



AN APPROVED GOVERNMENT CHARITY  
( GAZETTE NOTIFICATION NO. 1225 )

# Lanka Alzheimer's Foundation

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

## Message from the President



### Cautious Optimism

We see a glimmer of hope in an era of COVID 19. The global race for vaccines has borne fruit earlier than expected and some countries are seeing the benefits. Many in the western province of Sri Lanka, have been privileged to receive their first jab already.

This withstanding, the monster of corona still lurks around every corner and it is not a time for complacency. With more than 125 million confirmed cases and nearly three million deaths globally, cautious optimism is all we can have.

In an ideal world, the older adults and among them too, those with dementia and other disabilities should receive priority for the vaccination.

However, this has not always been the case. The equitable distribution of vaccines is being ardently debated. We will have to wait and see whether those in developing countries will be able to receive their share as the demand continues to far exceed supply. The rich and the privileged somehow appear to skip the line. There is still no global consensus on the distribution of vaccines despite the best efforts of WHO.

We are thankful that the staff and most volunteers of LAF have received their first dose of the Astra Zeneca vaccine. Our activity center has re-opened in March and we are slowly but surely stepping forward with all safety measures in place. We are delighted to see our clients trotting in again with smiles on their faces. The center is abuzz once again!

As we step in to our traditional New Year time in April, let us celebrate wisely and cautiously. Let it be a refreshing time of socializing, especially for our older adults with dementia, albeit with all safety measures in place to avoid exposure to Corona.

We wish everyone a joyful and corona free New Year!

**Shehan Williams**  
**President**

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## Free Memory Screening

**2021**

April - 9th 23rd

May - 7th 21st

June - 4th 18th

**Appointments are limited.**

**Please call 2667080**

## *A Carer's Story - By Ruma Lameer*

My mother, Ayn

My mother was born during the pre-war years - June 1929, to be precise.

She speaks of her childhood nostalgically, especially recalling her days in Thalangama, then a jungle, where the family relocated fearing bombing by the Japanese during World War 2. Many Colombo residents fled the city during the war. Away from the city, there was peace and nature was bountiful.

Mum is a good story teller, describing events animatedly and cheerfully—entertaining the guests with tales of days gone-by, of people long forgotten. As a hostess mum was hospitable to a fault. No visitor would leave our home hungry. Her cooking prowess was legendary: she found so much joy in entertaining, we were indeed fortunate.

She married my father, a sophisticated city businessman and enjoyed a happy married life.

Sadly, her married life lasted only nineteen years, my father passed away suddenly leaving her a widow with the care of six young children. My father's sudden demise was a cruel blow changing her situation overnight. Regardless, she bore it all with fortitude, striving against fate, undeterred and unafraid

Now, at age of 92, my mother can still read fluently in all three languages - English, Sinhala and Tamil. Writing however, has become a challenge which she finds quite tiresome, presumably due to her affliction. Despite her much reduced circumstances she was passionate about educating her children, encouraging us to read, while all the time ruling us with an iron hand. Music was another passion, a gift she shared with us all. We marvel at the fact that 'Mummy' enjoys the same music we do, overcoming the half a century gap between us. The Beatles are still a hot favourite with her.

Today, she enjoys a relatively healthy lifestyle. I attribute this to her most quoted motto; 'You must not live to eat but eat to live'. I hope and pray it will remain this way. May God Bless and keep her.

Alzheimer's, I have been told, is a regressive disease, but miraculously, my mother's condition has remained stable for the last five years. I attribute a lot of her stability to her weekly excursions to the Lanka Alzheimer's Foundation; she loves the bonding, singing and craft work they do there.

Thank You

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 get home



Hypoallergenic and Tamperproof ID bracelets are now available at

**The Lanka Alzheimer's Foundation**

Inquiries Call **0112667080 /82**

## *Volunteering amidst the pandemic*

The current COVID-19 situation that the world is currently battling, has been an unwelcome interruption in our lives. During the island-wide lockdown last March and the subsequent isolating of the area again in the latter part of the year, the Lanka Alzheimer's Foundation was forced to close its doors to its clients in the interest of everyone's safety. Being indoors for a long period and away from everyone was difficult for all of us. However, our volunteers at LAF knew that this would be especially difficult for the clients who often look forward to their weekly outings to the activity centre. Hence, since the centre was closed, the volunteers went out of their way to still be a part of the client's lives.

The volunteers reached out and kept in touch with the clients regularly via telephone and checking on them. I'm sure both clients and volunteers alike, looked forward to this. Additionally, clients were also sent an monthly activity work sheets, that included engaging tasks like adult colouring, word games, etc. This almost made it feel like the activity centre had come home. The volunteers also wished to ensure our clients were staying active and fit, especially at this time since movement is restricted. So chair yoga videos which were created by one of our very own volunteers, were uploaded to the LAF facebook page to encourage our clients to move around and exercise in the safety of their homes. These videos can be found on LAF facebook page

With the arrival of the vaccines and enforcement of stricter health regulations, the LAF opened the activity centre on 17th March & welcome our clients back . While ensuring that COVID regulations will be followed in the centre, the volunteers will continue to take that extra step and do what they can for our clients.

By Rachel Brohier



CALL OUR HELP LINE

**2667080**

Monday to Friday | 9am– 5pm

For information on dementia and dementia care management

## *Reaching out to silent sufferers*

### **Predicament of Alzheimer's patients during COVID-19**

Prof Shehan Williams in conversation with Rochelle Palipane - Sunday Island - 3rd December 2020

Recently, Prof Shehan Williams, a Professor in Psychiatry and Consultant Psychiatrist and President of the Lanka Alzheimer's Foundation (LAF), sat down to talk about the effects of the current COVID-19 on people with dementia.

At present, COVID-19 has had the biggest impact on dementia patients and their caregivers. Recent Alzheimer's studies in the west have shown that the most deaths were individuals who had dementia. Excluding COVID related deaths, most people who died were still dementia patients who died at the pandemic's peak compared to what was normally expected.

The most common symptoms that care givers reported in their loved ones with dementia were memory loss, difficulty concentrating, agitation/restlessness and stress or depression.

A few explanations have been put forward to explain this increase in dementia mortality rate. Firstly, people with dementia struggle to remember the set COVID health guidelines. This means that they would forget to wash their hands, social distance etc. This would make them susceptible to the COVID virus. Additionally, care givers have stated that isolation, depression and not understanding why loved ones can't visit them contributed to a loss of skills, independence and ultimately, premature dementia related death.

Another explanation for the number of deaths could be that health services didn't prioritize treatment and care for people with dementia. Further, the social isolation brought about by the pandemic had devastating effects on people with dementia.

The pandemic not only had an effect on dementia patients but on their primary caregivers as many reported feelings of exhaustion, burnout and feelings of being trapped with nowhere to turn.

Although the pandemic has progressed, there are some steps we can take to mitigate against further effects of the virus and those who are recovering as well as patients with dementia and their care givers.

People who make decisions regarding restriction and services should take into account that those with dementia need to be in contact with people. Additionally, attention should be given to the needs of caregivers who are an important part of the care system.

The COVID-19 pandemic has exposed the flaws in the health systems not only in our country but around the world as world. 'While it's difficult to change a system overnight, we can put the necessary foundations in place. It is inevitable that the Sri Lankan population will experience a rise in the number of dementia patients.

The needs of the dementia patients should be given priority by providing love and company, helping with eating, keeping cognitive and communication skills sharp, grooming and recreation and also advocacy and timely detection of changes in health. The Alzheimer's report also suggests that without visitors or excursions, patients will feel more lonesome and bored and this may be expressed through agitated behaviour or social withdrawal. The lack of physical activity may lead to loss of strength and the lack of cognitive stimulation may lead to greater cognitive decline. The needs of the care givers should also be considered with the highest regard.

The LAF offers personalized support to anyone with dementia as well as their care givers, families and friends and connects people to a range of dementia support by phone, online or face to face (under health guidelines). It's free of charge and puts them in touch with dementia advisers who give them the support they require.



Young at heart Never too old to paint with youthful minds at the activity centre

## ADI - Regional Meeting (Virtual) February 2021 - LAF was represented by Beverley Mirando



## Glenn Rees - Chairman ADI - Leaving Book – Message from LAF :



Thank you for your leadership & guidance at a global and national level that has led to the recognition of dementia as a major & growing concern.

On behalf of LAF we wish you all the very best in your future endeavours - good health & stay safe.

## Mini Sales - held at LAF in March 2021

Due to the COVID pandemic we were unable to have the Grand Sale in November 2020.

We decided to have mini sales in March 2021 for the LAF volunteers, family & friends.



## ***Obesity may exacerbate the effects of Alzheimer's Disease***

At present, while there is no cure for Alzheimer's disease, research is being conducted to understand the different risk factors that contribute to the onset of the disease. Additionally, research is bringing to light measures that can either prevent the disease altogether or slow its prognosis.

The Journal of Alzheimer's disease published research that stated that obesity can be linked to not only an increase in cardiovascular diseases but it is also a risk factor for Alzheimer's disease.

“We found that maintaining a healthy weight could help preserve brain structure in people who are already experiencing mild Alzheimer's disease dementia,” said Matteo De Marco, MD, University of Sheffield Neuroscience Institute. “Unlike other diseases such as cardiovascular disease or diabetes, people don't often think about the importance of nutrition in relation to neurological conditions, but these findings show it can help to preserve brain structure.”

This study concluded that obesity could contribute towards neural vulnerability in mild cognitively impaired and cognitively healthy patients. Cognitively healthy individuals with obesity showed neurological changes that are often associated with those who had Alzheimer's. This can indicate that obesity can progressively push the brain from cognitively healthy to mild cognitive impairment to mild Alzheimer's disease dementia and so on. In addition, Alzheimer's disease, dementia and obesity have a positive co-relation relationship.

Having a body weight that is ideal according to one's age can preserve brain structure and hence, protect the brain from aging and its related disorders. The study also shed light on the fact that if the participant with mild Alzheimer's disease maintained a healthy weight, it would lessen the chances of neural vulnerability that often occurs with the weight loss that ensues in the latter stages of the disease.

The study places much emphasis on early interventions; advocating for a healthier lifestyle, primarily focusing on lifestyle factors such as getting obesity under control during midlife as an effective measure to reduce the risk of developing Alzheimer's disease.

Dake, M., De Marco, M., Blackburn, D., Wilkinson, I., Remes, A., & Liu, Y. et al. (2021). Obesity and Brain Vulnerability in Normal and Abnormal Aging: A Multimodal MRI Study. *Journal Of Alzheimer's Disease Reports*, 5(1), 65-77. doi: 10.3233/adr-200267

Reference: <https://content.iospress.com/articles/journal-of-alzheimers-disease-reports/adr200267>

***Questions about  
dementia ?***

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## *Genes at odds; Aliria's story*

Aliria Rosa Pedralita de Villegas had a rare genetic mutation that would guarantee that she would develop Alzheimer's disease later on in her life. However, she only developed mild symptoms of dementia at the age of 72. This was puzzling to researchers because even though she had the assurance of developing dementia, her symptoms appeared past the normal development years of the disease which is between 50 and 60 years.

It confused her family as well as she 'didn't live an exceptionally healthy life' according to her children.

Presence of a high concentration of amyloid beta and tau have been closely linked to the development of Alzheimer's. Tau is said to spread the effects of the amyloid beta. Aliria's brain scans showed that although she had large amount of amyloid beta, she had very little tau present. Researchers determined that something had interrupted the degenerative activity that the gene would cause. By blocking this, it ensured that she would develop mild symptoms much later on and it spared her ability to function daily.

It was then observed through extensive brain scanning that Aliria carried two copies of another rare gene mutation that blocked the activity of the first mutation. Since this discovery, scientists are now studying the Christ Church mutation which is a variant of APOE that is associated with Alzheimer's development.

Drug therapies targeting amyloid betas have been unsuccessful. With the detection of this gene mutation, researchers have now hypothesized that the protective nature of Aliria's double ChristChurch mutation should be replicated. This has opened up a much needed new pathway for drug therapies and Alzheimer's.

Aliria died of cancer at the age of 78. Some say that Aliria's death stopped the further development of any more dementia related symptoms. While this has some foundation for argument, it cannot be overlooked that the ChristChurch gene did prevent the onset of symptoms till very late in her life and this is something that should definitely be further studied. After her death, her brain has since been donated for research.

Nytimes.com. 2021. *En vida desafió el alzhéimer. En la muerte, su cerebro puede mostrar cómo lo hizo.* [online] Available at: <<https://www.nytimes.com/es/2020/12/14/espanol/ciencia-y-tecnologia/alzheimer-cerebro-colombia-mutacion.html>> [Accessed 19 March 2021].

**WHEN YOU ARE FRUSTRATED WITH ME BECAUSE OF THE  
THINGS I CANNOT DO.....JUST IMAGINE HOW FRUSTRATED  
I MUST BE BECAUSE I'M NO LONGER ABLE TO ....  
BE MINDFUL  
SHOW COMPASSION**



# Current Services

- Raising awareness and eradicating stigma
- Education on risk reduction
- Education on care management
- Helpline +94 11 2667080
- Memory screening / assessments (Fortnightly)
- 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)
- <https://www.facebook.com/LankaAlzheimers>

## Caregiver Support Group (CSG)

The CSG meetings are conducted on a as need basis ;

- 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), Murtaza Esufally, Priya Fernando,  
Lilani Jayasuriya (Treasurer), Beverley Mirando, 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, 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**