

January—March 2020



It gives me great pleasure to wish you health and happiness in 2020. We start yet another decade! For those of us at LAF, it is another opportunity to dream and plan for better quality of life for those with dementia and their carers in Sri Lanka. There is so much that needs to be done.

First and foremost, there has to be awareness about dementia. Awareness on how to prevent or delay the onset of dementia which will affect a considerable number of us in the coming decade.

Awareness on how to deal with it if we are affected by dementia and how we can support a friend or family member with dementia. Overall, to be more accepting and accommodating of persons with dementia and develop dementia friendly communities. We need to sensitise the government and civil society on the need to develop a comprehensive dementia action plan for Sri Lanka. We are hopeful that we will be able to commence this process this year.

Our model activity center set up by our co-founder Lorraine Yu in Maradana, will continue to offer quality services for persons with dementia and their carers free of charge. Our volunteers do an amazing service in supporting the clients who attend the activity centre. It is an important resource for doctors, medical students, speech therapists, nurses and numerous other health personal who visit the centre.

The free memory screening clinics, literature on dementia care, newsletters and the information hotline are accessed by many. Our little shop 'memories' and the 'memory café' continue to bring joy to our clients.

We are thankful to all our friends and partners who support the work. We hope you will drop by our center sometime this year to see for yourself the work that is undertaken. I want to take this opportunity to thank you once again for your continued partnership in this journey.

Shehan Williams

AN APPROVED GOVERNMENT CHARITY  
( GAZETTE NOTIFICATION NO. 1225 )

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

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**Free Memory Screening**

January - 17  
February - 07, 21  
March - 06, 20

**Appointments are limited.**  
**Please call 2667080**  
**to register.**

## Living with Dementia by Gayathri Silva



Living with a dementia patient is no bed of roses; more so when your mum suffers from early onset dementia. Diagnosed during the early part of 2013 in her late forties, life has never been the same. We have watched her go from being a strong independent mother, to being the exact opposite of that. From walking to speaking, from eating to using the toilet, she now needs assistance with all of that. Pondering on when the next dip in her mental health would be, has become a part of our day to day thought process. These dips come without a warning. We always hope a certain level of mental strength will remain but that's never the case.

She soon went from cheery to depressed with a series of tears as a response to most things. The depression was coupled with raging angry fits that were (and still are occasionally) uncontrollable. Amidst all the angry lashing out (on her part) we tried to improve her quality of life. This was an impossible task, as both my brother and I work 9-5 jobs.

Last September, however, through one of my aunt's contacts, we had the pleasure of being introduced to the Lanka Alzheimer's Foundation. After registering her with the help of Lorraine and Gillian we have been able to ease her into a routine of visiting the foundation a couple of days a week.

The impact these visits have had on our mum is inexplicable. She comes home very cheery from her visits. She has more things to add to general conversation (a lot more than usual, at least). She brags about her singing, arts and crafts. She talks of the occasional dispute with another person at the Foundation in good cheer. She sings the songs she has sung during the morning and speaks of the volunteers (the names may not be accurate). The Christmas party in December was such a highlight for her, she still talks of it, even now.

Her depression and general mood have lightened up quite significantly (Medication too may have a part to play here) Our mum eagerly looks forward to the visits to the Foundation (even with her limited comprehension) and throughout the week you will find her constantly asking when her next visit is and sometimes you even find her trying to go on random days.

On the flip side these visits have also helped us so much. We have learnt the importance of a routine, and certain tactics for dealing with people suffering from diseases such as this. We don't have to go through the distressing temper tantrums as often as they used to be, and can safely say that we have made some significant changes to improve our mum's quality of life. Additionally we too were assured of a safe space to talk to someone (at the Centre) about dealing with our problems pertaining to caring for those suffering from dementia.

The Foundation itself is a pleasant setting with love and kindness overflowing, so I can only imagine that our mum must be very comfortable going there. While it's difficult to watch the deterioration of a loved one's mental health, knowing there is no cure, signing up with Lanka Alzheimer's Foundation has been a blessing indeed. LAF is a great organization dealing with one of the topics still considered taboo in Sri Lanka.

Thank you LAF and all the volunteers for the amazing work you do and for your never ending patience!

God Bless you.

*Questions about  
dementia ?*

CALL OUR HELP LINE

**2667080**

Monday to Friday | 9am– 5pm

# Cost of Dementia



A study published in 2016 by the WHO listed Alzheimer's disease as one of the top ten causes of death in the world. Deaths due to dementias more than doubled between 2000 and 2016, making it the 5th leading cause of global deaths in 2016 .

Dementia care on the long term is more expensive in terms of both direct medical costs and expenses borne by family carers, than heart disease or cancer. Considering that the number of deaths attributed to Alzheimer's and related dementia's continues to rise, while the number of deaths associated with other leading causes, such as heart disease, certain types of cancers, and stroke, are declining, the cost of dementia care on a national and global scale is growing. Despite this, the cost of dementia care receives less attention than cancer or other terminal disease.

Depending on how advanced the disease, your loved one may require anything from reminders on the walls, to regular in-home care, to 24hour supervision, to skilled care at a nursing home.

Certain dementia costs are fixed, no matter where you live and what level of care your loved one requires. These include medication, investigation & doctors' fees etc. Beyond those basics though, the cost and required level of care largely depends on the stage and progression of your loved one's dementia, as well as on the patient's wishes and your family's financial, emotional, and time resources. Common care costs include ongoing medical treatment for Alzheimer's related symptoms, diagnosis and follow up visits, prescription drugs, personal care supplies, in-home care services & full-time residential care services.

The diseases that cause dementia are often not diagnosed in the early stages, symptoms are often mis-attributed, misdiagnosed or ignored, and many studies showed that the socio-economic costs of these diseases typically begin in the years before a diagnosis is made. These could include the cost of diagnostic tests to rule out other conditions as symptoms start to manifest, higher costs of managing other health conditions that may be worsened by the person's dementia, and declining quality of life. Even after the confirmed diagnosis the cost for ongoing care can add up. In addition to the cost of prescription drugs, there is also the added expense of personal care supplies that would be a strain on the family's finances.

At the early stages many families choose to care personally for loved ones with dementia, insofar as their time and emotional resources permit. That said, dementia caregiving takes its own toll on caregivers and family members. And that's where in-home healthcare providers and caretakers come into the picture. Caregivers will help your loved one with anything ranging from personal hygiene and mealtime, to preventing wandering while you're away from home. In Sri Lanka an average cost for a paid care giver can vary from Rs. 150,000 per month (skilled) to Rs. 45,000 per month (Unskilled).

As the disease progresses and the family's financial resources permitting, some opt to place their loved ones in a residential care service. Residential care services in Sri Lanka are not equipped to handle dementia patients; such services are considered premium services and provided by only a few.

A new research review highlighting the hidden costs of dementia suggests that traditional measures only show the 'tip of the iceberg' of the cost impact on society. The study found that socio-economic costs such as the cost of healthcare for care partners/carers, reduced quality of life and "hidden" costs that stack up before diagnosis, are overlooked by current estimates of the condition's economic impact.

While prevention, early diagnosis can save millions to the economy, investing in research for cure and management is for the same reason a must. The figures themselves are an indicator why Alzheimer's and related dementias should be taken as a public health priority and require the need for a whole-of-government, multi-sectorial and multi-stakeholder public health response to dementia.

***The total estimated worldwide cost of dementia is US\$818 billion in 2015, which represents 1.09% of global GDP. By 2018, the global cost of dementia will rise above a US\$ trillion. if global dementia care were a country, it would be the 18th largest economy in the world. The annual costs exceed the market values of companies such as Apple (US \$742 billion) and Google (US \$368 billion).***



## Events & awareness

### A visit from the Nurses Training School , Durdans Hospital



The Lanka Alzheimers Foundation was encouraged to have forty four student nurses and two teachers from the Nurses Training School of Durdans Hospital visit us as a part of community health visits in their nursing curriculum. We hope that such visits will help sensitize and also highlight the benefits of non-pharmacological interventions in the treatment of dementia amongst health professionals and in general, create awareness and understanding about the disease.

### Students from Elizabeth Moir school visit LAF

Students from Form 2 of Elizabeth Moir visited the Lanka Alzheimer's Foundation as part of their community service program. They served the clients with tea and cakes, played games and sang. The clients and students enjoyed their day together and mutually benefited from the interaction.

As a part of its initiative to create dementia friendly communities LAF encourages younger people to spend time with persons with dementia as it provides children with awareness and the opportunity to understand how to be kind and empathetic to persons with dementia



### Christmas at LAF

Clients, volunteers and family care givers alike enjoyed an evening filled with Christmas spirit and fun at the annual Christmas party held on the 6th of December. A big thank you to our sponsors old and new. We could not have managed without your support



## Dates to remember



W<sub>4</sub> E<sub>1</sub> L<sub>1</sub> C<sub>3</sub> O<sub>1</sub> M<sub>3</sub> E<sub>1</sub>

**SCRABBLE BASH  
2020**

**Venue**  
Lanka Alzheimer's Foundation  
110 Ketawalamulla Lane, Colombo 10

**Date**  
Saturday, 29th February

**Time**  
9 a.m. to 4 p.m.

**Sponsorship**  
Individual - Rs. 2,500/-  
Corporate - Rs. 10,000/- (Team of 4)

Call 2667080/82/84 for more information

**SCRABBLE** Every word's a WINNER.

## EVENTS CALENDER 2020

### February

29th February - Scrabble Bash

### September

5th September - Run to Remember

21st September - World Alzheimer's Day

26th September - Memory Walk

### November

7th November - Grand Sale

### December

4th December - Christmas Party

*(Please get in touch with us on 2667082/4 if you would like to take part in /contribute to any of the above events )*

## A Volunteers Perspective

## A story of success and achievement by Srima Seneviratne

It was only 03 months ago that one of us volunteers met Erma leaving the premises after her first memory screening. We were informed that she was only in her early fifties. Actually I thought she was well into her sixties. This is how she came to be on our scheduled volunteer's day.

How difficult that first day was. Erma was non – corporative sullen listless and totally unresponsive. But about six of us volunteers turned on a mighty effort to breakthrough her wall of sickness and despair. Each of us in her own way showed her love and caring and by talking to her and listening, discovered what interested her. So we worked on that interest to break down the stony wall within her.

The first few days she entered with some sort of reluctance, but the day after the holiday break she entered with a genuine smile on her lips. As I write this, I can see her swinging from side to side on the sofa and playing with great interest the ball game in progress. Now she is playing a game of cards – constructed by two volunteers, there is much laughter and clapping, my one regret is that I cannot record her movements nor the joy and happiness in her face. As of this moment she has a naughty smile on her face.

LAF truly is a place of security, comfort and caring.

### Dementia given high priority at G20 Health Ministers meeting

Dementia was specifically recognized as a global health priority by G20 leaders in the declaration of the Osaka Summit in July 2019. The key extract from the declaration reads: *“We will promote healthy and active ageing through policy measures to address health promotion, prevention and control of communicable and non-communicable diseases, and through people-centered, multi-sectoral, community-based integrated health and long-term care over the life course in accordance with national context including demographic trends. We will implement comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers.”*

Following the initiative taken in Osaka, the G20 health ministers meeting displayed their on going commitment to addressing the biggest health and social care crisis of the 21st century. The G20 Health Ministers Meeting, which brought together Ministers of Health from 19 countries and the European Union, as well as invited guest countries and organizations, facilitated high-level discussion of major issues of global health including dementia.

The Okayama Declaration of the G20 Health ministers contained various important commitments around dementia, spanning six articles of the document. Article 29 states: *“We commit to developing and implementing multi-sectoral national action plans, adopting integrated approaches on dementia in line with the Global Action Plan to improve the quality of care and the quality of life of people with dementia, their families and caregivers.”*

Currently there are only 32 national plans in existence against a WHO target of 146 by 2025. National plans are the most important tools for governments in developing a strategy to tackle dementia and we are reassured by G20 countries taking such a global lead. Article 30 of the Declaration addressed risk factors and social determinants of dementia, early detection, diagnosis, and interventions and strengthening primary health care. An important commitment was: *“We also recognize the importance of including older persons with disabilities in efforts to support healthy and active ageing, including the provision of social and health services in line with the UN Convention on the Rights of Persons with Disabilities.”*

ADI and its members are delighted to see the ongoing commitment of the G20 in a number of key areas of the Health Ministers Meeting declaration. Japan has been a leader in dementia and healthy ageing for a number of years and it is most encouraging to see that the Government has been so willing to engage with civil society throughout this process. This level of open dialogue will ensure that dementia received the attention and robust policy action it so urgently needs.

Read More : <https://www.alz.co.uk/news/dementia-given-high-priority-at-g20-health-ministers-meeting>

### Pope Francis remembers those affected by Alzheimer's



Pope Francis remembered those affected by Alzheimer's disease and urged prayers for them, their families and those who care for them. The Pope recalled that it is “a disease that affects many men and women who often become victims of violence, maltreatment and abuse that trample their dignity. We pray for the conversion of hearts and for those affected by Alzheimer's, their families and those who care for them with love,” Pope Francis said.



### New drug for mild to moderate Alzheimer's approved in China



China approved a drug to treat Alzheimer's made by a Shanghai-based pharmaceutical company, the first new therapy endorsed for the disease in 17 years and a major breakthrough in the country's push to become a leader in scientific research.

The National Medical Products Administration said in a statement on Saturday that it granted conditional approval to Oligomannate. In trials, the drug statistically improved cognitive function in patients suffering from mild to moderate Alzheimer's as early as week four, Shanghai Green Valley Pharmaceuticals said in a statement.

The drug is slated to be available in China by the end of 2019, Green Valley said, and joins only a handful of Alzheimer's-related therapies worldwide. There are currently no globally approved treatments to slow or stop the neurodegenerative disease, which is the most common cause of dementia in the U.S. and robs people of their ability to remember and to perform basic tasks. Green Valley said it plans to apply for marketing authorization in "selected countries following the China launch." It will start global clinical trials early next year, with sites in the U.S., Europe and Asia. Pharmaceutical companies around the world have spent billions of dollars over decades chasing a cure for Alzheimer's, with little to show for their efforts.

Green Valley's drug is unusual in that it does not target beta amyloid, a protein that forms clumps of plaque in the brain and is thought to be a cause of the disease. After years of failure, a backlash has grown over the pharmaceutical industry's fixation on the compound as the key to a cure. The Shanghai drug is a low molecular acid oligosaccharide compound extracted from marine brown algae, according to the Chinese regulator's statement. The regulator said it needs further studies on the drug's pharmacology, safety and effectiveness after it's launched.

Read More : [https://www.bloomberg.com/amp/news/articles/2019-11-02/shanghai-green-valley-wins-china-approval-for-lzheimer-s-drug?\\_twitter\\_impression=true](https://www.bloomberg.com/amp/news/articles/2019-11-02/shanghai-green-valley-wins-china-approval-for-lzheimer-s-drug?_twitter_impression=true)

### A drug that can slow Alzheimer's dementia

A US drug company says it has created the first therapy that could slow Alzheimer's disease, and it is now ready to bring it to market. Currently, there are no drugs that can do this - existing ones only help with symptoms.

[Biogen](#) says it will soon seek regulatory approval in the US for the "groundbreaking" drug, called aducanumab. It plans to file the paperwork in early 2020 and has its sights on Europe too. Approval processes could take a year or two. If successful, the company aims to initially offer the drug to patients previously enrolled in clinical studies of the drug.

Aducanumab targets a protein called amyloid that forms abnormal deposits the brains of people with Alzheimer's. Scientists think these plaques are toxic to brain cells and that clearing them using drugs would be a massive advance in dementia treatment, although not a cure. Biogen's chief executive Michel Vounatsos said: "We are hopeful about the prospect of offering patients the first therapy to reduce the clinical decline of Alzheimer's disease." There haven't been any new dementia drugs in over a decade.

Read More : <https://www.bbc.com/news/health-50137041>

# Current Services

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

## Caregiver Support Group (CSG)

The CSG meetings are conducted on a as need basis ;

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

# The Board

Lakmali Cabral (Secretary), Yasmin Cader, Murtaza Esufally, Priya Fernando,  
Lilani Jayasuriya (Treasurer), Beverley Mirando, Prof. Shehan Williams (President)

**PLEASE SUPPORT THE WORK OF THE FOUNDATION  
BY MAKING A DONATION OR LEAVING A LEGACY**

**The Foundation is a Government Approved Charity (Gazette Notification no. 1225)**

Cheques should be crossed and made payable to the **Lanka Alzheimer's Foundation** and sent to Lanka Alzheimer's Foundation, 110 Ketawalamulla Lane, Colombo 10, Sri Lanka

Monthly/Annual donation can be made directly to

**Account number: 106110117418**

**Swift Code NDBSLKLX ,**

**National Development Bank PLC , Havelock Town Branch, 117, Havelock Road, Colombo, Sri Lanka.**

Please do keep the office informed so we could acknowledge receipt

**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**