Quarterly Issue - Vol. 231

July to September 2024

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President's Message

Time to Act on Dementia

We prepare for yet another World Alzheimer's month in September. Despite all our efforts, dementia is a national and global cross cutting challenge not just for health but also economic and social spheres that is sadly under recognized by governments and policy makers. The rapidly ageing populations in many nations including Sri Lanka, will result in more persons with dementia and the economic and social consequences could be appalling if we are not sufficiently prepared.

The exodus of younger people from Sri Lanka will further confound the issue. Will it mean that Sri Lanka will not meet its economic targets set out in its debt restructuring plans, with this greater burden due to ageing and conditions like dementia? These are points we all need to ponder. As electioneering fever is heightening, how many politicians are aware of these grave health issues that will determine the future of this country or have a policy framework to address these issues. Ignorance is not always bliss!

We hope that as the community for dementia advocacy in Sri Lanka we can all rally once again to raise awareness on this disease that silently robs the quality of life of thousands of older adults around us every year. We invite you to join hands with us once again in our annual 'run to remember' on the 7th September and the 'Memory Walk' on the 21st September (World Alzheimer's Day). The Lotus Tower will be partnering with us this year and will be lit up symbolically on 21st September, to mark the day and create a spark around dementia.

We are also heartened that the College of Community Physicians Sri Lanka (CCPSL), the apex professional body of public health specialists in Sri Lanka, will be collaborating actively with us in the next 12 months to bring dementia to the forefront of the public health agenda in Sri Lanka. This no doubt will give the cause a much-needed boost. We remain convinced that the time to act is now!

Prof. Shehan Williams

President

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Alzheimer's Disease International (ADI) 36th Global Conference 2024



From April 24th to 26th, the Alzheimer's Disease International (ADI) conference was convened in Kraków, Poland, drawing over 1,000 delegates from more than 100 countries. It began with a symposium focused on advancing brain health, followed by the first plenary session, which delved into diagnostic advancements and post-diagnostic support.

On the second day, the session titled 'Models of Care and Quality of Life' showcased innovative approaches to dementia care. Throughout the conference, there was a strong emphasis on the necessity of raising awareness, reducing the stigma associated with dementia, and promoting inclusive community strategies.

LAF participated in the Exhibition Portal App, using a virtual booth to highlight the information providing and showcasing its services. Materials, posters, and photos of events held during Alzheimer's month, as well as pictures of key activities were displayed digitally. A few are shown below:

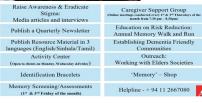














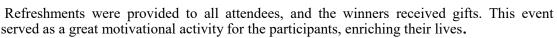


Website: The 36th Global Conference of ADI – marking 2024 as a year of global insights, innovations and inspirations | Alzheimer's Disease International (ADI) (alzint.org)

Sinhala & Hindu New Year Celebration at Kaluwagaha Janapadaya, Galle

LAF Programme Officer Ms. Wasanthi Gunawardena organized an Avurudu Uthsavaya in Galle with the collaboration of the Gonapinuwala Divisional Secretariat on April 25th at Kaluwagaha Janapadaya village grounds. Approximately 350 elders from various Grama Niladari divisions in the area participated.

The ceremony began with the lighting of the oil lamp by the Gonapinuwala Divisional Secretariat staff and the LAF Programme Officer. The event featured traditional New Year games, including 'Raban playing' and team games, which were enjoyed by all participants.













CALL OUR HELP LINES - 2667080 / 2667982 / 2667084

Mobile No: 076 082 7080

Monday to Friday | 9am – 5pm

LANKA ALZHEIMER'S FOUNDATION

Awareness Programmes

Western Province Department of Social Services Staff at LAF

The Department of Social Services requested Lanka Alzheimer's Foundation (LAF) to conduct an awareness program on dementia for their officers in the Western Province. Dilan Sadanuwan, Programme Officer, organized a one-day workshop on April 26, at LAF. Approximately 45 officials attended from the Colombo, Gampaha, and Kalutara districts. Among the attendees were the Director of the Western Province Social Services

Department, Senior Social Service Officers, Social Service Officers, Superintendents,

and Development Officers.

In his presentation, Dilan provided information on LAF services, how LAF can assist people living with dementia, and what can be done to mitigate the impact of dementia. Our guest speaker, Dr. Iresh Perera, Consultant Old Age Psychiatrist at North Colombo Teaching Hospital, delivered a presentation emphasizing the importance of recognizing dementia symptoms, obtaining an early diagnosis, and taking measures to reduce risk.

LAF President Prof. Shehan Williams concluded the workshop with a discussion and a Q&A session on the role of Social Service Officers in dementia care. Participants expressed their satisfaction and appreciation for the knowledge gained on dementia and thanked LAF for organizing the workshop.





Awareness



May

- 6 Katana DS Office Staff Members of Elders Societies in Katana Area
- 16 Negombo DS Office Staff Members of Elders Societies in Negombo
- 29 Mirigama Sethsevena Elders Home

June

- 7 Mith Sewana Chidren Home Dehiwela Staff Members of the Children Home
- 12 Dungalpitiya Elders Society Dungalpitiya Villagers
- 13 Millaniya DS Office Staff Members of the Elders Societies in Millaniya area

MOU with the College of Community Physicians Sri Lanka (CCPSL)

The Lanka Alzheimer's Foundation (LAF) is pleased to partner with the College of Community Physicians of Sri Lanka (CCPSL) in furthering the cause of Dementia Island wide. A Memorandum of Understanding (MOU) was entered into on 1st July 2024 for period of one year to collaboratively work on creating greater awareness on dementia and engage in health promotion activities that will help mitigate the impact of dementia.

The College of Community Physicians is the apex professional body of public health specialists in Sri Lanka. The CCPSL, among its many objectives, works to improve the health of the Sri Lankan population through the provision of high quality care and the promotion of public health initiatives. The partnership between LAF and CCPSL will target specific groups including community health and social services officers in improving their awareness of dementia and supporting persons with dementia and their families in the community.





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Alzheimer's takes a financial toll long before diagnosis

Credit scores among people who later develop dementia begin falling sharply long before their disease is formally identified. A year before diagnosis, these people were 17.2 percent more likely to be delinquent on their mortgage payments than before the onset of the disease, and 34.3 percent more likely to be delinquent on their credit card bills. The study finds evidence of people falling behind on their debts five years before diagnosis of the disease.

The research adds to a growing body of work documenting what many Alzheimer patients and their families already know that decision-making, including on financial matters, can begin to deteriorate long before a diagnosis is made or even suspected. People who are starting to experience cognitive decline may miss payments, make impulsive purchases or put money into risky investments they would not have considered before the disease.

People in the early stages of the disease are also vulnerable to scams and fraud, added Dr. Nicholas, who was not involved in the New York Fed research. In a <u>paper published last year</u>, she and several co-authors found that people likely to develop dementia saw their household wealth decline in the decade before diagnosis.

Shortly before he was diagnosed with Alzheimer's, Jay Reinstein bought a BMW he could not afford. The researchers hoped that the data could eventually allow them to develop a predictive algorithm that could flag people who might be suffering from impaired financial decision-making associated with Alzheimer's disease, although they stressed that there were unresolved questions about who would have access to such information and how it would be used.

Alzheimer's Takes a Financial Toll Long before Diagnosis, Study Finds https://www.nytimes.com/2024/05/31/business/economy/alzheimers-disease-personal-finance.html?smid=nytcore-android-share

World Alzheimer's Survey Report 2024

Alzheimer's Disease International (ADI) has launched the 2024 Attitudes towards Dementia global survey to gain a truly global perspective on attitudes towards dementia everywhere. Follow the link to take part in the survey https://tinyurl.com/bde9w8sf

| Country | 10 June 2024 | 17 June 2024 | comparison |
|-------------------|--------------|--------------|------------|
| Australia | 468 | 485 | 17 |
| Bangladesh | 3 | 4 | 1 |
| Brunei Darussalam | 303 | 303 | 0 |
| China | 164 | 168 | 4 |
| Hong Kong SAR | 609 | 612 | 3 |
| India | 234 | 301 | 67 |
| Indonesia | 646 | 698 | 52 |
| Japan | 296 | 355 | 59 |
| Macau SAR | 163 | 165 | 2 |
| Malaysia | 531 | 592 | 61 |
| Maldives | 16 | 17 | 1 |
| New Zealand | 630 | 634 | 4 |
| Pakistan | 86 | 108 | 22 |
| Philippines | 145 | 165 | 20 |
| Singapore | 264 | 275 | 11 |
| Sri Lanka | 77 | 90 | 13 |
| TADA | 2,721 | 2,746 | 25 |
| Thailand | 527 | 840 | 313 |
| Tonga | 2 | 4 | 2 |

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:

076 827080



Giving back to our parents and society - Volunteer Dinu Dehigama shares

How often do we picture our parents in their old age? Fathers are our rock, and mothers our inspiration. When we are young, our lives revolve around our own dreams and goals. It's not until we reach adulthood that the perspective changes. From the time we are born, the commitment and effort of our parents are often taken for granted. We only realize their value and understand what they have been through when we find ourselves in their place. With no set time, they wake up early in the morning and, till the end of the day, it's a constant battle.



This is the story of how I realized how much I must give back, though I can never fully repay what my parents have done to make me who I am today. On the 18th of February 2023, my father left us all peacefully. Covid took a toll on most elderly as they were confined to

limited spaces. At 80, he managed most of his work on his own, even as the founder of his own business. Moving around and traveling was his passion. A successful entrepreneur, respected, honored, and looked up to, my father was a true legend. His demise was a loss for many, especially for me.

During the latter part of Covid, my father had a fall while helping my mom. We knew it was a fracture and rushed him to the hospital. It was obvious that he had a hip fracture, and my life changed as a new chapter unfolded.

Suddenly, I transitioned from being a daughter to being a caregiver. I was there to feed him, wash him, change his diapers, and stay with him until he fell asleep at night. The smile on his face and the tear of gratitude and happiness he shed when he looked at me showed me that now it was my turn to look after him just as he had looked after me.

My decision to join the Lanka Alzheimer's Foundation (LAF) was driven by the desire to continue that love and kindness in memory of my father. I joined LAF in May 2023, and it has been the most amazing experience I've ever had. Volunteering at LAF made me more compassionate, concerned, and empathetic towards others' sufferings and misfortunes. LAF gave me the perspective to realize how grateful we should be and how unpredictable life can be. It also taught me that Alzheimer's doesn't discriminate by designation, profession, or character but strikes randomly and unexpectedly. My duty as a volunteer is to love and care for each client with all my heart because it's an opportunity.

LAF is a place of hope and happiness for clients. From a hot cup of tea with biscuits while chatting about everyday things, we take them to our auditorium for seated yoga and exercises. We then engage in activities like painting, crafts, word searches, or more challenging discussions. The most exciting and enjoyable part is the singing and dancing. We end the session with our national anthem, followed by a hot and sumptuous home-cooked lunch by Selvie and Lalitha, ending with something sweet. We wrap up the afternoon with more activities or games and a hot cup of tea before our clients return home. I too go home with a feeling of fulfillment and happiness.

Dates to Remember

- Saturday 7th September -Run to Remember-Taj Samudra Hotel 4.30 p.m.
- World Alzheimer's Day Saturday 21st September- Memory Walk 8 a.m. Starting point to be confirmed
- Saturday 9th November Grand Sale, Lanka Alzheimer's Foundation

The Lanka Alzheimer's Foundation Inquiries Call 011 2667080 / 2667082 / 2667084

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Mobile No: 076 0827080

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How speech and language therapy can help a person with Alzheimers disease by Naumi Ampemohotti



Alzheimer's disease is a progressive brain disease that damages and eventually destroys brain cells, leading to loss of memory, thinking, and other brain functions. It usually develops slowly and gradually and gets worse with the increasing loss of neurons in the brain. Alzheimer's disease is the most common type of dementia. In 2006, the worldwide prevalence of Alzheimer's disease was 26.6 million. It is forecasted that by 2050, 1 in 85 persons worldwide will be living with the disease.

While memory loss is its most known symptom, Alzheimer's also significantly impairs language and communication abilities, making everyday interactions challenging and frustrating. Language impairment is a significant issue in most persons with Alzheimer's disease as they pass through moderate to severe disease stages. The decline in language seems to follow a pattern, with the most recently learned language forms deteriorating first.

Stimulation of language skills is vital, given that the loss or impairment of communication ability affects not only the person with Alzheimer's disease but also their family members and caregivers, leading to a profound deterioration in their quality of life. Speech and language therapy offers this essential support to persons with Alzheimer's disease, by supporting them to maintain their communication skills and social participation.

Speech therapy for an individual with Alzheimer's disease will typically target a blended plan involving both language and cognitive skills. Given the progressive nature of this condition, therapy sessions will most likely focus on maintaining functional communication skills of the individual in relation to his daily routine and individualized needs. As such the speech and language therapist may implement direct and indirect intervention techniques delivered to both the individual and their family members. Direct therapy goals within a linguistic approach typically involve activities to support "finding their words," and certain cognitive tasks like following directions with one or more steps. Speech and language therapy may teach a person with Alzheimer's disease to use gestures, pictures, and non-verbal cues to supplement and/ or augment communication. These methods are particularly useful in the later stages of this disease when verbal expression becomes difficult. In a cognitive aspect, a speech and language therapist may teach a person with Alzheimer's disease to practice different ways to remember important information, use written words or pictures to help complete tasks, make "memory books" to help remember personal information. Equal or greater importance is placed on indirect intervention which trains family members and caregivers on successful strategies they can use when communicating with their loved one.

As the disease progresses, those with Alzheimer's disease may experience eating and drinking difficulties. Muscles and mechanisms in the throat that protect a person's airway may not function the same way they do in a healthy person, which could cause them to aspirate, which in turn can cause major health complications like aspiration pneumonia. Here the involvement of the speech and language therapist is necessary in identifying swallowing difficulties and in assisting the individual to eat and swallow food safely. The clinician may recommend different strategies, different types of food consistencies or simply eating in different ways, to help the individual safely eat and drink. Family members and caregivers play a critical role in ensuring sufficient nutritional intake.

In conclusion, speech and language therapy has a profound impact on the lives of persons with Alzheimer's disease, by helping them to <u>maintain satisfactory quality of life</u>, for as long as possible by enhancing their sense of independence.

September - World Alzheimer's Month - Time to Act on Dementia

September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. Each year, Alzheimer and dementia associations, alongside all those involved in the treatment, care and support of people living with dementia, from around the world, unite to organize advocacy and information provision events, as well as Memory Walks and fundraising days. "Campaign Theme - Time to Act on Dementia"

#TimeToActOnDementia; #TimeToActOnAlzheimers. #WorldAlzMonth

Saturday 7th September - Run to Remember, Taj Samudra Hotel – 4.30 p.m.

World Alzheimer's Day - Saturday 21st September- Memory Walk, 8 a.m. Starting point to be confirmed

From a Student Volunteer's perspective by M. J. Mohamed Hisshan

<u>Echoes of memory</u> - Volunteering at the Lanka Alzheimer's Foundation has been one of the most transformative experiences of my life. Stepping into this world, I was greeted with the warmth and resilience of individuals battling Alzheimer's disease. They are not just patients; they are people with rich histories and stories to tell, and my time with them has left an indelible mark on my heart.

One of the most memorable individuals I met, despite his struggle with memory loss, vividly remembered the intricate details of how he built his business empire from the ground up. His entrepreneurial spirit and wisdom were inspirational. I approached him with questions about balancing a career in medicine with a side business, and he offered me invaluable guidance, almost like a father advising his son. His words of wisdom on persistence and strategic thicking are lessons. I will carry



advising his son. His words of wisdom on persistence and strategic thinking are lessons I will carry forward into my future.

Another client at the Foundation, reminded me so much of my grandmother with her kind and gentle demeanor. Her presence was soothing, and her stories, though sometimes fragmented, were filled with warmth and love. Every interaction with her evoked a sense of nostalgia and reinforced the importance of compassion and patience. Her blessings and kind words felt like a bridge to my own grandmother, who has always been a pillar of strength for me.

The Foundation is a place where every day brings something new. The activities were not only engaging but also therapeutic for both the clients and volunteers. From crafting to exercises, each session was meticulously designed to stimulate the clients' minds and bodies. One of my favorite activities was the music sessions. At 11 a.m. every day, someone would play the piano, and we would all sing along. The joy and camaraderie in those moments were palpable, creating a sense of community and belonging.

The importance of patience was a recurring theme throughout my time at the Foundation. Alzheimer's is a disease that tests patience to its limits. Clients often ask the same questions repeatedly, forget who you are, and sometimes even where they are. Initially, this was challenging for me, but I soon learned to respond with empathy and kindness. Each repeated question became an opportunity to connect and engage with them anew. This experience taught me to see beyond the disease and appreciate the individuals for who they are, not just their condition.

The Foundation operates three days a week, Mondays, Wednesdays, and Fridays—from 9 a.m. to 3 p.m. Each day had its own unique rhythm and charm. The volunteers were equally engaging, as the younger batch of volunteers, including myself, brought a youthful energy to the activities. We often played games that resonated with our generation, creating a fun and lively atmosphere. One of my contributions was introducing the game Hangman on the whiteboard, which quickly became a weekly favorite. These moments of laughter and fun were not just enjoyable but also crucial in creating a positive environment for the clients.

The senior volunteers were excellent mentors, guiding us through various activities and ensuring that every session was enriching for the clients. One of the highlights was the craftwork we did, especially around festive times like Vesak when we made lanterns. Seeing the clients engage in these activities with enthusiasm and creativity was incredibly rewarding.

The physical environment of the Foundation also contributed to the overall experience. The activity center is well-ventilated, with large glass windows that offer a beautiful view of the outside world. These moments of tranquility amidst the storm created a unique bond between us, the volunteers, and the clients.

Another significant aspect of my experience was the life lessons shared by the clients. Many of them spoke about their past mistakes, offering advice on how to avoid similar pitfalls. Their stories about meeting their significant others and the importance of choosing the right partner were particularly poignant. These conversations reinforced the importance of family and relationships in one's life.

However, some stories were tinged with sadness. Several clients spoke about feeling neglected by their children in their old age. This was a stark reminder of the sacrifices our parents and grandparents make for us and the importance of caring for them in their later years. These conversations made me reflect deeply on my relationships and how I can better appreciate and support my family.

Volunteering at the Foundation also provided me with a sense of purpose and direction. Despite awaiting my Advanced Level exam results, I found solace and fulfillment in serving this community. The experience has solidified my desire to return to the Foundation as a doctor in the future, to continue making a difference in the lives of those affected by Alzheimer's.

LANKA ALZHEIMER'S FOUNDATION

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
- work towards caregivers' wellness
- help to dispel misconceptions and stigma

- 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:

- 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

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 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.