



# Living well with dementia and COVID 19



We live in unprecedented times. The COVID 19 pandemic has profoundly affected all our lives. No one, big or small, rich or poor, healthy or not, whatever our circumstances, is spared of its consequences. The challenges are numerous as we adjust to the ‘new normal’. Frequent hand washing, wearing masks and maintaining physical distancing have become part of our lives for the near future.

Those with dementia perhaps are among the most challenged. As we age our ability to adapt and learn new things decreases. For those with dementia, this is all the more difficult.

Furthermore, persons with dementia can be the most vulnerable if infected with COVID 19. Figures from the Office for National Statistics in the UK have shown that dementia and Alzheimer’s disease were the two most common pre-existing conditions found among deaths related to COVID-19 and were linked to 20% of all deaths involving COVID-19. Persons with dementia perhaps have become the most isolated during these times. Not being able to go for walks or outings and not having visits from loved ones must be disheartening and depressing. LAF sadly had to close its Activity Center from mid-March this year. As much as we would like to open it as soon as possible, we have to balance the risks and the benefits. The safety of our clients and the caregivers cannot be compromised. So, we are compelled to exercise zero risk tolerance.

If community spread of COVID 19 continues to be contained, we will hopefully open the Activity Center in August, with all safety measures recommended by the health authorities. In the meantime, we are organizing an exciting ‘virtual walk’ in September, to encourage all of us to keep healthy by walking or running wherever we are through an online app. You will find more details on this in this newsletter. We thank you for your continued support and encouragement in this journey together, improving the lives of persons with dementia and their caregivers.

**Prof Shehan Williams**

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## Free Memory Screening

July - 03, 07, 31  
 August - 14, 21  
 September - 04, 18

**Appointments are limited.**

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**Lanka Alzheimer’s Foundation**  
 Email: [alzheimers@alzanka.org](mailto:alzheimers@alzanka.org) Website: [www.alzanka.org](http://www.alzanka.org)

## A carer's story by Geetha Rajendran



My brother Jayaraju was always independent and seemed a healthy and normal person until about 3-5 months before he had a stroke. He left home when he was 21 to pursue his spiritual path. He has travelled widely and has been active throughout. Apart from taking an active part in arranging programs in different countries as well as in Sri Lanka, he would translate speeches / materials in 5 different languages. Though a man of few words he took a very active part in his ashram and was well respected and was assigned a lot of responsibilities which he loved doing.

Roughly about 3 months before he got a stroke at the age of 61 he would ask for advice about healthy diets and at times would complain about a headache. I live abroad so we used to talk quite often on the phone and I suggested he see a doctor but as he has never been sick before he took it lightly and never consulted a doctor. But over time his behaviour seemed to have changed. He would talk a lot and it felt like he was imagining or hallucinating. Even though I could not fathom the reasons I knew something was not right. I could not travel back home to attend to him as I had a fracture on my foot during the same time. I requested my nephew to take him to the hospital and get a complete test done but that was not fruitful either as my brother did not want to go.

Not long after this he was found unconscious on the floor one day and was taken to hospital with a severe stroke and was in a coma for two weeks. He recovered gradually and is not paralysed but his speech is impaired and his activities are limited. He is being cared for in a home and my friends and family take care of him by visiting him and taking him out for the day. He can walk with support and will answer with a Yes/No or Can't remember when you talk to him and is aware of what happens around him. On hindsight if I had forced him to consult a doctor and get some tests done on time I wonder if the stroke and the current situation could have been avoided!

The specialist referred him to Alzheimer's Foundation as he was diagnosed with dementia and that is the best thing that could have happened to him after the stroke. He was lucky enough to get a spot on Fridays. Since his stroke I have been to Sri Lanka and have accompanied him to the Foundation and I must say on Fridays he is a different person altogether. He looks forward to going to the foundation and you will find him with a big broad smile on his face after he is dressed up.

The staff and volunteers at the foundation are extremely passionate about what they do and talented and well experienced to get the best out of patients like my brother. They make them get involved in activities and interacting with each other. Every single one of them is treated and handled in a very special and caring way. The staff are very respectful towards the patients and they are so creative, empathetic, understanding and patient that they just light up the room. No wonder my brother must be feeling he is in a Wonderland. I am so very grateful to all at the Alzheimer's Foundation.

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 safe.

Hypoallergenic and Tamperproof ID bracelets are now available at

**The Lanka Alzheimer's Foundation**

# Memorable Steps- A Virtual Walk for Alzheimer's



September is the World Alzheimer's Month and the 21st of September is the World Alzheimer's Day. In previous years, our key activities for the month have been the Annual Memory Walk, which we have held for 17 years and the Alzheimer's Run which we have had for 5 years with ever increasing community participation. LAF also conducts a range of other activities during this month to increase awareness about the disease, to combat stigma and to raise funds for the cause. The pandemic and the consequent necessity for public safety reminds us that we cannot have a series of activities this year. Therefore, LAF decided to conduct a single activity with maximum impact.

Memorable Steps, is a virtual Walk LAF plans to carry out in partnership with ayubo.life this September. ayubo.life is the flagship brand of Digital Healthcare Solutions Pvt. Ltd whose vision is to create healthier and happier nations by inculcating fitness habits. LAF is happy to be associated with them as healthy life styles prevent and/or reduce the risk of dementia. The ayubo.life app can be downloaded free of charge by anyone participating in Memorable Steps. Details on how to join the Walk will be made available through diverse media soon.

## What is a virtual walk?

In a virtual walk, participants are given a target number of steps to complete within a specific time period. The virtual route, selected to elicit greater interest, is from Anuradapura to Sigiriya, a distance of 91,000 steps. LAF expects participants to complete the Walk during the period 1st September to 21st September. A longer time period is given to enable participants to join later than the start date or walk slower if necessary to reach the goal.

In a virtual walk, a participant is not required to physically walk the given route. Steps walked anywhere in any part of the world with the mobile device or fitness wearable connected to the ayubo.life app will capture the data and map the progress in the virtual route in real time. You can walk/jog in your garden or at any walking path of your choice or even jog indoors on a treadmill and the steps walked will be converted to virtual steps on the ayubo.life app and the participants can see their progress on the defined virtual route. Participants are encouraged to keep a tab on their progress as exciting gifts, prizes and raffle entries will appear along the route.

Dementia quizzes and information will be available along the way for participants and also for all users of the app at the touch of a button. ayubo.life already has a membership of 91,000 and this information will be available to all of them, irrespective of their participation in the Walk. There will be rewards even for those who opt for an early stop or do not complete the Walk as we wish to inculcate a healthy life style that encourages people to participate at their own fitness level. So, get ready for an exciting Walk this September and don't forget to register for Memorable Steps.

**Lakmali Cabral – Director**

Let's Talk  
about

DEMENTIA



## Did You Know?

- ❖ Dementia is not a normal part of ageing. It is a disease.
- ❖ 3 out of 4 people with dementia haven't received a diagnosis yet.
- ❖ Early diagnosis enable people with dementia to plan ahead.
- ❖ Dementia is nothing to be ashamed of. It is no one's fault.

So let's talk about dementia. Help build dementia friendly communities.

## Ageing and memory: Do we know enough?

We at LAF are also following the new age trend of conducting virtual meetings and webinars via apps such as Zoom, to reach audiences while maintaining social or rather physical distancing. Recently a lecture was delivered by the President of our Foundation, Prof Shehan Williams titled “Ageing and Memory: Do we know enough?” on 26<sup>th</sup> of May 2020 from 6pm to 7pm to an interested group of participants from the Colombo office of the London Stock Exchange.

The Professor spoke on dementia, its prevalence, the need for early identification, an understanding of the symptoms, support for the person with dementia and the caregiver and the current situation in Sri Lanka. He emphasized that the illness is largely under-diagnosed as a result of a lack of awareness not only in Sri Lanka, but also worldwide.

Dementia is often considered a normal part of ageing. It is believed that it is natural for people to be forgetful as they age. This is not true. People can live up to even a hundred years with normal memory. If a person is affected significantly by memory or cognitive decline it is certainly due to an underlying condition such as dementia. It is sad that people fail to understand this, he noted. He ended the lecture by referring to LAF, and its efforts in dementia advocacy and support for persons with dementia and caregivers in Sri Lanka.



  
Lanka Alzheimer's Foundation

**A VIRTUAL WALK  
FOR ALZHEIMER'S**

**91,000 STEPS | 21 DAYS**

*Virtually walk from Twin Ponds  
Anuradhapura to the Sigiriya Rock.*

*1st September to 21st September 2020*

  
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LIVE HAPPY



## Another day in the Community – By Malsha Jayasooriya



Listening to the musical sounds made by Bo leaves, I'm looking around for a familiar face as I enter Sri Siddhartha Temple, Kaduwela. Clad in a saree, feeling the heaviness of the laptop bag over my shoulder, I climb the steps of the assembly hall, to find Mr. Sugathadasa, President of the Senior Citizen's Society greeting me with a smile on his face. As I enter the hall, I'm met with a busy scene. I see achchis and seeyas enthusiastically jumping to their feet, promising to bring food and other stuff for an upcoming almsgiving, while some are planning among themselves. Mr. Sugathadasa announces my arrival and within a minute chaos becomes serenity, and I see eager faces waiting for the presentation to begin.

“How many of you have heard the word Dementia/ Alzheimer's disease before?”, I start with my usual question. Not surprisingly only less than 10 hands go up in a room of around 100 people. Even those who have heard the word before, don't know anything beyond that it's related to forgetfulness. Patiently I take them through my presentation, “Preface to Dementia”. We discuss the human brain, what dementia is, 10 warning signs, prevalence, symptoms, risk reduction, treatment and last but not the least about Lanka Alzheimer's Foundation.

This group is very different from the previous communities I had the discussions with. As I witnessed myself, this community is a living example of active ageing, going on monthly trips, organizing almsgivings and many more activities conducted throughout the year. Many said they meditate daily, and wanted to know whether it can be counted as a risk reduction strategy even though it was not on my slides. With a very satisfied heart I ended my discussion praising and encouraging them to keep on doing what they were doing.

They shower me with gratitude and are also surprised to find, LAF is doing these awareness programmes and offering other services free of charge. A line is immediately formed to get leaflets and to ask various questions about LAF, which they haven't known before. Mr. Sugthadasa delivers a thank you speech, and we discuss about doing some more programmes in the neighbourhood communities before I bid farewell.

## From a Visitor's Perspective by Rahul Kothari



I guess our family volunteer experience could be summed up in one word. Surprise.

Surprise at how differently Alzheimer's affects each person it takes hold of. During our visit, some clients were quiet, some were chatty, some kept to themselves and some sought out our company. Some welcomed us as family members (literally albeit mistakenly) while others thought we were the devil (again literally but hopefully mistakenly as well). Surprise at how amazing the facility is. It's openness. It's brightness. The tasty food. The beautiful art. Surprise and awe at the kindness and dedication of the staff. We only got a glimpse of what a herculean effort it is to care for those ravaged by this cruel disease.

How trying it must be to be a client and the permanent caregivers of a client. That an organization like LAF and its staff exists to provide some support and relief to those devastated by this disease, restores one's faith in humanity. That was the most pleasant surprise of all.

## Sri Lankan mace for Alzheimer's disease



Sri Lanka is one of the leading exporters of spices in the world market as it produces high quality spices with unique aroma and flavour. The country has a long history of spices and it was known as *Isle of Spices* since Ceylon spices attracted traders and explorers including Arabs, Persians, Indians, Europeans etc. Spices are used in many ways as flavouring, colouring agents and to enhance the texture of food. In addition spices are widely used in traditional medicine due to their enormous medicinal values. Scientific studies have proven spices provide many health benefits than just a flavour in food.

A group of Sri Lankan scientists led by Prof. Lalith Jayasinghe of the National Institute of Fundamental studies, Kandy and Dr Nilupa Amarasinghe of the Faculty of Allied Health Sciences, University of Peradeniya have investigated local spices for their potential health benefits including their ability to slow down the memory impairment in patients with Alzheimer's disease. Acetylcholine is a chemical that serves as the messenger to carry information from one neuron to another in the neuronal connection. One of the treatment strategies involves the use of acetylcholinesterase inhibitors (or anticholinesterases). These drugs inhibit the acetylcholinesterase enzyme which breaks down the neurotransmitter acetylcholine present in the neuronal connections in the brain. Inhibition of acetylcholinesterase can increase the availability of acetylcholine for nerve impulse transmission. Drugs help to reduce the cognitive decline in patients with Alzheimer's disease.

Currently available anticholinesterases have side effects hence there is a need to find natural anticholinesterases with less side effects. Out of the twelve spices subjected to testing, mace (fruit aril of nutmeg, Vasa-vasi; Sinhala, Saadikaitthol; Tamil) had a very good anticholinesterase activity indicating its potential application to treat Alzheimer's disease. Seed kernel is known as nutmeg and the cover is known as mace. Both are popular spices. Nutmeg seeds are traditionally used to treat diarrhea, rheumatism and to improve cognitive activity. Mace is used in folk medicine to assist digestion, relieve pain and to treat rheumatism.

Further investigations lead to the separation of the compound that has the ability to inhibit acetylcholinesterase. The active compound was previously reported and identified as malabaricone C. Laboratory studies revealed, chemical compounds present in mace to have good antioxidant activity and blood glucose lowering potential. Both oxidative stress and high blood glucose levels are considered as risks factors of Alzheimer's disease. Interestingly mace has the ability to control both risk factors. Hence the present study revealed that Sri Lankan mace contains chemical compounds that can be used to treat Alzheimer's disease.

Available scientific literature and these findings have shown that mace has promising activity against neurodegenerative diseases through multiple mechanisms. However further studies are required to understand the way that chemical compounds in mace interacts within human body, their efficiency and safety.

This research was supported by a National Science Foundation grant NSF/RG/2016/HS/04. Further information available through: S. Sathya, N.R. Amarasinghe, L. Jayasinghe, H. Araya and Y. Fujimoto (2020). Enzyme inhibitors from the aril of *Myristica fragrans*, *South African Journal of Botany*, 130, 172-176.

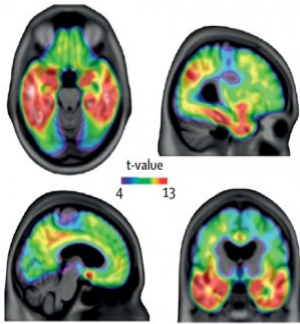
**Questions about  
dementia ?**

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**Monday to Friday | 9am– 5pm**

### Game-changing blood test accurately detects Alzheimer's disease



A simple blood test that can detect Alzheimer's disease (AD) has been discovered and validated in a joint effort by a McGill team and researchers in Sweden. Their results are published in the May issue of *The Lancet Neurology*. An accompanying commentary calls the discovery "transformative." The blood test accurately measures one of the proteins – P-tau181 – implicated in AD. Blood P-tau181 indirectly measures tau hyperphosphorylation in the brain, which is one of the hallmarks of the disease along with the clumpy plaques caused by the protein amyloid  $\beta$ . Prior to this discovery, detecting the proteins and confirming an AD diagnosis was possible only through expensive PET scans, invasive lumbar punctures, or autopsy.

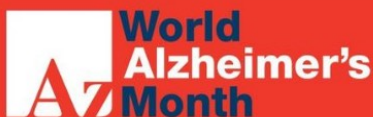
The search for an AD blood test has been years in the making, but a test sensitive enough to detect tau long eluded researchers. The new assay is sensitive enough to detect even the very low levels of the protein in blood in patients showing no signs of cognitive impairment. The team is leading another trial to ascertain the clinical utility of this biomarker in clinical settings and test how the biomarker performs in real life. The test should be widely available in two to three years.

There are several important clinical applications for the test, including as a screening tool in the primary care setting; to monitor the disease progression; and as a way of ensuring that subjects enrolled in clinical trials indeed have Alzheimer's disease and that the drugs they are testing are effective against AD. The assay could greatly reduce costs of diagnosing and studying the disease here and in the developing world.

The test is also sensitive enough to differentiate Alzheimer's patients from patients with other neurodegenerative disorders, including front temporal dementia. It will also be possible to rule out Alzheimer's in patients with mild cognitive impairment, indicating there is some other cause for their memory issues. Dr. Tharick Pascoal, who just completed his PhD in McGill's Integrated Program in Neuroscience (IPN) and who is a co-author with Thomas K Karikari who works with Kaj Blennow and Henrik Zetterberg at the University of Gothenburg notes that about 30% of patients currently diagnosed with AD don't actually have the disease. Dr. Serge Gauthier, Director of the Alzheimer's Disease and Related Disorders Research Unit of the McGill University Research Centre for Studies in Aging (MCSA) and Professor in the Departments of Neurology & Neurosurgery, Psychiatry, and Medicine at McGill adds, 'We're not talking about 90 year olds, we're talking about 60 year olds where there's uncertainty about the diagnosis when you're that young.'

Dr. Gauthier is quick to point out that the test, used at this early stage, will identify a risk factor, but is not a diagnosis. He compares it to a cholesterol test that can indicate a risk factor for heart disease. "There is no treatment for mild cognitive impairment (MCI) except for lifestyle changes, especially lowering blood pressure, keeping the mind and body busy – all the good things you're supposed to do," he says. "But people will be more motivated to do it if they know they have elevated proteins and are at risk."

Source : <https://www.mcgill.ca/newsroom/channels/news/game-changing-blood-test-accurately-detects-alzheimers-disease>



**September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma.**

**Each year, Alzheimer associations from around the world unite to organize advocacy and information provision events, as well as Memory Walks and fundraising days.**

# Current Services

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

## 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

# The Board

Lakmali Cabral (Secretary), Yasmin Cader, 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.**

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

**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**

**Thank you**