Quarterly Issue - Vol. 223

President's message

July-September 2022

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<u>Website: www.alzlanka.org</u> G : alzheimers@alzlanka.org

Together, we can do so much !

The 11th World Alzheimer's Month campaign begins on 1 September, and this year's theme will once again be 'Know Dementia, Know Alzheimer's' and have a special focus on post-diagnosis support.

Throughout the month and under the campaign message of 'Together, we can do so much', the Alzheimer's associations in more than 111 countries will be highlighting the importance of support for people living with dementia and families following a diagnosis, as well as the importance of recognising the warning signs, practicing risk reduction, challenging stigma and encouraging people to seek out information, advice and support.

In Sri Lanka too, we will be marking the month amidst the national chal-

lenges we all face. As always, in times of crisis, it is the marginalised and vulnerable populations who are affected the most. Those with medical issues and disability will find it all the more challenging to get by. Persons with dementia certainly belong to this group.

Lack of fuel and transport limitation lead to further social isolation. The cost of medicines is spiralling. Inflation is at an all time high leading to ever increasing food costs. All of the above will plague those with dementia and ensnare them in numerous ways.

Our ever-vibrant activity centre for persons with dementia which resumed function this year, after Covid issues last year, has had closures due to the ongoing fuel crunch. The clients and volunteers have difficulty attending. We are also mindful of the cost of operating the centre although we are confident of continuing the standard of care thanks to the generous donations we receive from our well-wishers.

We look forward to the 'Virtual Walk' and other activities we will be planning, once again, this year in September. Every cloud has a silver lining! The current impasse has compelled many of us to walk and cycle more. There is no sine qua non like exercise and physical wellness to prevent dementia and other noncommunicable diseases. So, let us put on our walking shoes and march forward to fight the threat of Alzheimer's and dementia in the coming months.

Prof Shehan Williams

President

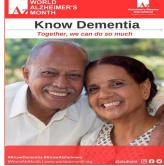


September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. World Alzheimer's day is celebrated annually on 21st September.

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Free M	emory	Screen	ing

	202	22		
July	-	8th 22nd		
August	-	5th 19th		
September	-	2nd 16th		
Appointments are limited.				
Please call the Helpline 2667080				
to register.				



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From a Volunteers Perspective - My Journey at LAF



My journey with The Lanka Alzheimer's Foundation (LAF) started nearly 14 years ago when I first met Lorraine Yu, co-founder of LAF. The Centre was then in the making, and Lorraine and her team were working hard raising funds to complete the construction of LAF Information and service Centre.

Lorraine invited me to join her on the campaign the following year. Being in full time employment, I was able to keep her company only in the evenings, and on weekends. She would spend the entire day at a supermarket, occupying the space allocated to her, selling raffle tickets and other Alzheimer's related souvenirs as well as raising awareness with customers who would come in to do their shopping. Most often by herself. The campaign would go on for 3 months culminating in September to coincide with World Alzheimer's Day -21^{st} September. Lorraine would brief interested customers on the work the Foundation was engaged in. In fact, one of our present volunteers came after meeting Lorraine at a supermarket. Lorraine would continue working into the night, reconciling her accounts at the end of each day at the supermarket. When I woke up the next day, I would see a message from her telling me the number of

ticket books sold by me and a breakdown of the total amount raised. I found the time at the supermarket most enjoyable. For as long as the sale of raffle tickets was done at supermarkets as part of the campaign, I was there whenever I had the time to spare.

Every year thereafter I would participate in the annual 5 km walk held in September. The last 2 years however, due to Covid, the walk has been a virtual one, spread over 3 weeks. A musical concert too, was then, a much looked forward to annual event. Two of our clients have performed at these concerts.

In September 2011 on World Alzheimer's Day, the elegantly designed Centre was officially opened. At the end of that year I retired from full time employment and was therefore free to give of my time to LAF.

In January of the following year, LAF commenced its services, one of which was the Activity Centre which focused on providing therapeutic activities with a person centered approach to people diagnosed with dementia. This service is provided free of charge. Donations are given by family members of the clients who can afford to do so. Initially this was done on a Wednesday. The programme started with just about 4 to 5 clients. I came in as a volunteer a couple of months later, and have been a volunteer ever since. As of now, I can claim to be the longest serving volunteer at the Centre.

Being such a volunteer was certainly an eye opener for me. When I see the clients, - who they have been in the past, and the shell of their former self now, it is ever so saddening. They are people from all walks of life, some of them widely known, and have excelled in their careers and professions. Volunteers keep them entertained through the day, engaging them in activities they can cope with. These activities vary depending on the capabilities of the clients. Each week a singing and dancing session is conducted. This is the highlight of the day for most clients. Family carers are pleasantly surprised when shown video clips of their loved one singing and dancing.

I find these clients to be lovable people. Whenever rude remarks are directed at volunteers, they are taken in stride. It is important that insults are not hurled at each other. If we observe any aggression between clients, they are separated.

One client who was in her 80s (now sadly no more) said she had to go home early as 'mummy is waiting for her.' Another, (whose husband passed away some years ago), said her husband would not eat till she got back home. Another client who was permanently hungry stated that she was not allowed to have breakfast, as she had to go to the 'Hotel'.No sooner she came to the Centre, she would demand food. When my own son visited the Centre a couple of years ago, another client clung onto him and stated that he was her son, and forbade him to leave her sight. I could go on and on.

Over time, the Activity Centre opened on Mondays and Fridays as well. Thus, there were 3 teams of volunteers. However, clients could only register themselves for two days per week. We would all meet and get to know each other at various combined events. Immediately prior to the Covid lock down, the Activity Centre was running to full capacity. Sadly, most of them are not able to come after the Centre reopened, while some have crossed the bridge.

In September 2019, Lorraine our much-loved founder, who was a great inspiration to us all, voluntarily retired from LAF and to date is greatly missed. As I continue my journey with LAF, serving as a volunteer, I wish that all members of the present team continue the good work of its Founders.

Savi Gunasekera

CALL OUR HELP LINE

2667080

Monday to Friday | 9am– 5pm

For information on dementia and dementia care management

A Carer's story - by RG

My mother was diagnosed with early Alzheimers' Disease last year when she was 87 years old. This was after she fell in our backyard trying to prevent the cat from climbing a tree. She broke her forearm just above the wrist and we struggled to bathe, dress, and feed her, while her arm was in plaster and having to be held above her heart all the time. I could not do much to address the longer-term health issue of Alzheimers other than Google a bit and go with the medication that the neurologist prescribed. One of my friends whose mother-in-law had Alzheimers, did suggest that I take my mother to the Alzheimers Centre. But we were in then in the middle of the pandemic with intermittent lockdowns, and the Centre was closed.

When COVID-19 abated at the beginning of 2022, it seemed as if the Centre may be open again. So, in February I took my mother for a memory screening test in which she fared much worse than she expected. Piqued, she refused to enrol for the activity sessions. But I struck a deal with her. I told her that she must go once a week for a month and see how she likes it. Having tried it if she still didn't like it, then she could decide not to go. But if she did like it, then we could see whether she could go twice a week. We also did another brain scan around the same time and discovered that the disease had made rapid progress. It was imperative that she started a complementary course of therapy, as the neurologist also said that there was a limit to what drugs alone could do.

As it turned out, she enjoyed herself so much the first day at the Centre that she was secretly pleased when I suggested that she goes twice a week from the second month onwards. Now, her week is signposted and referenced with her "going to school" as she puts it, twice a week to the Centre, on Mondays and Wednesdays. The days in between are marked in terms of what she will do before she goes, when she will oil and shampoo her hair, whether she needs her nails cut, whether it's time to paint them again, and most importantly, what she will wear. She always remembers what she had for lunch at the Centre, the exercises she did, the songs she had sung, and the pictures she had coloured. She looks forward to Mondays and Wednesdays and is always cheerful and upbeat when she is picked up. And I too get a precious respite while she is at 'school'.

My mother always looks forward in going to the activity centre, but given the fuel shortage, and when there is days when the AC is closed, I will have to find something to keep her entertained at home this week then...perhaps YouTube videos of the Queen's Jubilee Celebrations ...

10 warning signs of Dementia

- * Memory loss
- * Difficulty performing familiar tasks
- * Problem in language
- * Disorientation to time and place
- * Poor or decreased judgement

- * Problem keeping track of things
- * Misplacing things
- * Changes in mood and behaviour
- * Challenges understanding visual and spatial information
- * Withdrawal from work or social activities

If you are experiencing these symptoms or know of someone who is, talk to a doctor or call us on 2667080 and make an appointment for a free Memory Screening.

Galle - Dementia Friendly Communities

Awareness programs & activities were conducted by Wasanthi (our project coordinator) for elders within the Gonapinuwala district, at the Arachchikanda community centre, Berathuduwa community Center & Gonapinuwala Temple.



Introducing LAF's new board member



Ms Romany Parakrama is the latest addition to the Board of Directors of the Lanka Alzheimer's Foundation. She is the Executive Director, Corporate Communications, of David Pieris Motor Company. She is a seasoned financial services executive with 24 years of multi functional experience in the banking industry in two significantly different geographical locations, Singapore and Sri Lanka.

She has an in depth understanding of international banking and commerce with experience in both corporate and consumer banking and a proven ability to deliver in a results -oriented culture. Her expertise is in all aspects of corporate communications: media relations, internal communications, issue and crisis management, brand and sponsorship, and executive communications. With her excellent networking and communication skills, we know she will be a valued member of the Board .

35th Global Conference of Alzheimer's Disease International - 2022

The ADI 2022 Global Conference was held as a hybrid event with over 1,000 delegates from across the globe participating, in person or virtually.



The Lanka Alzheimer's Foundation was represented virtually by Beverley Mirando (Director)

LAF was presented in the Member Showcase as follows :

*To mark World Alzheimer's Month, LAF once again organized a virtual walk in September. "Memorable Steps 2021" was held from the 10th to the 30th September. The challenge required participants to walk 100,000 steps 'virtually'. A separate 'Team challenge' was also introduced to enable teams of 5 members to take up the challenge of completing 500,000 steps each. Many teams from corporate organisations joined in the team challenge .

* After a lapse of a year, it was wonderful to have everyone back at Lanka Alzheimer's Foundation for the annual Scrabble Bash Tournament that was held on February 26 2021th.

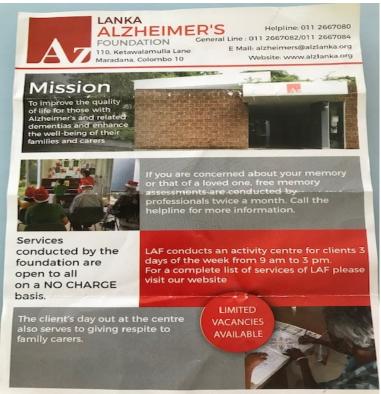
* In August 2021, LAF began a strategic planning exercise resulting in a plan for the next five years 2022—2026. LAF thanks Strategic Inspirations for providing the consultancy service to facilitate this process and the WHO Sri Lanka for financially supporting this initiative.

* LAF believes that local **Dementia Friendly Communities** have the capacity to meet the needs of persons with Dementia, their carers & promote awareness about Dementia and its risk reduction. With this in mind, we have started the Dementia Friendly Communities initiative as a Pilot project in Galle from January 2022. Mrs.Wasanthi Kumudini, is our new Project Co-ordinator who works in the Gonapinuwala Divisional Secretariat area engaging with Elders societies and helping them support their own elders with dementia. We are happy that we obtained the necessary permission for our work from the District Secretariat in Galle.

* Clients & volunteers enjoyed the Avurudu celebrations on their Activity centre days, just before the April vacation. It was amaz ing to see how our clients participated in the activities that the volunteers organized.



Colombo Swimming Club

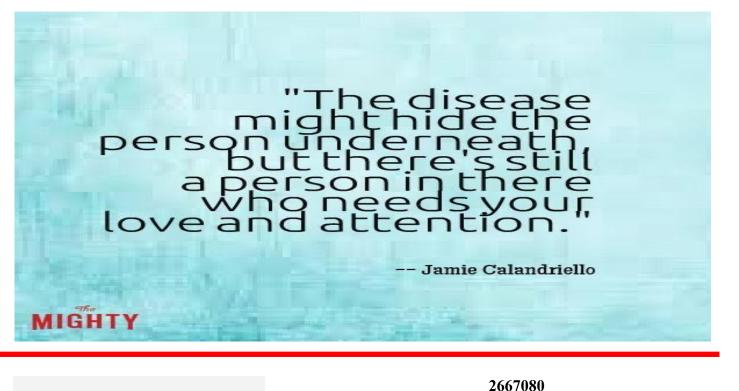


The right to confidentiality is maintained at all times.

Thanks to Eugene one of our Wednesday volunteers, a brochure regarding LAF was circulated among the membership of the Colombo Swimming Club.

We are most grateful to Eugene for taking the initiative and designing and printing the brochure as well as to the Board of Management of the Colombo Swimming Club for circulating this to their membership.

We hope this link we have established with CSC will lead to further collaboration to take forward our mission to care for people with dementia.



Questions about dementia ?

Monday to Friday | 9am– 5pm For information on dementia and dementia care management

Healthy lifestyle associated with more years without Alzheimer's Dementia

A healthy lifestyle was associated with a longer life expectancy among both men and women, and a longer proportion of their remaining years without Alzheimer's dementia, according to a study published in *BMJ*.

The Chicago Health and Aging Project examined the effects of a healthy lifestyle among 2,449 men and women aged 65 years and older. A healthy lifestyle score was developed based on 5 modifiable lifestyle factors: a diet for brain health (Mediterranean-DASH Diet Intervention for Neurodegenerative Delay-MIND diet score in upper 40% of cohort distribution), late life cognitive activities (composite score in upper 40%), moderate or vigorous physical activity (\geq 150 min/week), no smoking, and light to moderate alcohol consumption (women 1-15 g/day; men 1-30 g/day).

Results showed that women with 4 or 5 healthy factors had a life expectancy of 24.2 years and lived 3.1 years longer than women aged 65 with zero or 1 healthy factor (life expectancy 21.1 years). Of the total life expectancy at age 65, women with 4 or 5 healthy factors spent 10.8% (2.6 years) of their remaining years with Alzheimer's dementia, whereas women with zero or 1 healthy factor spent 19.3% (4.1 years) with the disease.

Life expectancy for women aged 65 without Alzheimer's dementia and 4 or 5 healthy factors was 21.5 years, and for those with zero or 1 healthy factor it was 17.0 years.

Men aged 65 with 4 or 5 healthy factors had a total life expectancy of 23.1 years, which was 5.7 years longer than men aged 65 with zero or 1 healthy factor (life expectancy 17.4 years). Of the total life expectancy at age 65, men with 4 or 5 healthy factors spent 6.1% (1.4 years) of their remaining years with Alzheimer's dementia, and those with zero or 1 healthy factor spent 12% (2.1 years) with the disease. Life expectancy for men aged 65 without Alzheimer's dementia and 4 or 5 healthy factors was 21.7 years, and for those with zero or 1 healthy factor life expectancy was 15.3 years.

"A healthy lifestyle was associated with a longer life expectancy among men and women, and they lived a larger proportion of their remaining years without Alzheimer's dementia," wrote Klodian Dhana, Rush Institute for Healthy Aging, Rush University Medical Center, Chicago, Illinois, and colleagues. "The life expectancy estimates might help health professionals, policy makers, and stakeholders to plan future healthcare services, costs, and needs."

Reference: https://www.bmj.com/content/377/bmj-2021-068390

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



Hypoallergenic and Tamperproof ID bracelets are now available at

The Lanka Alzheimer's Foundation

Inquiries Call 0112667080 /82

dementia to get back home safely.

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

Caregiver Support Group (CSG)

The CSG meetings are conducted as needed .

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

The Board

- Quarterly newsletter
- Resource Centre/ Information and resource materials
- Caregiver support group (CSG) meeting
- Memory Garden Cafe
- Identification bracelet
- Website : <u>www.alzlanka.org</u>
- www.facebook.com/alzlanka

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.

Lakmali Cabral (Secretary), Priya Fernando,

Lilani Jayasuriya (Treasurer), Beverley Mirando, Romany Parakrama, 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