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Lanka Alzheimer's Foundation

Email: alzheimers@alzlanka.org Website: www.alzlanka.org

AN APPROVED GOVERNMENT CHARITY
(GAZETTE NOTIFICATION NO. 1225)

Dementia care during COVID-19

The first Sri Lankan patient with COVID - 19 was detected on 11th March. LAF decided on 16th March, to close the Activity Centre as a precautionary measure. On 20th March, the government imposed a curfew, essentially a lockdown, where everyone was confined to their homes.

At LAF, we were aware that the closure of the Activity Centre would be a great setback for our clients. We decided to reach out to individuals and families remotely to offer support and guidance. Our volunteers rose to the occasion and kept in touch with the clients and their caregivers. The insights we gained through the brief reports circulated by the volunteers on their phone meetings are fascinating. This was what one volunteer reported, “She was rather upset that she can’t go to pay the bills. I explained why she shouldn’t”. Another had this to say, “Spoke to the son. He is as usual upset about what happened to mom. He really appreciates that we call and check on her”.

We were happy that all our clients are supported by their children, relatives or paid caregivers. In one instance, the son had moved in with their elderly parents along with his family, to care for them during the lockdown. These were the concerns of some family caregivers. “He is not keeping too well the last couple of days. He is having something like Parkinson. I am praying for him. Only upset that we cannot go to church”. Another said, “She is doing a bit of walking up to the gate and back. Please tell her if she wants to be healthy she has to walk around and needs to cut down on her sugar & desserts. She listens when someone from the centre tells her”.

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NOTICE

LAF works with a group of people especially at risk for COVID-19.

Therefore, our regular activities including the Activity center, memory screening and outreach programs have been temporarily suspended.

Please call on 112667080 / 0719670338 or reach out on our FB page for updates.

A Carer's Story

By Wilson Mathuranayagam

In 2015, brothers Edward and Wilson noticed a slur in Charles's speech. Before that Charles used to complain about constant headaches. The brothers insisted on him seeing a doctor, but he ignored that suggestion. Around September that year, one of his sisters visited him and was able to convince him to see a consultant neurologist. After MRI scans, it became apparent that his brain was damaged and that it was a progressive disease which could be managed but not reversed. He continued to run his business, he went for speech therapy, received acupuncture treatment and had medications to control his high blood pressure etc.

He was able to communicate. Occasionally his speech was clear, but most of the time the listener had to guess what he was trying to express. But he chose not to write down what he wanted to say. He made sure he did exercises by going for long walks in the evenings. He would do his own shopping and ate what he liked. He got frustrated when people did not understand what he was trying to say, especially his brothers. He was still very independent. The brothers assumed he had a psychiatric condition as they were not aware of Dementia. At the suggestion of his niece, he was shown to a neurologist in India. The diagnosis was the same. Back at home, Edward accompanied him to the hospital for his monthly clinics. Charles was asked to maintain a note book, which he did occasionally.

His condition deteriorated further around April/May 2019. He became unaware of his surroundings and was becoming very aggressive towards his brothers and customers. When people did not understand what he was trying to communicate, he became angry. Wilson was always beside him and acted as the mediator between him and the customers, explaining his condition and what he was trying to say. Controlling him became very difficult. The only option now was medication. The brothers did not allow Charles go out on his own. They also decided to close the business which was in the front section of the house and the door in between was always kept locked. Charles would relentlessly knock on the door, day and night. This troubled the brothers, as they could not have a peaceful sleep. He was still able to identify his siblings and his friends. He maintained his personal hygiene with a bit of coaxing. He bathed for hours and now that he had lost sense of time, he would bathe even in the early hours. If the brothers did not go along with what he wanted to do, he would become agitated.

In September, they heard about the Lanka Alzheimer's Foundation. He was registered as a client in October, which was an eye opener for Wilson. He began to understand about Dementia. Wilson noticed how the carers handled Charles. During the first few visits, Charles never made any eye contact with his carers. But he was always close to Karen, listening and responding to her. He ate the meals provided in the Centre. The Centre helped him to communicate through writing and music. After the day at the Centre he would sleep very well in the night.

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A Carers Story… *continued from page 2*

It was a not easy to get him to the Activity Centre of LAF as dressing him was not easy. His sister on a visit, showed the brothers a gentler way of getting it done. She accompanied Wilson when taking Charles to the Centre and visiting relatives. He loved the company of people. He would reluctantly leave when he was shown a written note to say it was time to leave. When travelling by trishaw he developed a habit of spitting all the time. The carers at the Centre suggested giving a towel for him to spit into. Getting him ready to go to the Centre wasn't a problem anymore. Wilson would inform the day before that Charles has to go to the Centre, so he would be up and ready early morning. He did get muddled when dressing, but would correct it, when the brothers got him to read a written note pointing it out to him.

The restriction to stay within the house frustrated him. He enjoyed his visits to the Activity Centre on Fridays. His eating habits changed. By this time, he preferred snacks to the regular rice and curry. He still liked the company of people and enjoyed watching certain programs on TV and playing games on his electronic Tablet and Smartphone. His concentration span became very short.

On the 2nd of April while having dinner with his brothers he got up from the chair to fetch a glass of water collapsed and passed away peacefully.

From a Volunteer's Perspective

by Karen Jayaratne

I remember that first Friday Charles arrived with his two brothers, one on either side, Edward and Wilson. Charles was unable to communicate and he was not at all interested in following any verbal instructions. Additionally, he did not interconnect or even make any eye contact with us volunteers. This was going to be a challenge. Gradually all that changed and Charles did truly transform during his time with us. A laminated sheet with the Friday itinerary, a notebook and a pen. Success ….we can now communicate! Charles wrote of his regular attendance to church on a Sunday. He wrote of his sisters and his brothers. Always ending his writing with '3pm' I assume to mean 'waiting to return home.'

As the weeks rolled on, when Charles arrived at the centre, he began to look at us and even started to smile at us. Then when leaving the centre, he would smile again and wave goodbye to us all. He always joined us at the activity table and always sat in the same chair. He would not participate in the activity but enjoyed observing. Until one day when we offered him some crayons and a drawing paper and wrote in his notebook asking if he would like to join in. Unexpectedly and with enthusiasm Charles started to draw….it was such a rewarding moment. Charles was a man of routine and independence. He was aware lunch was at noon and even if lunch was running late, Charles would happily get up, leave the music activity and sit in the dining room on the same dining chair and patiently wait for his lunch. I certainly will miss that sweet shy smile on a Friday morning and that eager wave 'good bye' at 3PM.

Events & Awareness

Scrabble Bash 2020

The 11th Annual ‘Scrabble Bash’ was successfully concluded on Saturday 29th February with the participation of 56 seniors and students. LAF promotes this event as Scrabble is one of the games that stimulate brain activity as it requires players to constantly come up with new words. Studies suggest that decades of playing Scrabble has had positive effects on cognitive abilities.

Winners of Category ‘A’ was Mr. Indunil Amarasinghe and Runner Up Miss. Sandali Vithanage of Musaeus College . Winners of Category ‘B’ was Ms. Mary Ridgeon and Runner Up Ms. Lilanthi Jayaratne. LAF is thankful to adjudicator Shaila Amalean and her team; Anushika, Praveeni, Pradeepani and the volunteers who always support this event.

This event would not have been possible without the numerous sponsors of Prizes; Hilton Colombo, Shangri-La Hotel, Hilton Colombo Residences, Cinnamon Grand, Cinnamon Lakeside, Taj Samudra Colombo and the Galadari Hotel and last but not the least, the Chinese Dragon Café, who sponsors lunch every year.

We hope to see all you scrabble enthusiasts next year too on the last Saturday in February.

Outreach programs to create dementia awareness

February	
16th February	Makola South Welfare Society, Makola
17th February	Elders Home, Attidiya
23rd February	Arunodaya Welfare Society, Mawaramandiya
March	
07th March	Purana Viharaya, Kaduwela
14th March	Sri Siddhartha Temple, Kaduwela

Raising awareness about dementia is important so that people can recognize the early signs, seek medical advice, learn/ help educate the families to understand the different stages of the disease and what to expect. Early management of the disease will lead to better quality of life for a person with dementia and the family. **Call us on 112667080 or reach out to us on our Facebook page to organise an awareness program in your area/organization/club**.

Why I chose to do my Elective at the Lanka Alzheimer's Foundation

by Fathima Marzia Abdussamad

The black couches that you can sink into, the auditorium that is always filled with singing and laughter, Selvi Akka's lunch that everyone looks forward to, the wonderful people and the peaceful greenery that surrounds all this. Two months ago, if you had asked me about Dementia or Alzheimer's I would have probably rattled off a few facts but the Lanka Alzheimer's Foundation has completely transformed my perspective.

While the rest of my batch was appealing for spots at hospitals and research projects, I approached LAF for my Clinical Electives Program. I remember having doubts about how much I would gain from my time here, but eight weeks later, I have learnt more here than any textbook or lecture could ever teach me. As a medical student, I've found myself focused on Dementia as a disease, forgetting about the person that has been buried beneath it. Every day that I've spent here has only amazed me on how much more there is left to do for someone with Dementia; things beyond our prescription papers. When I walked in on my first day and seated myself next to Irangani, colouring away at the table, I wasn't sure what to say. I worried that I would say the wrong thing, but in less than two minutes, she had me engaged in a delightful conversation about her (and my) favourite things: flowers and drawing. I didn't know what to expect that morning, but when I went home that day, and every day after that, it was with a full heart and a massive smile: from Frank's infectious energy, Charmaine's dancing to all the lovely anecdotes that get shared around. I have enjoyed every aspect of my days spent here.

The friendly staff, volunteers and all the lovely clients who have given me memories I will cherish for years to come. I couldn't be more thankful to Professor Shehan and the rest of team, for giving me this opportunity.

Dementia care during COVID-19 … *continued from page 1*

It was good to note, with families at home, they seem to have more time to spend with the person with dementia. With no school, grand children had time to play cards, board games, sing and spend more time with their grandparent with dementia. At the same time, in some instances the caregiver had no respite. As our clients enjoy music, we shared a video clip of old songs produced with clients and caregivers. We have also set up a new temporary helpline as our regular helpline was office based. Our facebook page too is regularly updated with tips to stay physically and emotionally healthy.

We await the day it will be safe to start the Activity Centre again. When we meet again, the chats, memories and challenges spoken of would perhaps lead to a stronger bond between clients, caregivers and the volunteers.

Beverley Mirando - Director LAF

Aphasia and Dementia

Aphasia is most often caused by a stroke that affects the left part of the brain, which controls the speech and language centre of the brain. In a stroke, a clogged or burst artery in the brain disrupts blood flow. If the speech and language centre of the brain gets damaged, the result is aphasia. More extensive damage typically leads to vascular dementia. Aphasia can also be caused by diseases such as frontotemporal dementia (FTD). Aphasia is most pronounced in the type of FTD called Primary Progressive Aphasia (PPA).

Progressive aphasia may begin in people as early as their forties. One or more language abilities may become impaired. Symptoms often begin gradually and progress slowly over a period of years. As the disease progresses, memory and attention may also be impaired and patients may show personality and behaviour changes. Many, but not all, people with progressive aphasia eventually develop additional symptoms of dementia. People with aphasia are often frustrated and confused because they can't speak as well or understand things the way they did before their stroke.

There are several forms of aphasia. They include

- **Global aphasia** — People may be completely unable to speak, name objects, repeat phrases or follow commands.
- **Broca's aphasia** — The person knows what they want to say, but can't find the right words
- **Wernicke's aphasia** — A person with this aphasia can seldom understand what's being said or control what they're saying.

A person with aphasia and family members will need the help and support of a doctor, counselor and speech pathologist. It's a good idea for family and friends to:

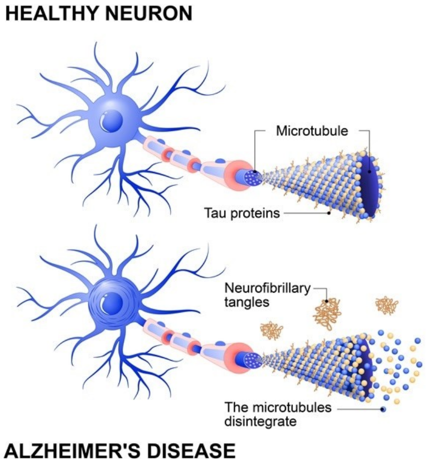
1. Be open about the problem so people can understand.
2. Always assume that the person with aphasia is listening and understanding. Check understanding with yes/no questions.
3. Set up a daily routine for the person with aphasia that includes rest and time to practice skills.
4. Use sentences that are short and to the point.
5. Keep the noise level down and stand where the person with aphasia can see you.
6. Remember to treat the patient as an adult and let him or her share in decision-making. No one likes to be ignored. Include the patient in your conversation.

Adapted from ***Aphasia in Dementia*** from *http://www.alzheimersweekly.com/2013/08/aphasia-in-dementia-word-jumbles.html*

Dementia Research

Tau Shows Promise as Achilles’ Heel for Alzheimer’s and Similar Diseases

Alzheimer’s disease has long been characterized primarily by the buildup of two proteins in the brain: beta-amyloid and tau. Decades of focus on beta-amyloid has failed to significantly help patients. So researchers are turning more attention to the second member of the duo. Tau was long thought to be a secondary actor. Amyloid plaque builds up first, largely outside of neurons, followed by tau tangles—filaments of the tau protein—which clog their insides. But research has found that people can continue to function well with amyloid in their brain. It is only when toxic tau starts to spread that people begin confusing “breakfast” with “baseball,” forgetting not just where they left their keys but how to use them.



Now scientists in labs across the world are trying to better understand the role of tau in neurodegenerative diseases and to figure out ways to track and tame it before brain cells—and families—suffer. Normal tau helps assemble and maintain the structural scaffolding of brain cells. But various molecular changes can cause the protein to turn toxic and wreak havoc. Toxic tau misfolds like a shoelace tied in a mess of double knots instead of a neat bow. In this contorted state, tau appears to cause the misfolding of other tau proteins, which then clump together. A study published in January in *Science Translational Medicine* showed that where tau builds up in a living brain predicts which areas of the organ will degenerate. Research shows that tau tangles form a distinctive shape that is always the same within a single patient and also varies in each of the several diseases it can cause.

Researchers have only begun to understand what causes tau to turn toxic. A number of recent studies have suggested that the protein may take an aberrant turn after an inflammatory trigger, such as gum disease or an infection, or different conditions, such as “leaky gut,” in which microbes and other particles leak from the digestive system into the nervous system. George Tetz, a consultant at the Human Microbiology Institute, an independent nonprofit research organization in New York City, recently published a study showing that DNA can spur the seeding of toxic tau. “We strongly believe that the starting point for different neurodegenerative diseases is the appearance of certain bacterial DNA in the central nervous system,” he says.

If this theory proves true, it suggests there might be ways to stop the spark of an infection or another untoward event from igniting the raging fire of Alzheimer’s. But it is still very early days, Goedert notes, and more work needs to be done.

Source : https://www.scientificamerican.com/article/tau-shows-promise-as-achilles-heel-for-alzheimers-and-similar-diseases/

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

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 informed 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