



## President's Message

### Never too early, never too late !

The World Alzheimer's month is fast approaching. The campaign slogan 'never too early, never too late' continues, reinforcing the fact that it is never too early or never too late to learn about dementia, to make a diagnosis or provide support and care to persons with dementia and their carers.

We are happy that we can recommence the 'Memory Walk' and the 'Run to Remember' this year. We look forward to enthusiastic participation and the opportunity to raise awareness on the cause through our activities. We are planning some special awareness programmes using puppetry to educate the public and especially government officers who deal with persons with dementia and their family carers.

The fight against dementia intensifies globally too. The first disease modifying drug for Alzheimer's appears to have arrived. On 6<sup>th</sup> July the US Food and Drug Administration (FDA) granted full approval to the drug lecanemab for people with confirmed amyloid positivity and a diagnosis of mild cognitive impairment (MCI) or mild dementia stage of Alzheimer's disease. While giving a ray of hope, it is unlikely to make a difference for around 55 million persons living with dementia currently.

In this back drop, we look forward to an engaging and stimulating World Alzheimer's month campaign in Sri Lanka to bring greater awareness of the condition and improve the lives of those living with dementia and their caregivers. We thank you for your continued partnership in these efforts.

Prof Shehan Williams  
President



*September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. World Alzheimer's day is celebrated annually on 21st September*

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### Free Memory Screening

**2023**

July - 7th & 21st

August - 4th & 18th

September - 1st & 15th

**Appointments are limited.**

**Please call the Helpline 2667080 to register.**

## Upcoming Events for September 2023 - WAM

We are planning a series of public events including a “Run to Remember” on 2nd September and a “Memory Walk” on 23rd September.

A puppet show featuring well established characters in Sinhala folk lore will be the highlight of our activities. The tailor – made, commissioned programme will focus on early identification and caring for a person with dementia. Similar puppet shows on other social issues have had significant community engagement and channel for education.

Six shows in all will be conducted in three districts – two in the capital, Colombo and two each in the highly populated districts of Gampaha and Galle where we have already commenced working with elderly societies and other Government stakeholders

On World Alzheimer’s day, 21<sup>st</sup> September, the awareness media event coupled with the puppet show will be held in Colombo. The puppet shows in the districts of Gampaha and Galle will take place on September 22<sup>nd</sup> and 26<sup>th</sup>. Galle district is where LAF’s Dementia Friendly Communities project begun in 2022 and is ongoing.

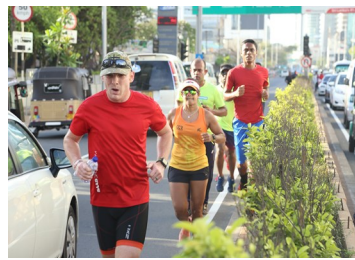
Through these events, we hope to reach and engage different target audiences on ‘Never too early, never too late’ the campaign on understanding and identifying the warning signs and risk factors for dementia.

**LETS GET READY FOR THESE EVENTS IN SEPTEMBER !!!**

### Memorable Steps - Virtual Walk 2022



### Run to Remember - 2019



### Memory Walk - 2019



**CALL OUR HELP LINE**

**2667080 / 2667082 / 2667084**



## Ode to Service

When I joined the LAF as a student volunteer in April 2022, I didn't know just how meaningful the whole experience of it was going to be for me. I had just moved from Australia to wait for my permanent residency to move to Canada and had no friends in Sri Lanka. For the first time in 18 years, I found myself in the great in-between, rumbling with uncertainty, adjusting to the culture shock and several other practical constraints, as I transitioned from one phase of my life to the next.

With every passing day, I became increasingly aware that I was so far away from everything that felt safe and familiar. I was miserable, feeling every moment pass me by, waiting desperately for the wait to be over, and to move on. I had previously worked in aged care and disability, and my mother had been a volunteer at the LAF for

many years - so I understood the concept of respite care, and the nature of the services provided to the clients. So, when I attended a Sinhalese/Tamil New Year celebration in April 2022, it occurred to me that I might enjoy working with the clients once a week while I waited. So, things were set in motion, and I joined the Friday volunteers soon after.

Structurally and spiritually, the LAF has such a warm, welcoming energy, the staff and other Friday volunteers are a pleasure to work with, and as I expected, it was an absolute delight getting to know the clients, and hearing about the experientially rich and varied lives they've lived. I had finally found a meaningful pursuit to contribute to, which felt like the balm I needed for my soul.

In my experience, the LAF feels like a place where we can leave all our stresses at the door, and spend a day being fully present with the clients. The spacious, airy, green environment contributes to it feeling like a sanctuary, and the time spent engaging with the clients felt wonderfully restorative to me.

It was during this time that I got to meet Lorraine Yu, the co-founder of the LAF, and the centre sprung to life in my eyes, as she gradually told me the story of how the Alzheimer's foundation came to be. It became clear to me that this project to serve individuals living with dementia was a labour of love to her - every part of the building was thoughtfully constructed with the clients' needs in mind. That said, no part of the entire compound feels insulated, stark or cold like a hospital.

In fact, while largely spartan, for the clients' safety, the building looks fresh, clean and inviting through flowering plants, trees and creepers, a water feature, easy to maintain structures and furniture that age very well. The artwork done by the clients are also displayed in the form of tablemats, and through beautiful collages that look like paintings.

Further, this flat, wide-open structure with very few doors allows wandering clients to safely wander, and strategically placed, large cement flowerpots and a security guard keep them safely within the designated area. It also ensures that they are visible to everyone in case they need help.

Speaking to Lorraine also helped me learn more about communicating with clients living with dementia, and, on the administrative side, how to be strategic and thorough.

During my time, I also got to attend a volunteer training event where Lorraine and João Marçal-Grilo spoke. João had been a volunteer when the LAF was in its early days and has spent many years working with individuals living with dementia. So, this training addressed some key issues to educate volunteers and allowed them to bring up any questions or concerns in providing appropriate care, while also giving all the volunteers from different days the chance to meet each other.

Above all, I enjoyed working with the other volunteers and staff: the fact that they embody the spirit of teamwork, and are very committed to giving clients the best possible care makes everything run smoothly. Susan, who runs the office has also always been friendly and cheerful, and willing to help. This warm, nurturing environment, and the commitment of kitchen staff like Selvi (who manages to remember how each person in the centre likes their tea!) and Lalitha (who is easily one of the warmest people I've met) is a testament to the values instilled into the organisation, as a whole.

I also want to mention the truly lovely tea and food that the pair of them make. The food is fully vegetarian, and made with a few, simple ingredients, but always proves to be far more than the sum of its parts.

A final addition to my story is a rather pleasant one - I met and worked with Sharmini (who organised the list of carols and played the piano in this instance) to lead the choir for the Christmas Carols event. It was a truly enjoyable experience working with her, before and during the event, as I could see exactly how much the clients enjoyed the musical component of each week, and how Sharmini enthusiastically encouraged the clients to participate.

Amazingly, when they first join the LAF, clients come in appearing apprehensive and withdrawn but as time passes, even quieter clients appear visibly joyful, more engaged, and playful - possibly going through the same transformation that I did - they feel a renewed sense of purpose and excitement, thinking about all the fun they're going to have on Friday, in a safe, green environment with all these lovely people.

All in all, this has been a great experience for me, one that I highly recommend to anyone who has the time and inclination to learn more about and contribute to helping individuals living with dementia. I promise you, the benefits don't go in just one direction.



## Highlights of the Activities done by our Clients at the Centre

Clients & volunteers doing their activities on their respective Activity Centre days. It was amazing to see how our clients participated in all the activities that the volunteers organized.



Painting and preparing to make a flower basket



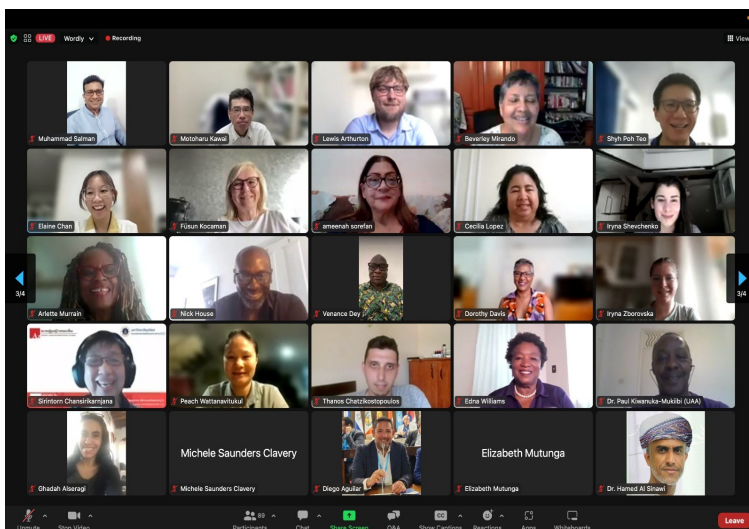
Clients making their own Sandwich



Time for Nature - Celebrating World Environment Day in June



## ADI Annual Council Meeting - June 2023



The ADI annual council meeting was held on 13th June 2023. LAF was represented online by Mrs Beverley Miranda.

Two documents were tabled:

### 1. Strategic Plan July 2023 - June 2026

The strategic objectives are:

- Make Dementia a global health priority
- Reduce stigma
- Strengthen membership
- Facilitate research
- Enable ADI to achieve its objectives

### 2. The updated Memorandum of Association between ADI and its members.

## *Dementia Friendly Society - In collaboration with The Asia Foundation (Gampaha)*



In collaboration with The Asia Foundation, we commenced our Dementia Friendly Societies project in April. We completed 12 Memory screening clinics and 10 Dementia awareness programs in the **Gampaha District**. Dr. Amodha and 7 Clinical Psychology MPhil students, who were on their community placement at LAF, conducted the memory screening clinics and dementia awareness programs.

We collaborated with elders' societies in the Gampaha district and the Elders' Rights Promotion Officer of Gampaha. More than 362 elders screened positive for dementia and were referred to a local hospital for further care and treatment. We had programs in Kandana, Katana, Attanagalla, Wattala, Minuwangoda, Kelaniya, Mirigama, Mahara, Gampaha, Dompe and Ja-ela.

Tahaan Jayewardene - Project Coordinator

## *Galle Project - Activities and Awareness Programmes*



**Fancy Dress activity held for Avurudhu**



**Caregivers Society Meeting**



**Elders society making picture puzzles**

We had Avurudhu celebrations in two villages. It was held on the 15<sup>th</sup> of April, for the elders in Berathuduwa and Thilakagama villages. About 55 elders and their family members participated, organized by those who attend the Berathuduwa activity sessions and myself. We had fourteen New Year games and the winners got gifts.

The elders performed an Avurudhu dance, previously rehearsed. The Elder Rights promotion officer attended the function and not only commended us on the program but also helped out in conducting the Avurudhu games. The Balamandalaya Treasurer helped out with the announcements.

It was a great day to all the elders as they enjoyed the program.

Mr Jyothi Chandran - General Manager of Sunpharma handing over a cheque to Prof Shehan Williams - President of Lanka Alzheimer's Foundation..

Thank You Sunpharma for your continuous support to LAF.



Dr Mani Krishnan, Chair of the Old Age Faculty of the Royal College of Psychiatrists in the UK visited the LAF Activity Centre on Monday 26th June 2023.

He met with the volunteers and was inspired by the work carried out by LAF in Sri Lanka





## Sleep Apnea Increases Alzheimer's Risk

A new study published in *Neurology* has found that sleep apnea and a lack of deep sleep may be associated with poorer brain health, leading to increased risks for stroke, Alzheimer's disease, and cognitive decline. Sleep apnea is a chronic sleep disorder that can also increase other health risks, including cardiovascular disease and hypertension. The research involved looking at sleep factors and biomarkers of brain health and suggests that people with sleep apnea who spend less time in deep sleep are more likely to have brain biomarkers associated with a heightened risk of these conditions.

The study included 140 people with an average age of 73, all of whom had obstructive sleep apnea but did not have dementia before the study. Researchers found that for every 10-point decrease in deep sleep, white matter hyperintensities increased, which were the equivalent of being 2.3 years older. Further, each 10-point decrease in slow-wave sleep lowered axonal integrity was "similar to the effect of being three years older." The more severe a person's sleep apnea was, the higher volume of white matter hyperintensity and lower axonal integrity their brains had.

While the study cannot say whether this association causes the alterations or vice versa, diagnosis is critical. There are steps people can take to reduce sleep apnea risks, including lifestyle modifications such as weight loss, avoiding sleeping on your back, and treating nasal congestion. The mainstay treatment for sleep apnea is a Continuous Positive Airway Pressure (CPAP) device, which delivers air pressure to keep airway passage open, reducing or eliminating snoring and sleep apnea risks. Whether you have sleep apnea or not, experts share that sleep quality is important for overall well-being. Maintaining a regular sleep/wake schedule, avoiding electronics before bedtime, doing something uninteresting if unable to sleep within 20 minutes of laying down, avoiding naps close to bedtime, and maintaining an environment that promotes good sleep are all ways to improve sleep hygiene. Poor sleep quality is associated with worse brain health, but changes and discussions with your healthcare provider can help you course-correct.

<https://www.pressrundown.com/health/sleep-apnea-increases-alzheimers-risk>

## LAF Dementia Awareness social media campaign a resounding success

### SCREENSHOT OF VIDEO



Our Dementia Awareness campaign on Facebook which started on the 23<sup>rd</sup> of March concluded on the 15<sup>th</sup> of June with excellent results. With a total investment of Rs. 1 million, sponsored by AIA Insurance, we were able to produce a trilingual video and boost that and a series of 12 posts in all 3 languages.

The campaign reached nearly 4 million people and created 7.4 million impressions with people viewing multiple times. The campaign engaged with over 1 million people, with a majority of them viewing the very effective video. Engagement was also reflected in significant reactions (likes) of 40,000+ and sharing of 8,000+ and nearly 2,500 comments. Relevant comments were responded to by the trainees who worked with us during this time.

As a spill-over effect, the LAF Facebook page gained a significant number of new followers, going up from 700+ to 2,500+ without any additional investment to boost the page.

The campaign was conceptualized and created by NGage Strategic Alliance on a *pro bono* basis.



**Questions about  
dementia ?**

**2667080 / 2667082 / 2667084**

**Monday to Friday | 9am– 5pm**

**For information on dementia and dementia care management**

## Large trial shows Alzheimer's drug slows cognitive decline

Eli Lilly has announced that its experimental medication, donanemab, significantly slowed the cognitive and functional decline of Alzheimer's patients by more than a third in a large clinical trial. The drug works by removing the amyloid plaque buildups in the brain that are a hallmark of Alzheimer's disease. Based on the results, Lilly plans to file for approval from the US Food and Drug Administration (FDA) by the end of June. However, there were three deaths in the trial, two of which were attributed to adverse events such as brain swelling or microhemorrhages, known as amyloid-related imaging abnormalities or ARIA.

Alzheimer's affects more than 6 million Americans, with an estimated 1.7 million to 2 million people over 65 in the early stages of the disease, according to Lilly. Drug development for Alzheimer's has been riddled with failures, but Lilly's drug is among a new group showing promise. The first, Eisai and Biogen's Leqembi, received accelerated FDA approval in January. The medicine is given by infusion once a month. Donanemab clears amyloid so effectively, the company says, that a majority of patients in the trial – 52% – were able to stop taking the medicine by one year, and 72% were able to do so by a year and a half. Researchers will continue to monitor these patients' progress.

Lilly filed for accelerated approval with the FDA for donanemab based on earlier results but was rejected in January as the agency sought more data. With these results, the company will file for full approval, which is expected to lead to broader insurance reimbursement for the medicine. Leqembi was approved on an accelerated basis in January, and Medicare is not expected to cover the drug broadly until it receives full approval as well, most likely by early July.

Leqembi is priced at \$26,500 a year. Lilly's chief scientific and medical officer, Dr. Daniel Skovronsky, declined to discuss potential pricing for donanemab before the drug is approved. However, he noted that almost half of the participants taking the drug, 47%, showed no decline on a key measure of cognition over the course of a year, compared with 29% of people taking a placebo. Skovronsky said that this was "the kind of efficacy that's never been seen before in Alzheimer's disease."

Overall, the trial results for donanemab are promising, and the drug has the potential to be a significant breakthrough in Alzheimer's treatment. However, the deaths and adverse events reported during the trial are a concern, and the drug's safety profile will need to be closely monitored as it moves towards approval

<https://www.pressrundown.com/health/large-trial-shows-alzheimers-drug-slows-cognitive-decline>



A patient with cognitive impairment who wanders outside alone can easily become confused, injured and get lost.

An identification bracelet can help a loved one with dementia to get back home safely.



Hypoallergenic and Tamperproof ID bracelets are now available at

**The Lanka Alzheimer's Foundation**

**Inquiries Call 0112667080 / 2667082/ 2667084**

## *Current Services*

- Raising awareness and eradicating stigma
- Education on risk reduction
- Education on care management
- Helpline + 94 11 2667080
- Memory screening / assessments done twice a month on Fridays
- Activity Centre
- Quarterly newsletter
- Resource Centre/ Information and resource materials
- Caregiver support group (CSG) meeting
- Memory Garden Cafe
- Identification bracelet
- Website : [www.alzlanka.org](http://www.alzlanka.org)
- [www.facebook.com/alzlanka](http://www.facebook.com/alzlanka)

### **Caregiver Support Group (CSG)**

Online meetings are conducted every 1st & 3rd Tuesdays of the month from 7.30pm - 8.30pm

- support caregivers through discussion and sharing
- listen and learn from care experiences
- share common concerns

### **Collaboration :**

- Sensitise medical students of the Kelaniya University & the Kotelawala Defence University on non-pharmacological approaches to Dementia.
- Practical training for students of the speech therapy unit of the Kelaniya University.

## *The Board*

Lakmali Cabral (Secretary), Priya Fernando, Lilani Jayasuriya, (Treasurer)  
Beverley Mirando, Romany Parakrama, Nimal Gunewardena , Prof. Shehan Williams (President)

**PLEASE SUPPORT THE WORK OF THE FOUNDATION  
BY MAKING A DONATION OR LEAVING A LEGACY**

**The Foundation is a Government Approved Charity (Gazette Notification no. 1225)**

Cheques should be crossed and made payable to the **Lanka Alzheimer's Foundation** and sent to Lanka Alzheimer's Foundation, 110 Ketawalamulla Lane, Colombo 10, Sri Lanka

Monthly/Annual donation can be made directly to

**Account number: 106110117418**

**Swift Code NDBSLKLX ,**

**National Development Bank PLC , Havelock Town Branch, (formerly Jawatte Branch)**

**117, Havelock Road, Colombo, Sri Lanka.**

**The Lanka Alzheimer's Foundation is a community based charity and relies on donations in order to sustain the services provided to persons with dementia and their family carers.**

**Your support makes a difference - please give generously**