Quarterly Issue - Vol. 228

Oct to Dec 2023



# Alzheimer's Foundation ers@alzlanka.org Website: www.alzlanka.org

Email: alzheimers@alzlanka.org

# President's Message

# LAF activities during World Alzheimer's month

The World Alzheimer's Month, a month of many activities for LAF, has just ended. The 'Memory Walk' and 'Run to Remember' were conducted successfully as planned with good participation from all walks of life. We are delighted that we were also able to stage a puppetry-based drama around dementia with 'Mahadanamuththa and his golayas' by the Power of Play group headed by Sulochana Dissanayak in Colombo, Gampaha and Galle.

We are also thankful that Cinnamon Grand and Taj Samudra hotels unreservedly sponsored our 'Memory walk' and 'Run to Remember', respectively. As always, the support of our friends and well-wishers have been invaluable in making the events a resounding success.



Our dementia advocate and ambassador Johann Peiris was at the helm of all the public activities, and we also had the privilege of Chaminda Vass flagging off the run and Asha de Vos joining the run and coming first in the female category. Yasmin Cader as always was a tower of strength with her incredible network and meticulous planning and execution of all the events.

We had fantastic publicity for our events with print, electronic and social media coverage beyond expectations as you will see from our reports in this newsletter. Hi and Wijeya newspapers as always partnered with us and Grants assisted us with the visuals and audio clips. We also had NGage joining in the media campaign boosting our social and print media presence. We are also grateful to the generous sponsors who contributed in numerous ways to keep our costs down.

Our volunteers, directors, and office staff (Susan and Manoja) delivered their untiring service in an admirable way, far beyond expectations. The kudos are to the whole Team and the collective strength of our organization which achieves so much with so little financial expenditure.

As we move forward, we can but only pause a moment to look back. We must keep marching forward more resolutely as those affected by dementia are increasing by the day. With lack of awareness, access to a diagnosis and care, the suffering of those affected and their families continues unabatedly. Our mission is still unaccomplished...

Prof. Shehan Williams

President

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# Free Memory Screening

2023
Oct - 6th & 20th
Nov - 3rd & 17th
Dec - 1st & 15th
Appointments are limited.

Please call the Helpline 2667080 to register.

# World Alzheimer's Month events command high visibility and participation

Three key events conducted by the Lanka Alzheimer's Foundation to mark World Alzheimer's Month, driven through significant personal, social, and earned media promotions, drew high levels of participation during September.

The first of these, a 5 km "Run to Remember", kicked off at the Taj Samudra Hotel North Lawn on Saturday 2<sup>nd</sup> September at 4 pm. The run was revived after a break of 3 years due to the pandemic and other crises that followed. The event received engagement on social media from over 1,000 enthusiasts with over 300 responses. Individual runners and teams from National Rugby pool, the Hashers, Colombo City Runners and Ceylon Night Runners joined the run, and were flagged off by celebrity cricketer Chaminda Vas and the General Manager of Taj Hotels the sponsors of the post run treat. Leading the women at the finish was celebrity marine biologist Asha de Vos, while among the men, Heshan Rajapakse was flagged in by LAF President Prof. Shehan Williams.

The "Memory Walk" started in the morning of  $23^{rd}$  September and drew an equally large response and participation. The Cinnamon Grand Hotel played host with a delectable breakfast spread and treats for attendees both before and after the walk. Despite a slight drizzle, the walk was completed successfully with a DJ truck leading the procession to keep everyone to a beat and draw the attention of bystanders. A raffle was held at the end of the walk with a ticket to Singapore from Sri Lankan Airlines and other prizes.

A new initiative, this year, was an original production commissioned to edutain on 'Dementia and risk reduction and caregiving' featuring Mahadenamuththa and his modern day Golaya in a puppet show performed by the Power of Play group led by its Artistic Director Sulochana Dissanayake. The show drew packed houses for the morning and afternoon shows in Colombo, Gampaha and Galle starting on World Alzheimer's Day, 21st September. A Q &A session after the performances saw significant audience interactions and anecdotes which highlighted the relevance, appeal, and value of this form of awareness creation. LAF President Prof, Shehan Williams was on call to field the questions. Videos of the performance have been produced to go online on YouTube and the LAF Facebook Page, to share the programme with a wider audience.

Significant earned media coverage was obtained with over 12 appearances in newspapers, including an editorial and several articles, 26 online website exposures, plus an online video interview and radio coverage.

## Nimal Gunawardena













CALL OUR HELP LINE

2667080 / 2667082 / 2667084

Monday to Friday | 9am-5pm

For information on dementia and dementia care management

# Run to Remember

# Reduce risk now, its never too early, never too late

Runners, well-wishers, and volunteers gathered at the Taj Samudra to kick off World Alzheimer's month with 'Run to Remember' on Saturday 2nd September, after a lapse of 3 years.







# **Memory Walk**

This was held on Saturday 23rd September at the Cinnamon Grand, Colombo, City Club Garden. Family careers, persons with Dementia, well-wishers and volunteers participated and distributed leaflets and other informational materials to by standers.









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# **W**View

# World Alzheimer's Day and Sri Lanka's challenge

WORLD Alzheimer's Day falls on 21 September each year and it is a day to focus attention on a disease that is on the rise world over including in Sri Lanka. According to the data published by the World Health Organisation (WHO) in 2020 Alzheimer's and Dementia deaths in Sri Lanka reached 6,939 or 5.98% of total deaths and this trend is on the rise

As the risk of Alzheimer's disease, degenerative disease of the brain, increases with age, Sri Lanka with one of the fast-est ageing populations in the region, has much to focus on to assist those who would be afflicted by the related conditions in years to come. The Sri Lanka Alzheimer's Foundation (LAF) says that predictions are that by 2036 every fifth person in the country will be over 60 years and we can expect an increasing number of people with dementia. Alzheimer's disease is the most common cause of dementia, and it is estimated that by 2050 there will be almost half a million people living with dementia in Sri Lanka.

The LAE a member of the global association, Alzheimer's Disease International (ADI), is focused on post-diagnosis support for those living with Alzheimer's and other related dementias and to enhance the wellbeing of their family carers but this is an area which would need governmental sup port in the future. While there is still no cure for Alzheimer's disease, its onset can be delayed, and progression prevent ed from worsening with early screening and treatment of patients.

As the initial signs of Alzheimer's disease and onset of dementia are subtle, it is usually ignored as forgetfulness that sets in with age. Medical professionals advise that you seek help if there are any memory or cognitive changes that concern you. The advice is to seek an assessment by a doctor instead of making self-diagnosis which could delay a person from getting the required treatment. As with any other medical condition, treatment of Alzheimer's disease and other dementias is most effective when started early. Treatment includes medications as well as some alternative therapies.

Lanka Alzheimer's Foundation President Professor Shehan Williams in a recent interview touched on an aspect of concern with regard to patients with these conditions which is often not addressed. He warned that a person with dementia is vulnerable to exploitation and abuse. Given the harsh economic conditions that a majority of people in the country face, the exploitation of such people is likely to take ore often than not.

The LAF campaign slogan for this year is 'Never too early, never too late' to learn about dementia and take steps to prevent its onset and progression. As more awareness of these conditions grows among the public, there is an increase in reported cases which has made more people seek professional help early on but there is little help for families by way of advice on how to handle such patients.

There is a mammoth task ahead for the country as it faces a future with an ageing population and with an increased risk of persons afflicted with conditions such as Alzheimer's diseases as well as dementia. It will take a concerted effort not only by institutes such as the LAF but also governmental bodies to train caregivers as well as related medical personnel so that there would be a proper structure in place to assist those who will end such care. Raising wider public awareness is also of equal importance

# Healthy lifestyles, early screening helps manage patients with Alzheimer's more effectively

-President, Lanka Alzheimer's Foundation



# In four days time the world

other cognitive impairment beyond a handred years of they are not affected by this disease.

The commonent cause of dementia today is Alabeimer's disconcility. It is a degenerative disease of the bains that seek in a gradually eventually leading to dementia. According to epidemiologi-cult studies it is suff in according to the common the common of the common provent of all dementias. Other condi-cutations is the sufficient of the com-tensity of the common of the com-dementia, Parliance's disease related dementia, functions years and alcohol related dementia, infections were a textual to the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the com-tensity of the common of the common of the common of the com-tensity of the common of the common of the common of the com-tensity of the common of the common of the common of the com-tensity of the common of the comm

A. Smoking is well established as a toxin to the whole body including the brain. Smoking contributes significantly to atherosciencies or damage to blood vessels in the body due to atheromatous plaque formation. The brain highly deposition of the brain onatous plaque formalion. The brain is highly depondent on oxygen. Even a blockage to the smallest vessels to the brain can compromise the oxygen supply to the brain. Big blockages result in strokes—which manifels as sudden walkness or loss of consciousness. Strokes result in permanent paralysis and disability and even death. What is lesses known is the impact of minor strokes knows as micro infarcts that

A. Excessive alcohol is clearly humidal to the brain. Long term alco-hol use leads to shrinking of the brain date to loss of brain cells because of this direct toxicity. There are various orther mechanisms use its depiction of "elarmins in the body due to alcohol. A de-ficiency of vistami in or Thiannine is well evaluished in long term alcohol use. Thiannine deficiency can lead to a condition called Wernicke's encopi-aleously when the person becomes

If this deficiency is not rectified im-mediately it could lead to a condition called Korsakov's syndrome where a

diabets mellitus and cholesterol let-ch are implicated in most forms of dementia. These diseases contrabito to poor blood mapply to the brain that to their long terms directs on the brain when not properly treated. Therefore, it is not stimum importance that people take proper treatment for blood pres-sure, diabets and Hyperchelesterol acmia as neglect of these conditions will not only result in strokes, kinder failure and heart diseases but also de-mentia.

Do you see an upward curve in the number of dementia cases being reported country wide?

A. Yes certainly. There are two main reasons for this. First, with recossing awareness of dementia, more and more people are seeking belp. Secondly, people are living longer and the number of older persons is increasing the number of older persons is increasing the country of the number of older pensons is increasing the number of older pensons in increasing andly, poople are living longer and the number of clder persons is increasing by the day. The predictions are that by 2006 every fifth person in the cour-try will be over 60 years. So, it is not surprising that we will be having over increasing numbers of people with de-months.

mal forgetfulness. Yes, all of us forget and should not start worrying each time we misplace something or forget someone's name or a familiar place However, if someone keeps misplace

Q. Gender wise are men or omen more likely to develop AD!

A. Women have a three-fold high-rehance of getting AD, although this ary not be the case in other forms of ementie such as vascular dementia or ls it necessary for the final agnosis to be made by a specialis





Prof. Shehan William

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ognicive impairment (MGT). The progression of the disease can be very
variable. There are many persons with
dements who manage well in the mild
stages of the disease for many years.
They remain independent and lead active lives even driving, shopping and
cooking on their own or with some minor assistance.

(i) is Alzheimer's and dementia rurable or reversible?

A. A cure for AD has still not been found although some new drugs like Adenatumah and Leeaamah appear to have some effect on reversing the progression and have been termed the

O If screened and treated rly can its progression be at least ntrolled or managed?



amely Donepezil and Evastigmine rhich can delay the decline in mild to moderate AD. Another drug called fernantine is useful in moderate to

A. Managements for care.

A. Management of risk is a major concern. Often a person with demential is vulnerable to capitonion and abuse. Planarcial copholation is the confidence of a person with demendia can minagenpride mosey from hite. Similarly, a providence with demential can minagenpride mosey from hite. Similarly, a providence with demential could get lost while on a wallabout

# 1 The theme for World

mentiss and enhance the well-being of their families and carers'. Lorraine Yu, a co-founder dedicated 20 years of her life to raise funds for the Foundation.

in 2011, developed resource material in all three languages and mobilised volunteers to carry out activities for elders with dementia. Regular media and advocacy programs were conduct

# Social Media Coverage







# Living with dementia, Voices from Asia Pacific - A Sri Lankan story

Dr Deepthi Amunugama, son and caregiver for Madam Podimenike Amunugama shares the story of his mother's dementia journey.

## FACE TO FACE WITH THE UNTHINKABLE

It was around 2018 when the early signs started emerging. My gentle mother suddenly became suspicious of the housemaids. Initially, I just replaced them but then when her irrational behaviour persisted, realized it was due to mild paranoia. As a doctor, my medical training kicked in. I had her checked out by a colleague who is a psychiatrist and obtained a formal diagnosis and the necessary treatment. Soon, however, she began to show additional symptoms which were further exacerbated by my father's illness that saw him bedridden, for a short while, before he passed away.

Theoretically, I was well aware of what to expect and the natural progression of the disease. Despite all of which, my mental reaction as a son and the main caregiver took centre stage. I questioned why this calamity had to happen to my mother who has served for years as a government servant, managing one of the largest oncology units in the country. Had she not survived and overcome cancer and been in remission for over 30 years? I went through the entire gamut of emotions that I believe all family members of dementia patients go through. The knowledge and understanding of what to expect did not make the burden of the illness any different or less.

Even as I struggled with the emotions and depression that family members often face in light of a dementia diagnosis, I was committed to ensuring that my mother got the best possible treatment. This was the time my mother needed me the most and I was going to do my utmost to keep her in her own home with 24/7 care.

This was much easier thought than done, as an only child without a large extended family to share my responsibilities, the role of the main caregiver fell on me. My job as a surgeon meant irregular and long hours and as I worked exclusively in Government service, without a private practice, I did not have limitless financial resources.

Like many in Sri Lanka, I was faced with a lack of structured support, trained professional caregivers, and social welfare for patients living with dementia. My mother's case was further complicated as she had undergone a permanent colostomy during her battle with cancer and had a stoma bag in addition to a neuropathic leg which made her gait unsteady. Most caregivers have little or no training in the care required in such cases, especially with the added issues of dealing with the symptoms of dementia such as psychosis, delusions, etc.

I am fortunate that through my network in the medical fraternity, I have access to those who can provide this training but the rapid turnover in caregivers means this process is endless. There is simply no institution or organisation that offers these services, and it is up to the family to be 100% involved in the process of proper care, with little ability to step away or take a break from full-time supervision. Sri Lanka desperately needs infrastructure and social support that provides professional, customized advice on the care for each patient, which can be implemented within the financial means of the individual's family.

I try to give my mother as much social interaction as possible. I have found that social events are less stressful when I give others a 'heads up' on her situation and explain that she has a medical condition that makes her behave in a manner that is not 'herself'. It pains me that people see a very different person from the confident, caring professional she was and just consider her as 'insane'. I am well aware that many are compelled to keep their loved one confined to their home to avoid being mistreated or misunderstood in public which leads to even further social isolation and no break for the carer.

Since she started attending the activity centre managed by the Lanka Alzheimer's Foundation (LAFs), I found that my mother's interpersonal skills and use of her hands, be it to write, draw or handle implements; has increased significantly. Perhaps, because she meets different people outside her usual circle of family and caregivers, she is less introverted. When I tell her she is going to LAFS, there is a marked sense of anticipation and positive mood

enhancement. The benefits have been immense and does much more for her than anything I or her caregivers can provide, once again reflecting that structured care and trained support can make a marked difference in both the lives of the patient and the caregivers.

This journey has not been without many personal sacrifices, my mother's illness and lack of specialised support has meant that my own career and personal life must take a back seat. It is impossible for me to be away for an extended period for additional training or exposure overseas both of which are critical to my progression in the field of surgery. But I have no regrets and I'm just grateful that I can be there for my mother who made me who I am today.

Even though I have many advantages due to my medical training and access to information and financial resources even if limited in the circumstances – I still often feel that I'm alone in my battle and that the help she gets is inadequate and far from what I would like to ideally provide her. I can't even imagine the plight of families who don't have even the basic knowledge or support and have to deal with so much social stigma as well, with little or no tools or coping skills.

To read the entire eBook click on the following link.

https://online.fliphtml5.com/ndtu/calg/#p=115

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# On a Unique Journey of Compassion and Learning



As a doctoral student specializing in neuropsychology at the University of Utah, my commitment to understanding the aging brain found a meaningful expression through my voluntary engagement with the Lanka Alzheimer's Foundation. This immersive experience allowed me to merge my academic pursuits with community service, fostering a deeper connection with my roots while contributing to a cause that resonates deeply with me. This is a reflection of how a summer of service intertwined with my personal and academic aspirations, leaving an indelible mark on my journey.

During my time volunteering at the Lanka Alzheimer's Foundation, I had the opportunity to engage in a diverse range of activities that aimed to make a positive impact on the community. One of the primary areas I was involved in

was memory screening clinics that screened for dementia, here I helped organize and conduct sessions to assess and support individuals with memory-related concerns. These clinics not only provided vital information and resources to those seeking help but also offered a supportive and empathetic environment for individuals and their families. In addition to memory clinics, I actively participated in community engagement and information sessions. These sessions played a crucial role in raising awareness about dementia and related issues and educating the community about the Foundation's mission and services. Whether it was through workshops, seminars, or public talks, I found these experiences incredibly rewarding as they allowed me to interact directly with community members, answer their questions, and address their concerns.

Witnessing the impact of these activities on the community was truly inspiring. I saw individuals come in feeling anxious or uncertain about their memory health and leave with a sense of relief, armed with knowledge and a plan for seeking further assistance if needed. Against the backdrop of my homeland, Sri Lanka, this past summer unfolded as a chapter of profound significance. Amidst the vibrant tapestry of my native culture and the lush landscapes that have always held a special place in my heart, I embarked community engagement sessions fostered a sense of unity and awareness, making me realize the power of education in destignatizing sensitive health topics. However, this volunteering experience wasn't without its challenges. Sometimes, individuals attending the memory screening clinics were understandably anxious, and effectively communicating with them required empathy and sensitivity. Over time, I learned to approach each situation with patience and understanding, tailoring my communication to the needs of each individual. From this experience, I learned valuable lessons about the importance of effective communication, adaptability, and the impact that even small gestures of kindness and support can have on someone's life. I gained insights into the inner workings of charitable organizations and witnessed firsthand the dedication and passion of the individuals behind them.

This volunteering experience has left a lasting impression on me. It has reinforced my belief in the significance of clinical work, community engagement, and the potential to make a difference in people's lives through education and support. In the future, I plan to carry forward the spirit of volunteering by continuing to engage with organizations that focus on health and well-being, using the skills and insights I gained at the Lanka Alzheimer's Foundation to contribute positively to the communities I am a part of because of my experience with Lanka Alzheimer's Foundation, I return to the United States as a second-year doctoral student at the University of Utah, more confident about my clinical mission and trust in community engagement. I thank the fantastic individuals who are part of this incredible Foundation that carries out deeply needed work in Sri Lanka for letting me be a part of this mission...

Tuan Zanooz Cassim

Doctoral Student - Clinical Neuropsychology University of Utah

Questions about dementia?

2667080 / 2667082 / 2667084

Monday to Friday | 9am – 5pm

For information on dementia and dementia care management

# World Alzheimer Report 2023

# Reducing dementia risk: never too early, never too late

The World Alzheimer's Report 2023, "Reducing dementia risk: never too early, never too late", focuses on dementia risk reduction as a practice. The report helps to understand dementia risk in an easy-to-read format.

Every three seconds, somebody develops dementia. Currently, 55 million people worldwide are estimated to be living with this neurological condition, that two thirds of people still mistakenly believe is a normal part of ageing.

Lanka Alzheimer's Foundation (LAF), a Member of ADI, the International umbrella for over 100 national Alzheimer's associations, focuses on the 12 proven modifiable dementia risk factors - smoking, physical inactivity, excessive alcohol consumption, air pollution, head injury, infrequent social contact, less education, obesity, hypertension, diabetes, depression, and hearing impairment which, if addressed, could delay, slow progression, or prevent up to 40 per cent of dementia cases worldwide equating to 55.6 million cases globally by 2050.

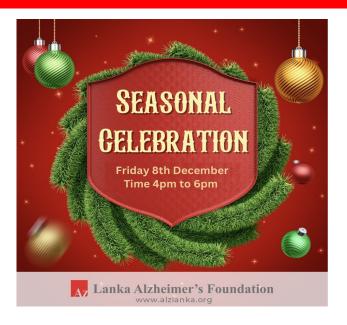
The events organised by LAF this year focused on improving awareness on dementia and addressing the risks.

Interactive and engaging shows using puppetry and music from folk stories by a group of artists from the 'Power of Play' drama outfit on the risk factors and supporting persons with Dementia were conducted in Colombo, Gampaha and Galle.

A physical "Run to Remember" and "Memory Walk" were held to promote physical activity, social contact and a healthy weight.

# Dates to Remember





# ICCB BAZAAR - 3rd DECEMBER 2023 AT GALLE FACE HOTEL - TIME: 11 AM to 3 PM

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

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# **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)**

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

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

# The Board

Lakmali Cabral (Secretary), Priya Fernando, Lilani Jayasuriya, (Treasurer)

Beverley Mirando, Romany Parakrama, Nimal Gunewardena, Prof. Shehan Williams (President)

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

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.

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