



# Lanka Alzheimer's Foundation

Website: [www.alzanka.org](http://www.alzanka.org)

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## President's Message



We wish our family of clients, caregivers, volunteers and all our partners, health and happiness in 2024! We are happy that LAF was able to continue its mission successfully in 2023 and are extremely grateful for the unstinted support extended by all our friends.

We look forward with renewed commitment and vigour to advance our efforts in supporting those with dementia and their families this year. Sri Lanka is yet to develop a comprehensive plan for those with dementia and at risk of cognitive impairment despite having the fastest ageing population in South Asia. With the health services facing numerous challenges with the rising cost of medicines and medical services, the older folk including those with dementia will have unsurmountable challenges to receive the care they deserve. We hope the government will prioritize its expenditure and ensure that the most vulnerable amongst us including those with dementia will have access to a reasonable level of care.

Conditions like dementia are everybody's business. Burying our head in the sand or looking away as we often do when we feel helpless in the face of circumstances we have no control over, will not make the problem go away. We will all have to eventually face this condition which will strike those near and dear to us, if not our own selves sooner or later.

LAF believes in dementia friendly communities. We anticipate continuing dementia awareness among different communities across our island nation. Like in Galle, we hope we can engage elders' groups to take on the role of supporting elders with dementia. We will remain determined as we march ahead in 2024.

"The new year stands before us, like a chapter in a book, waiting to be written!" – Melody Beattie. Let us write another memorable chapter together!

**Prof. Shehan Williams**

**President**



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## Free Memory Screening

**2024**

January - 5th ; 19th

February - 2nd ; 16th

March - 1st ; 15th

**Appointments are limited.**

**Please call the Helpline 2667080**

**to register.**

## Volunteers Workshop

LAF organized a workshop for volunteers on the 19th of October 2023 at Cinnamon Lakeside, Colombo. This is part of our ongoing efforts to broaden our understanding of dementia to enable volunteers to support our clients at the Activity Centre better. The interactive programme commenced with Laki Cabral doing the introduction, acknowledging and expanding on the role of volunteers. Prof Shehan Williams spoke on 'A window into the workings of the brain'. This was followed by 'Nutrition among the elderly' by Dr. Manoji Gamaga, Nutrition Consultant at the Ministry of Health.

Emily Ong, the post lunch speaker, who joined us via zoom from Singapore, built on the foundation laid in the morning session. Emily is a consumer and patient advocate, trainer, speaker, facilitator and program content developer on dementia related topics and a board member of ADI. She spoke on 'Living with and supporting others with dementia'. Her personal insights on living with progressive changes and decline in cognition and functioning, and the interventions that slow down progression of the disease to the next stage, enabling her to live independently and meaningfully, were thought provoking. In the second half of her presentation, she focused on how she supports others through what she called the 'multi-domain intervention'. The volunteers found the practical approach and insights very helpful.

The volunteers also had a lively session on the challenges they face when dealing with clients and how they overcome the same or mitigate the impact. Cross learning from volunteers was the objective of this session. Lorraine Yu, Co- founder of LAF and Beverley Mirando joined the programme.



## 2023 INAUGURAL ACADEMIC CONFERENCE

### INAUGURAL LIFESTYLE MEDICINE ACADEMIC CONFERENCE

LAF was a sponsor and participated in the inaugural Lifestyle Medicine Annual Conference and was able to create awareness on how to reduce the risk of dementia by also submitting an article on the subject.

**CALL OUR HELP LINES**

**2667080 /2667982/2667084**

**OR**

**Mobile No: 076 082 7080**

**Monday to Friday | 9am– 5pm**

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



## LAF Annual Christmas Party

The Annual Christmas party was held at the LAF Auditorium on 8th December 2023. Weeks prior to which, clients helped decorate the tree, made banners and other decor to give that all important festive feel to LAF. They practiced carols and made cards for their loved ones. Some of our clients who had become rather quiet over time enjoyed singing carols. It was clear that they, or at least some of them, felt the approaching season.

It was delightful to see almost all our clients and their family carers present on the day. They sang carols with gusto. When the ballroom session started after carols, clients quickly lost any inhibitions they may have had and enjoyed themselves thoroughly. The arrival of Santa Claus was greeted with much merriment and no doubt brought back fond memories of yesteryear. The evening ended with fellowship and a wide variety of refreshments donated by well-wishers. The smiles on the faces of clients and the oft voiced acknowledgement of having had a good time, was gratifying. Considering that most of our clients are well into the mid stages of the disease, it was even more surprising that quite a few remembered the party the next week and relived the feeling of having had a good time. It is moments like this that make our day at LAF.



## NHS to try out blood tests for Alzheimer's disease

A study to assess whether blood tests could help diagnose people with very early Alzheimer's disease, is being launched by the NHS. Spotting the condition much sooner would mean people could have more support and new treatments to slow the disease, say experts.

The five-year project has £5m funding from the People's Postcode Lottery.

Currently, there is no single test for Alzheimer's, and patients can wait years for a diagnosis.

A blood test would not be able to rule in or out Alzheimer's 100% of the time but might be a cheap and easy way to help doctors spot which patients have hidden physical signs of the disease, years before telltale symptoms appear.

There are lots of different ones in development around the world - some are already used in private clinics in the US.

They look for traces of brain proteins that have leaked into the bloodstream.

These proteins, such as tau and amyloid, start to build up in the brain a decade or more before people develop memory loss and confusion.

New Alzheimer's drugs, such as donanemab and lecanemab, can clear some of that brain build-up.

Most amyloid-lowering drug trials so far involve people with advanced disease, and many researchers believe that by the time symptoms set in, the window of opportunity for preventing cognitive decline may have passed already.

The drugs might be more effective earlier on, in people who have amyloid build-up but do not have symptoms yet, which is why a blood test could be really useful.

Fiona Carragher, from the Alzheimer's Society, said: "Nearly four in 10 people in the UK who have dementia have not received a diagnosis. We also know that those who do have a diagnosis have often waited many months, sometimes years, to receive it.

"This means thousands of families are stuck in limbo, trying to manage symptoms and plan for the future without access to the vital care and support that a diagnosis can bring.

"New drugs targeting early-stage Alzheimer's disease are just around the corner, but without a diagnosis, people simply won't be able to access them if they are approved."

Having a measurable biomarker for the disease would provide a way to monitor how well new treatments work too.

The NHS Blood Biomarker Challenge will look to recruit at least 1,000 NHS patients.

The Alzheimer's Society, Alzheimer's Research UK and the National Institute for Health and Care Research are working with the UK Dementia Research Institute at University College London on the project.

Dr Susan Kohlhaas, from Alzheimer's Research UK, said: "We need to move these tests out of the lab and assess their effectiveness in real-world settings like the NHS."

UK regulators would still need to approve a blood test, and research would need to show it is cost-effective for the NHS to use.

Emma Ruscoe, 55, from Solihull, said it took four years for her husband Simon to be diagnosed with young-onset dementia.

"When Simon received his diagnosis, I felt a sense of relief. I knew something was wrong and I was battling for so long. If a blood test had existed, it would have saved a lot of heartache. The uncertainty was really hard to deal with as a family."

Alzheimer's disease affects about six in every 10 people with dementia in the UK. Alzheimer's is not a normal part of ageing, but the chance of developing the disease increases as we get older.

<https://www.bbc.com/news/health-67355717>



## A student volunteer's perspective - Joshua Joseph Kirshnan



I met with the co-founder Ms. Lorraine Yu in July, she briefed me about the activities that I would take part in and I began my service at the Foundation on the 9th of August. I opted to volunteer on all three days to learn as much as I could about each group of clients that were present on each day. As most would expect, I was least prepared on my first day, even initially mistaking a clients for a volunteer! On that day I spent most of my time assisting one client and observing the other volunteers. Over time, I slowly learnt the approaches that volunteers use with clients.

I noted the routine that the clients followed: they come in from around 8:50 to 9:45 a.m., and were interested in talking up to the time activity start. Monday and Friday groups opt to begin with a fun event for the clients which range from crosswords to arts and crafts, whereas the Wednesday group begins with an exercise session. However, all three groups allocated time to sing with the clients, which I believe is integral for clients to enjoy their time at the Foundation. Even watching clients who have trouble speaking properly break into song, was heartwarming.

I think that student volunteers may feel diffident at first, given that clients in the Foundation are so different to one another and that there isn't a catch-all solution to assist them. I found it very rewarding to find my own ways to assist particular clients, which I believe has helped shape my positive thoughts on the experience being offered at the Foundation. I've enjoyed conversing with the clients themselves and learning of their past as schoolteachers, photographers, military personnel and much, much more. I implore any future volunteers to take a genuine interest in the clients, for they will speak to you fondly like a friend. The volunteers have always tried to be as welcoming as they can to me, and therefore I felt that the environment at the Foundation has been very serene. I will continue to cherish the experience that I have had at the Foundation for a long time.

## LAF Grand Sale -25<sup>th</sup> November 2023

The Grand Sale was a great success. Special thanks to Saroj Amalean for her untiring efforts in organizing it.

We also thank all our volunteers for arranging a variety of food stalls with delicious items for all.



## ICCB Sale - 3rd Dec 2023

LAF participated once again in the ICCB Sale held on 3<sup>rd</sup> December 2023 at the Galle Face Hotel.

A big 'Thank you' once again to Saroj Amalean and her band of "Merry" helpers



# 'SL must get ready to cope with Alzheimer's'

• The Lanka Alzheimer's Foundation's President Prof. Shehan Williams on Sri Lanka's preparedness to face a rapid increase of people with Alzheimer's

## KALEIDOSCOPE



**S**eptember was the world Alzheimer's month, but despite these reminders, there is little awareness about the disease, the challenges it brings, and coping for both the patient and the community. Globally, 75% of people with dementia are not diagnosed, which is about 41 million people. For 47% of people living with dementia, a lack of trained clinicians serves as a barrier to diagnosis, while for 46% of them, the fear of diagnosis itself acts as a barrier to proper care. The World Health Organisation reports that dementia is the seventh leading cause of death among all diseases worldwide.

In Sri Lanka, it is estimated that approximately 400,000 will be afflicted with Alzheimer's in the next few years, with little resources to manage the disease.

In this interview, *Kaleidoscope* speaks to the Lanka Alzheimer's Foundation's (LAF) President, Prof. Shehan Williams about this disease.

The following are excerpts from the interview:

**What exactly is Alzheimer's and what are the causes?**  
Alzheimer's is the predominant cause of dementia. Dementia is when a person ages and develops memory problems coupled with difficulties in being able to think for themselves, and to use their brain like before.

**What is the most common myth is that people become forgetful as they age and it's a normal process of ageing. In reality, it's not**

**How is Sri Lanka coping with Alzheimer's?**

As a nation, we haven't really considered the extent of the problem. We are the fastest ageing South Asian country, and by 2030, every fifth person in this country will be over the age of 60. Many of us will have to face this condition in the future: either in ourselves or within our families. We have to be prepared to help and support the people who get affected by this condition, because there is no cure right now.

**What does the LAF do?**

We are the only organisation in Sri Lanka committed to dementia and Alzheimer's exclusively. We want to raise awareness and bring it to the forefront, as it will become a major problem in the years to come. We need Government support, as well as for the community and society to be ready for this, because there will be a large number of people with Alzheimer's to take care of and treat.

**What are some common myths surrounding Alzheimer's?**  
The most common myth is that people become forgetful as they age and that it's a normal process of ageing. In reality, it's not. Many of us can live into our hundreds if we don't get afflicted by this condition or any other related condition like Parkinson's, or suffer a stroke.

**Medically, what strides have been made?**  
Numerous global clinical trials are being conducted but a cure is yet to be found. There are some drugs which afford hope, but the world is still far away in finding a cure for Alzheimer's, which affects the brain.

**What should family members of a patient be aware of in navigating the disease?**  
Firstly, it's important to think of prevention. We must keep ourselves mentally and physically active to keep the condition at bay as long as possible. Unfortunately, due to genetic reasons and environmental factors, some of us will be affected. As a society, we need to identify the condition early and take steps to plan and support the affected person and their family in the right way as soon as possible. This is so that the person with Alzheimer's may live well for as long as they can with the condition.

**What are the problems that people with Alzheimer's face?**  
The brain, and our cognitive functions - to think, to act, and to remember things - are fundamental to being a human being. When these things get affected, it's a real challenge for the individual concerned. Sometimes, the individuals themselves do not realise the extent of the problem and the effect it has on those around them. They may not realise it or be in denial, which often then leads to lots of interpersonal conflict and exploitation, and sometimes, serious risk to the life of the affected person, including wandering off, getting lost, eating inappropriate food, and not remembering allergies.

**What are the early signs of Alzheimer's?**  
The signs can be very subtle in the early stages. Someone replacing things and then accusing others of taking their things, giving money to people without realising that they are doing it repeatedly,



The LAF holds an annual memory walk as a fundraiser

Scan the QR code or visit the channel 'Kaleidoscope with Savithri Rodrigo' on YouTube for the full programme of 12 October 2021

judgement being compromised, and becoming aggressive and irritable are all early signs. Dementia could come at any age as we move along in life, although it is usually after 60. When these signs begin developing, it's good to make an early diagnosis with a doctor so that the best arrangements can be made for the person with Alzheimer's.

**What resources are available for Sri Lankans who are diagnosed with Alzheimer's?**  
When it comes to the ageing population, Sri Lanka has very limited resources. We don't have sufficient schemes or proper pensions for the aged. In the current context, it's going to take many years to have the financial



The LAF is a day care for those with Alzheimer's



The LAF keeps those with Alzheimer's active three times a week

resources in place to facilitate the required services. Hence, in the meanwhile, we must mobilise the community to support each other, to be dementia friendly, to care for each other, and look out for others in the community. Younger elders could perhaps support older elders, and elders without dementia could help elders with dementia. We need a big social community approach, in addition to just the medical approach to the condition.

**Can Alzheimer's be prevented?**

Certainly. We must ensure that we keep ourselves mentally and physically active, in addition to controlling other non-communicable diseases like blood pressure, diabetes, and high cholesterol,

which affect the supply of blood to the brain. We must live in a healthy environment with good air, nutrition, and an overall level of wellbeing.

**Is there stigma surrounding a person diagnosed with Alzheimer's in Sri Lanka?**

Of course. Like with all medical conditions, especially when a person's cognitive abilities are impaired, many don't want to accept the condition. They find it difficult to talk about as a family, and even harder to take the person to a doctor for a diagnosis. This is because society labels stigma on a person whose mental wellbeing is impacted in some way.

*(The writer is the host, director, and co-producer of the weekly digital programme 'Kaleidoscope with Savithri Rodrigo' which can be viewed on YouTube, Facebook, Instagram, and LinkedIn. She has over three decades of experience in print, electronic, and social media)*





## DATES TO REMEMBER

**.Get ready to dabble in some scrabble!**

The Annual Scrabble Bash will be held on Saturday 24<sup>th</sup> February from 9 a.m. to 4 p.m. at the Alzheimer's Service Centre at 110 Katalawamulla Lane, Colombo 10.

The event is held annually and all proceeds will be used to support the work of the Foundation. **The tournament will be open to Children under 16 years and Adults.** More details are given in the below flyer.

## EVENTS CALENDER 2024

### February

24th February - Scrabble Bash

### September

7th September - Run to Remember

21st September - World Alzheimer's Day

28th September - Annual Memory Walk (TBC)

### November

9th November - Grand Sale

### December

6th December - Christmas Party

*(Please get in touch with us on 2667082/4 if you would like to take part or contribute to any of the above events)*



The flyer features a grid of Scrabble tiles at the top spelling 'WELCOME'. Below this is a large grid with 'SCRABBLE BASH 2024' in the center. The text inside the grid provides details about the event: Venue (Lanka Alzheimer's Foundation, 110, Ketawalamulla Lane, Colombo 10), Date (Saturday, 24th February), Time (9 am to 4 pm), Sponsorship (Children Under 16 (A Category) - Rs. 2000/-, Adult - Rs. 3000/-, Team of 4 Adults - Rs. 10,000/-), and a contact number (Call 2667080/82/84 for more information). At the bottom of the flyer is the Scrabble logo and the slogan 'Every word's a WINNER'.

## IDENTIFICATION BRACELETS

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.

The personalized bracelets are available at the Foundation.

The bracelet is a tough yet supple device, with rounded edges to protect sensitive skin, hypo allergic; designed to prevent wearer's removal, water and sweat resistant and is personalised with contact details of the family carer.



Hypoallergenic and Tamperproof ID bracelets are now available at

**The Lanka Alzheimer's Foundation**

**Inquiries Call 011 2667080 / 2667082 / 2667084**

**or**

**Mobile No: 076 0827080**

## *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 :**

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

## *The Board of Directors*

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

**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 cares.**

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

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 NDBSLK LX ,**

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

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

**Please notify the LAF Office to acknowledge receipt of your donation.**