaboratively with them. DAI Chair and co founder, Kate Swaffer was re-elected as a board member, serving her second three-year term from July 2019.

**Boehringer Ingelheim International GmbH (BI):** The \$20,000 restricted funding received from BI was provided specifically for the following:

1. Attendance at the CoSP12, June 2019
2. A Capacity Building Program, held in LA in July 2019
3. Publication on Capacity building and engagement, in progress, to be launched at the ADI2020 conference in Singapore

**Dementia Australia (DA):** DAI now has a strategic partnership with Dementia Australia, which included a small donation of unrestricted funding, with discussions in progress for 2020.

**Australian Community Hubs Grant:** DAI received a small restricted Community Hubs Grant in Australia, for the period July 1, 2019 to June 30, 2020, which is to be used to fund the cost of peer to peer support group co-host training and zoom or website costs.

**Other:** A small number of research projects also support our time and expertise with funding; Graphic Print have continued to provide pro bono printing for DAI, for which we are extremely thankful; we also received a generous grant from an Individual Partner, Lisa Poole, allocated for use to support the funding of a new publication.

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has. (Margaret Mead)



# DEMENTIA ALLIANCE INTERNATIONAL

The global voice of dementia

- Exclusive to people with dementia
- A global community that promotes living beyond the diagnosis of dementia
- Advocacy, education & awareness
- Eradicating stigma, isolation & discrimination
- Weekly online support groups for people with dementia

 email: [info@infodal.org](mailto:info@infodal.org)  website: [www.infodal.org](http://www.infodal.org)

 [www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)

 [@DementiaAlliance](https://twitter.com/DementiaAlliance)





**DEMENTIA  
ALLIANCE  
INTERNATIONAL**

The global voice of dementia

**GRAPHIC**   
PRINT GROUP



*The work of Dementia Alliance International is supported by many individual donors, and these major sponsors*

email: [info@infodai.org](mailto:info@infodai.org)

web: [www.infodai.org](http://www.infodai.org)

join DAI: [www.joindai.org](http://www.joindai.org)



[www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)



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