



Voice OF Dementia

The newsletter of the Alzheimer's Disease Association

VOLUME **4** ISSUE **2**
JULY 2020

ALL IN A DAY'S WORK

**BLESSED WITH THE
SKILLS, LANGUAGES,
AND PASSION TO CARE
FOR THE AGED**

HEAR ME OUT!

**CALLING FOR THE
RIGHT SUPPORT**

DONOR SPOTLIGHT

**REACHING OUT IN
TIMES OF CRISIS**

ON THE FRONTLINE

THE POWER OF COURAGE

Facing his diagnosis with courage, Anjang Rosli readily speaks up about dementia, inspiring others with his firm resolve not to let the condition define him.

SUPPORT FOR PERSONS LIVING WITH DEMENTIA OVER THE COVID-19 PERIOD (SPOC-19)

In May 2020, ADA, in collaboration with the Agency for Integrated Care (AIC), and with support from the Ministry of the Environment and Water Resources (MEWR), launched the SPOC-19 initiative. SPOC-19 aims to offer additional support to persons living with dementia and their caregivers who may inadvertently violate COVID-19 safety measures due to their condition.

Some persons living with dementia may lack the cognitive ability to fully understand the COVID-19 situation and would have found it challenging to follow circuit breaker measures. Caregivers and social service agencies have also voiced concerns regarding the safety of those with dementia, and their inability to comply with safety measures.

“

“The process to apply for the ADA Memo is very clear and straight to the point. I would recommend caregivers to apply for their loved ones with dementia.”

Michael Chang, caregiver to his mother Tan Lian Huay who attends New Horizon Centre (Bukit Batok).



“It’s important to help families have the peace of mind, knowing that their loved ones will not be at a disadvantage when they wish to go outside independently to run errands, for example. Dignity is maintained with identifiers like the ADA Memo in place during COVID-19.”

Agnes Lee, caregiver to her father Peter Lee who is living with dementia.



“I feel secure with the ADA Memo on hand. It’s difficult to stop my sister from heading out of the house, even more so when she doesn’t like to wear a mask.”

Tay Nga Woo, caregiver to his sister Tay Sai Chu who attends New Horizon Centre (Bukit Batok).



Scan to read more.

REIMAGINING DEMENTIA CARE

ADA was formed in 1990 out of growing concern for the needs of people with dementia and the needs of their families. In 1991, the first dementia day care centre in Singapore, New Horizon Centre (Toa Payoh), was set up. Fast forward 30 years on and today, whilst there has been an increase in the number of services and facilities for people living with dementia and caregivers, there is much more work to be done for Singapore’s future.

It starts with the voices of people living with dementia and their families; Voices like the late Dr Richard Taylor who said “Our humanity is still and will always be intact”; Christine Bryden who, in her book ‘Dancing with Dementia’, describes dementia as a “mystery illness that robs us of who we think we are”; Kate Swaffer, who, at 49 years old was diagnosed with young-onset dementia, and is a living testament to the statement “I can live well with dementia and should be respected for who I am.”

Voices continue to reverberate in Singapore. ADA’s ‘Voices for Hope’ programme advocates Wong Lai Quen and Steven Lau shared their struggles and pains in coping with dementia in The Sunday Times in May 2020. In the article, Steven said: “I am not ashamed to have dementia, and I need to speak up because somebody has to champion it.”

Many more conversations are necessary to continue to innovate and improve services and quality of care, showcase best practices in dementia care, improve the lives of people living with dementia and caregivers, increase awareness, transform dementia care the person-centred way, enable access to information and resources, and build on inclusion in dementia-friendly communities. We will also need to continue influencing policies and adapting to new ways of working and delivering services via digital technology in a post-COVID-19 world.

My wish is to overcome the stigma of dementia and reimagine dementia care. I would like to lend my voice to advocate for positive living with dementia. This means shifting the negative language of dementia and removing the walls of fear, to the positive language of acceptance, encouragement, engagement, respect, and sense of belonging in the community.

My hope is that one day, there will be a cure or a world without stigma. What would that world look like?

– Contributed by Mrs Theresa Lee, Former Deputy CEO of ADA

Having been connected to ADA since its inception, and working with ADA for the past 19 years, it is with heavy heart that ADA bids farewell to Mrs Theresa Lee, who embarked on her retirement in May 2020. ADA expresses our enormous gratitude to Mrs Lee for her dedication and commitment in supporting the dementia cause over the decades, and for her contributions to building ADA to what it is today.

“



WAM 2020

World Alzheimer’s Month (WAM) is back – bigger and better than before! Following last year’s successful outdoor WAM 2019 Carnival, ADA aims to once again get people out and about for a good cause. Bearing the overarching theme of ‘Empowerment’, WAM 2020 aims to empower and enable every person in Singapore’s dementia community, be it a person living with dementia, caregiver, relative, friend or ally.

Enter the ADA Walk2Remember 2020, a nationwide steps challenge to encourage one and all to actively support the dementia journey of some 82,000 persons living with dementia in Singapore. As a fully virtual walk-a-thon, participants simply need to register for the challenge online and start moving!

Kicking off on 1 September 2020, the number of steps each person clocks will be logged over 21 days, culminating in a finishing e-ceremony on 21 September, which is World Alzheimer’s Day. There are also prizes up for grabs for those who clock in significant steps, such as above 50,000 or 100,000 steps!

The ADA Walk2Remember 2020 is proudly supported by Cerecin. For more details on WAM 2020 and other fringe activities, visit alz.org.sg/wam2020.



CHANGING WORDS TO TOUCH LIVES AFFECTED BY DEMENTIA

In April, Alzheimer's Disease Association (ADA), together with Lien Foundation, launched the Dementia Language Guidelines booklet, titled "Changing Words, Touching Lives". The guidebook contains appropriate and inappropriate words and phrases to use when dealing with or speaking about dementia, and is available as a hardcopy book. Easily downloadable glossaries in Singapore's four official languages are also available from the ADA website.

Adapted from Dementia Australia's 2018 language guidelines, the guidebook lists preferred words and phrases, as well as terms to avoid, with a localised perspective. From casual conversations to social media posts and publicity materials relating to persons with dementia, the guidebook hopes to spur the community to consider the importance of each word; empowering words can go a long way to enabling people living with dementia to live full and dignified lives, instead of using hurtful words that can negatively affect the perception of the condition.

The guidebook is part of the Forget Us Not initiative by the Lien Foundation, Khoo Teck Puat Hospital, and ADA, that seeks to build a dementia-friendly community that enables persons with

dementia to lead active, engaged lives for as long as they can.

"The way we talk about dementia and people living with dementia affects how others view the condition. So communication is important in our fight against dementia stigma and must come before true inclusion in our societies can happen," said Mr Jason Foo, CEO of ADA.



For more information or to download the Dementia Language Guidelines, scan this QR code.

POST DIAGNOSTIC SUPPORT

In June 2019, ADA's Caregiver Support Services team embarked on a brand-new model of care named Post-Diagnostic Support (PDS), in partnership with Lien Foundation. Targeted at newly diagnosed persons with dementia and their families, the programme enables ADA to reach out to those who are unsure as to how to approach their loved one's recent diagnosis. Bridging the gap between diagnosis and embracing the new norm of life with dementia, PDS thus proactively equips families with information, care connections, plans, and tools to ease the confusion, pain and helplessness that is common upon initial diagnosis.

ADA works with Tan Tock Seng Hospital and Khoo Teck Puat Hospital to receive referrals for PDS. Over a journey of one year, ADA keeps in regular contact with the family to ensure that they are well-equipped to start their caregiving journeys, such as through developing a personalised and flexible Advanced Care Plan. The programme also facilitates linkages with caregiver peers, with the goal to create a group of like-minded caregivers who can continue to provide inter-personal support even after the PDS programme is over.



Words
can
hurt.

UNFORGETTABLE TRIP TO TAIPEI

From 27 November to 3 December 2019, 12 graduates from Voices for Hope, who subsequently joined the advocacy network "Forget Us Not Network", went on an overseas exchange trip to learn from Taiwan Alzheimer's Disease Association (TADA), one of ADA's partners in the region. Taipei has been praised for its efforts in empowering persons with dementia—something that the group hoped to learn more about. The one-week trip not only gave them more insights into what other dementia associations are doing in the region, but also provided opportunities for the families to foster their bonds as they continue to support each other in this self-advocacy journey.

ADA is thankful for this unforgettable trip funded by Lien Foundation with support from Singapore Airlines.



“

Caregivers have shared with us that it is very difficult to get someone with dementia to travel – and we always wondered why. When Lien Foundation suggested that we organise the trip for persons with dementia and observe what it is like, we seized that opportunity.”

Mr Jason Foo, CEO, ADA

“Every night she would wake and ask me ‘Are we in Singapore? How come the room is different?’ and I would remind her that we are in Taiwan, with the Voices for Hope graduates, and she would acknowledge it.”

Belinda Seet, caregiver

“Over the one-week trip, I have seen so much love and patience from the group. I can see how they care and constantly look out for one another.”

Ruth Wong, Programme Lead, ADA

Watch the families' journeys here!



CERTIFICATION AS A PRO LEARNING ENTERPRISE

On 17 February, ADA received the Learning Enterprise Award and became a member of the Learning Enterprise Alliance (LEA). Nominated and organised by the Institute of Adult Learning, the 2020 LEA Award was received by 18 enterprises in Singapore, including ADA, which was the only social service agency among the recipients. As a member of the LEA, ADA is

committed to using our workplace to optimise and promote continuous learning and performance.

The grant received through the Award also enabled ADA to engage an external consultant and learning specialist, to implement and co-create a workplace learning transformation project on Fall Management and Safety at our centres. The transformation programme was successfully completed on 15 April.

The aims of the project were to:

- Develop a quality improvement programme on 'Fall Management and Safety' at our centres
- Increase staff knowledge, skills, and competencies in Falls/Risks Management and Safety, through workplace learning based on best practices
- Ensure the Fall Safety of clients at our centres through regular risk assessments and training



THE POWER OF COURAGE

“I JUST DON’T KNOW HOW TO LOSE”

In this issue, we shine the spotlight on Mr Anjang Rosli, a young dementia advocate. Diagnosed in 2014 at just 50 years old, Anjang is living with mixed dementia—a combination of young-onset and lewy body dementia, and Parkinson’s disease. As a graduate from ADA’s Voices for Hope programme, and now the star of the second #DespiteDementia video titled ‘The Power of Courage’, let’s find out more about Anjang’s journey to becoming an advocate.

Growing up, Anjang Rosli was never a particularly proud nor flashy person despite facing many challenges in life. He recalls the difficulties during his courting days with his now wife, Mdm Sarima Mohd Tajudin, and how he was intimidated by her family who initially disapproved of the union. But knowing she was “the one” for him, he persevered and eventually earned their trust and support.

Another struggle he had to overcome was when his first child was born. Overwhelmed and overworked due to his many jobs, Anjang feared he was not the ideal father. Yet through Sarima’s guidance and assurance, he came out the other side a loving and loyal father.

In 2014 however, life presented his biggest obstacle yet. After suffering from unusually bad migraines and instances of not being able to operate basic things like the kitchen stove, Anjang decided to get a doctor’s check-up. He was soon diagnosed with young-onset dementia.

As someone who had suffered through periods of depression in his younger days, he describes life post-diagnosis as one of the lowest points in his life.

His children took the news the hardest, as they refused to believe that their strong and always-in-control father was now declining in health and cognition. Their reactions forced Anjang to step up and put an end to the doom and gloom.

Now aged 56, Anjang recalls lifting himself up with the words, “Come on, I don’t want my life to be this way”. He researched all he could on his condition, then gathered his children and said, “Enough, we move on, this is not the end.”

“Enough, we move on, this is not the end.”

– ANJANG

With a brand-new outlook on life, Anjang proceeded to share his knowledge with his extended family and friends. He started a Facebook page, where he regularly shares his experiences living with dementia, as well as how others can help the dementia community in little ways. In late 2019, Anjang also joined Voices for Hope, ADA’s self-advocacy programme.

Despite still experiencing bouts of depression, hallucinations, and memory loss due to dementia, Anjang’s refusal to let the condition take over his identity is extremely commendable and is a testament to his courage and perseverance. Today, he readily accepts speaking opportunities despite his fears of public speaking, and is always willing to share his life stories to anyone who asks.

“I share my stories to support other persons with dementia. After all, courage is not the absence of fear, but the triumph over it,” says Anjang.



Watch ‘The Power of Courage’ here.



BLESSED WITH THE SKILLS, LANGUAGES, AND PASSION TO CARE FOR THE AGED

Although born as 'Kamala D/O Samy Michael Louis', Kamala prefers to be called Ann, which she attributes to growing up with a Chinese step-father. Shuttling between home and a convent school, Ann learnt Mandarin, Cantonese, Hokkien, and Teochew dialects, as well as Malay. This command of languages comes in handy as she leads the way with almost 15 years of experience at New Horizon Centre (Tampines), working with the elderly and persons with dementia. Peppering her sentences with "dear" or "sweetie", it is also no wonder that Ann's kind and loving nature shines through in her daily work, as she treats each person with dementia and their family members with care, concern, and patience.

Serving as a Senior Nursing Aide at the centre, Ann, now 66 years old, was also one of ADA's Silver Award recipients at this year's Singapore Health Quality Service Awards (SHQSA) 2020, which honours healthcare professionals who have demonstrated remarkable commitment in delivering quality care and excellent service.

Describe your regular work day. Work starts at 7.30am and the clients with dementia arrive at 7.40am. At the New Horizon



Ann (standing on the right) facilitating activities for our clients at New Horizon Centre (Tampines).

Centre (NHC), my daily work includes doing daily exercises with the clients (which differs from day to day according to our roster, and consists of activities like word games, physio, reminiscence time, and other group activities), getting them meals and helping them with toileting. At around 2.40pm, we serve a small tea break and help prepare clients to go home. When they all leave, we work together to wipe down and clean the whole centre to prepare for the next day. Usually, I end my day at the centre by 4.30pm.

What, or who, inspired you to get into this line of work?

Before joining ADA, I volunteered at All Saints Home and daycare centre for four years. Amongst the usual elderly residents, I never understood why some of them [with dementia] would act a certain way, almost like children. There was one case which stood out to me—one ah ma with dementia who suffered from elderly abuse. She always came to the daycare with bruises. When I asked her about it, she would tell me it's because she fell down. One day



when she was dropped off, her bruises were quite bad and she was very weak, so we took her to hospital. When she was warded, I found out that her children had been abusing her as they were unable to manage her dementia condition.

Long story short, I vowed to gain a better understanding of how or why a person gets dementia, and I wanted so much to look after them.

After leaving that job, I happened to meet one of my friends who worked at ADA at the time, and she encouraged me to join NHC. The person who inspired me to work in dementia daycare was Stephen Chan [ADA's current Head of Caregiver Support Services. Stephen was previously Ann's colleague at NHC (Tampines) and subsequently Centre Manager]. When I first joined NHC (Tampines), I felt quite depressed and helpless as I didn't know how to handle the clients with dementia. Stephen showed me the compassion, love, understanding, care, and tenderness that we need to possess with the clients. He stayed back with me every Friday to teach me how to do proper toileting, showering, and other skills. He keeps me going till today. He is my mentor. But I'm very proud to say that now I'm also an expert lah!

What makes you smile or keeps you going?

The happy look on my clients' faces when they see me every day. They always remember to remind

me to have my meals. And even though they can't tell me verbally, they say "thank you" through a touch of the hand or a smile.

Working with them every single day, it's a very intimate thing. Over the 15 years, when my clients pass away, their children would inform me and I will go to their wakes. They are like family. I worry for all of them. I worry if I don't go today and see them, tomorrow they may be gone.

What are people's usual reactions when you tell them what your job is?

Their first reactions are always "Wah, that's not an easy job! You can handle them? You need a lot of patience!"

How did you feel about winning the SHQSA 2020 Silver Award?

I felt happy that ADA recognised my work. This is a job that I love so much, and I wouldn't trade it for anything else.

Any other comments you would like to add about yourself?

I want to be able to always look after dementia clients and help to ease the load on their family, even if it's only for a few hours a day to give them respite. I also hope to be a better and more understanding person towards all my clients with dementia. I want to give them a good life and a good journey before their life ends.

CALLING FOR THE RIGHT SUPPORT

By Emily Ong

There is a pressing need for timely, appropriate post-diagnostic support and interventions for persons with young-onset dementia.

While there has been a growing focus on developing community awareness of dementia in Singapore, the special needs of younger people living with dementia and their families have not been properly addressed. Almost all existing post-diagnostic services and support systems are developed with the elderly in mind, since dementia is more prevalent in this age group. This results in services and support that don't adequately meet the specific needs of those affected by young-onset dementia.

The sole existing option is limited to cognitive stimulation therapy, which is provided through the National Neuroscience Institute (NNI) and its external partner agencies (i.e. ESTEEM with ADA, Stroke Memory Rehabilitation

Programme (SMaRT) with AIC, and Therapy through Work with Apex Harmony Lodge Nursing Home). Yet, we know that the impact of a diagnosis of dementia can cause significant family distress and social isolation. Younger persons living with dementia and their families have a greater need for emotional, socio-psychological and relationship support, regardless of their dementia stages upon diagnosis. The sense of grief over the 'loss of person within' and multiple other losses can have major effects on persons with dementia and their life together as couples and family unit.

It's important to realise that generic dementia services are not suitable if the nation wants to help younger persons with dementia, who are often still physically fit, maintain an active life and stay independent for as long as possible. As a person living with dementia, I would say we need post-diagnostic support and interventions that support us in engaging socially, enable us to be involved meaningfully, and empower us in a dignified

manner. A diagnosis of dementia does not make individuals a lesser being. We still have the same needs, and want to continue feeling like valuable, productive, and contributing members of our family, community, and society.

An increasing number of people are diagnosed with young-onset dementia each year, and it is imperative that we consider these special needs when planning future dementia policies and implementing post-diagnostic support and interventions. Policy makers, health, and social care providers should proactively consult and engage younger persons living with dementia and their families to ensure that what is implemented is appropriate. This will leave those with young-onset dementia, and their families, better equipped to deal with changes in abilities, relationships, and roles that may arise as the condition progresses. We need more than a 'one-off' kind of support—ongoing guidance and support is necessary to enable them to live well and meaningfully despite dementia.



About Emily Ong

Emily was first diagnosed with neurodegenerative disorders at the age of 49, and provisionally diagnosed with Frontotemporal Dementia (FTD) when she was 51. Emily has been a participant and co-facilitator of Voices for Hope programme under Alzheimer's Disease Association, and passionately advocates for a dementia-enabling environment.

REACHING OUT IN TIMES OF CRISIS

Due to COVID-19, the past months have challenged all of us to think and act beyond our comfort zones. Despite these difficult times, ADA has witnessed individuals and organisations who have come forward to offer help to our clients and promote public awareness of dementia at the same time. Many have sent encouraging notes to us and we are grateful. This is the driving force that uplifts us and keeps us going!

One of our supporters, **The Social Co.** was quick to act. Knowing that some of our clients and families are facing financial difficulties, they launched a campaign on Giving.Sg and GIVE.asia to raise funds, which enabled ADA to purchase NTUC FairPrice vouchers for the affected families. The campaign has raised over \$20,280.

Campaign #SGPAYSITFORWARD is another ground-up initiative to support the disadvantaged in Singapore. In this campaign, local organisations pool their resources together to deliver care packs to 100,000 people across Singapore. **Community Foundation of Singapore** also donated Gojek transport vouchers to our clients and families.

Corporate partner **Musim Mas** generously donated 108 tubs of dr.MCT Powder, an energy supplement to give a boost to our staff as we continue our work in this pandemic.



Individuals like **Mr Andy Gan** donated 1,000 face masks to ADA. **Mr Delane Lim**, co-founder of FutuReady ASIA, a youth development social enterprise, and Executive Director of Formwerkz Architects, donated 1,000 bottles of hand sanitisers.

ADA also organised its inaugural virtual fundraising effort with **Ms Audrey Ng**, Founder of Art Peace. Together with co-trainer Gina Lim, they conducted a 3-hour Nagomi art workshop on Mother's Day to over 160 participants virtually and raised \$8,960.

"COVID-19 dealt a heavy blow to fundraising as most of our planned events were cancelled or put on hold. We are blessed to have these groups of people championing our cause during these difficult times and we want to thank them from the bottom of our hearts. Please continue to support our initiative #HelpUsHelpThem." – Alice Wong, Head of Fundraising.



HELP US HELP THEM!

Generosity does not need to #stayhome. Scan the code and make a difference in the lives of those living with dementia.



DEMENTIA IN NUMBERS



At least
6 out of 10
caregivers find that
their social life suffer as
a result of their caring
responsibilities



Less than
70%
of the public thinks that
there are enough healthcare
professionals for the
diagnosis and treatment of
dementia



2 out of 3
people still think that
dementia is caused by
normal ageing



63%
of people living with
dementia in Southeast
Asia have their symptoms
joked about by others



About
8 in 10
respondents would take a
genetic test to learn about
their risk of dementia

Statistics from World Alzheimer Report 2019

ADA in Singapore

We strive to be the leader in dementia daycare and a voice for persons with dementia and their caregivers, with a vision towards a dementia-inclusive society. Established in 1990, we seek to enable persons with dementia and their families to live with dignity by providing quality care and support through research, education, and training.

Dementia Helpline

☎ 6377 0700
🕒 Monday - Friday: 9.00am - 6.00pm

Headquarters

Caregiver Support Centre Family of Wisdom (Bendemeer) Resource & Training Centre

📍 20 Bendemeer Road
#01-02 BS Bendemeer Centre,
Singapore 339914
🕒 Monday - Friday: 9.00am - 6.00pm

ADA Café

Family of Wisdom (Toa Payoh)

📍 7A Lorong 8 Toa Payoh
#01-01 Agape Village,
Singapore 319264
🕒 Monday - Friday: 8.30am - 5.30pm

Family of Wisdom (Tiong Bahru)

📍 298 Tiong Bahru Road
#10-05 Central Plaza,
Singapore 168730
🕒 Monday - Friday: 8.30am - 5.30pm

New Horizon Centre (Bukit Batok)

📍 Blk 511 Bukit Batok Street 52, #01-211,
Singapore 650511
🕒 Monday - Friday: 7.30am - 6.30pm

New Horizon Centre (Jurong Point)

📍 1 Jurong West Central 2 #04-04
Jurong Point Shopping Centre,
Singapore 648886
🕒 Monday - Friday: 7.30am - 6.30pm

New Horizon Centre (Tampines)

📍 Blk 362 Tampines Street 34, #01-377,
Singapore 520362
🕒 Monday - Friday: 7.30am - 6.30pm

New Horizon Centre (Toa Payoh)

📍 Blk 157 Toa Payoh Lorong 1, #01-1195,
Singapore 310157
🕒 Monday - Friday: 7.30am - 6.30pm

JOIN US IN OUR FIGHT AGAINST DEMENTIA!

DONATE



alz.org.sg/donate



giving.sg/alzheimer-s-disease-association

VOLUNTEER



alz.org.sg/volunteer

SIGN UP FOR VOICE OF DEMENTIA (ONLINE) AND GET LATEST EVENT UPDATES!



alz.org.sg/vod

SCAN TO DONATE



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