

Quarterly Issue - Vol. 210

April to June 2019

## Sinhala/Tamil New Year Celebrations



## Happy New Year to all our readers

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### Free Memory Screening

April - 05, 26  
May - 03, 17  
June - 07, 21

Appointments are limited.  
Please call 2667080 to register

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)

# Scrabble Bash 2019



The tenth annual 'Scrabble Bash' was successfully concluded on Saturday 23rd February. The winners and runners-up walked away with some exciting prizes donated by Hilton Colombo, Shangri-La, Hilton Colombo Residences, Taj Samudra and Galadari.

The Scrabble Bash brought together people of all ages. The winner and Runner up of Category A was Indunil Amarasinghe and Priya Fernando respectively. Nazeefa Anees and Sajda Hussain emerged the winner in Category B and Sandali Vithanage, the runner-up.

Our sincere appreciation to our numerous sponsors, adjudicator Shaila Amalean ably assisted by Anushika Kuruppu and Praveeni Jayasekera, our many sponsors, and volunteers for their continued support.

The Scrabble Bash is held on the last Saturday in February every year—we look forward to your participation in 2019 which will be our tenth anniversary.

## Donation from ICCB



Our sincere appreciation is extended to the Committee Members of the International Christmas Charity Bazaar (ICCB) for their annual donation in support of the Foundation's Activity Centre.

Fatema Jaferjee, Chairperson of the ICCB presented a cheque for Rs. 420,000/- to the Lorraine Yu, President of the Lanka Alzheimer's Foundation.

Also seen in the picture are the Friday volunteers who support persons diagnosed with dementia.

From left to right Karen Jayaratne, Anoma Fernando, Marlyia de Cozar, Anuradha Chandrasekaran, Fatema Jafferjee, Lorraine Yu, Alnaas Esufally, and Jacinta Kuru Utumpala.

## Appreciation



It is with a mix of sadness and gratitude that the Board of Directors announce the resignation of Mrs. Ren Lan Mather from the Board of the Lanka Alzheimer's Foundation, with effect from 31st March, 2019.

Mrs. Mather joined the Board in 2009 and held the post of Honorary Treasurer from 2009 to 2015, during which time she improved the financial stability of the Foundation.

We cannot thank Mrs. Mather enough for her hard work, dedication, and enthusiasm during the past ten years. She will be greatly missed by the Board, volunteers and staff alike.



# Awareness:

## January

- 14 - Pinhena Elders Society, Piliyandala
- 17 - Director Counselling/District Counselling  
Coordinators/Staff, Sethsiripaya, Battaramulla
- 17 - Staff/Field Officers -Divisional Secretariat, Kotte
- 21 - Elders Societies, Divisional Secretariat, Padukka
- 24 - Doctors/Nurses - Panadura Base Hospital
- 25 - All Ceylon Buddhist Women's Association
- 28 - Maampe North Elders Society, Piliyandala
- 29 - Elders Societies/Staff, Divisional Secretariat,  
Wattala
- 28 - Field Officers/Staff, Divisional Secretariat  
Meerigama
- 30 - Elders Societies, Divisional Secretariat Office,  
Colombo

## February

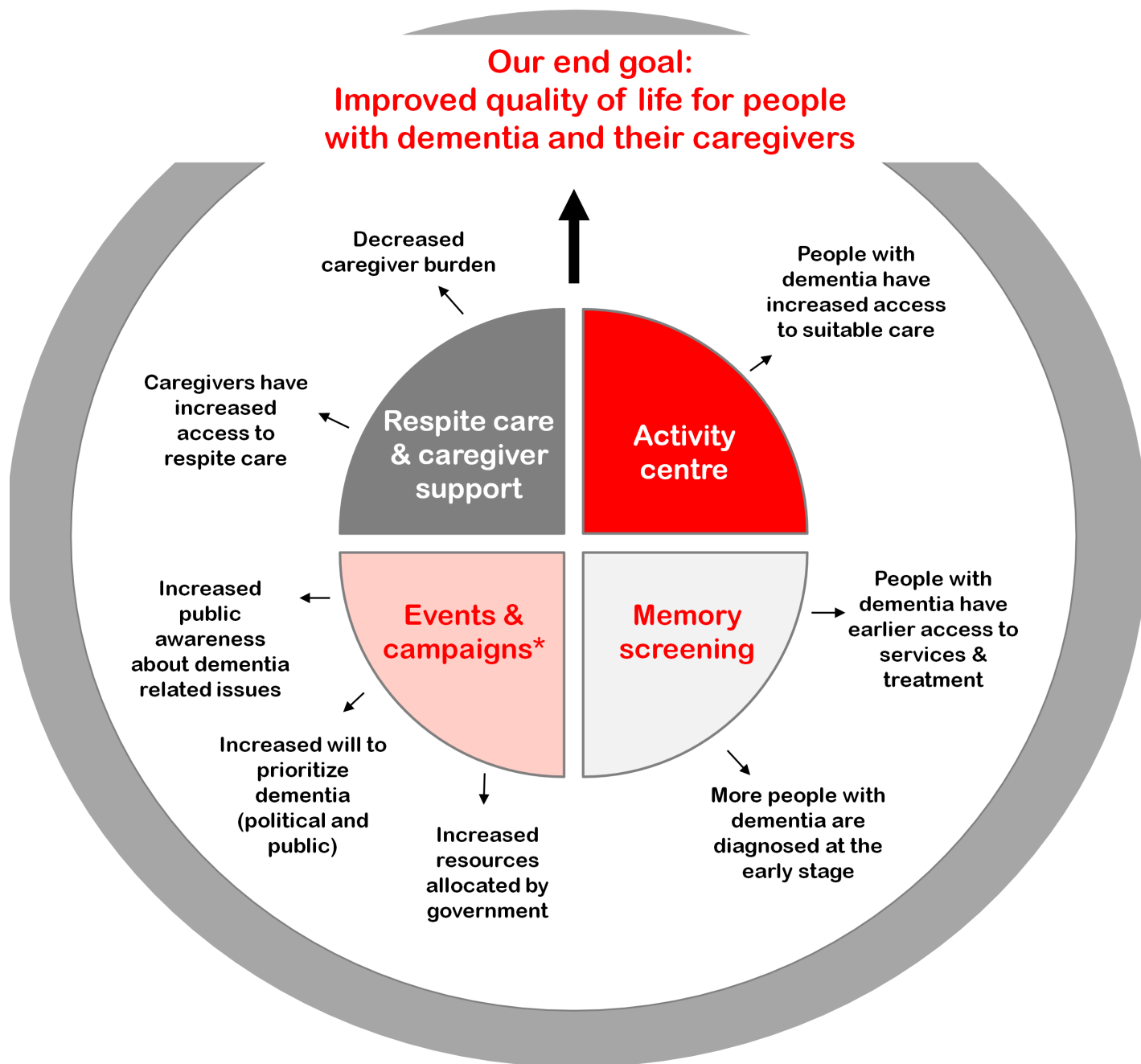
- 08 - Suwadiwi Asiri Elders Society, Piliyandala
- 13 - Field Officers/Staff, Divisional Secretariat  
Maharagama
- 26 - **National Savings Bankeshta Purawasi Kamituwa,  
Moratuwa**
- 27 - Staff Members of the Planning Division, Divisional  
Secretariat, Kesbewa

## March

- 05 - Maharagama North Elders Society
- 11 - Nanpamunuwa Elders Society
- 15 - Director/Social Service Workers/Staff -  
Sethsiripaya, Battaramulla
- 16 - Samagi Welfare Society, Egodawatta
- 22 - Directors of Social Services Centre - Islandwide  
Sethsiripaya, Battaramulla



# OUR THEORY OF CHANGE



# Why we think we are making an impact

As a volunteer run organization with limited resources, we are not able to collect systematic data to track our impact, e.g. the exact number of caregivers who experienced less burden as a result of our support. However, we do have a body of evidence and experience that allows us at least to assume that our work is making a difference. The main assumptions in our impact model are as follows:

**1** We assume that people with dementia will experience improved quality of life if they spend 1—2 days per week at our Activity Centre because:

- Our Activity Centre provides a type of high quality, specialized care that people with dementia could not otherwise access because there is no other similar service in Colombo
- The design of our service (a combination of physical, mental and social stimulation in a welcoming environment) aligns with research\* showing that this type of approach can help to protect cognitive functions and maintain other aspects of ‘quality of life’ for people with dementia
- We know from informal feedback and staff/volunteer experience that many of the Activity Centre clients have experienced improvements in various aspects of their quality of life (e.g. emotional wellbeing) and that these improvements seem to be at least partly attributable to our support.

*\* For example: Park, D., & Reuter-Lorens, P. “The adaptive brain: Aging and neurocognitive scaffolding” Annual Review of Psychology 2009, 60; Ngandu T, Lehtisalo J, Solomon A, et al. “A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people: a randomized controlled trial”. Lancet. 2015 Jun 6; 385(9984):2255-63)*

**2** We assume that caregivers will experience reduced burden if we provide respite care for their loved one and informal advice and information. Our rationale for this assumption is:

- We know from informal interviews with new caregiver clients that all of our caregiver clients have few or no other options for respite care apart from our Centre. Hence, our service allows them to have more time for themselves than they otherwise would.
- Not having enough time for oneself is widely understood to be a key component of caregiver “burden” (for example, it features strongly in the widely used Zarit Burden interview tool for measuring caregiver burden).

**3** We assume that our awareness raising events and campaigns will help reduce stigma and prompt more people to go for screening, which in turn will lead to earlier diagnosis and intervention. We assume this because:

- We have witnessed over the years that many people with dementia and their families feel ashamed or alienated from society, which directly impacts their quality of life. Meanwhile, most of the public do not have a good understanding of how to support and relate to people with dementia—unless they themselves have had direct experience of the disease. Our awareness raising events therefore aim to contribute - over time - to reducing stigma and building a more dementia friendly society.
- We have also seen how people can hold back from going for screening if they think they have symptoms. Some of our screening clients tell us that they would not have gone for screening without being prompted by our information, encouragement and accessible screening service.

# Defining dementia

## What is dementia?

Dementia is a term used to describe various different brain disorders that have in common loss of brain function which is usually progressive and eventually severe. There are over 100 different types of dementia. The most common are Alzheimer's disease, vascular dementia and Lewy body dementia.

People with dementia have particular problems with their short-term memory. They consistently forget things that they have just said or done, even though they can often recall clearly events that happened many years ago. Their sense of time and place is typically lost. They may develop problems with finding words and it becomes increasingly difficult of them to learn new information and to do new things. As time goes on, people with dementia need help to perform even the most basic tasks of everyday living, including washing, dressing and eating. Eventually, people with dementia may become uncommunicative and incontinent. Sometimes there are severe behavioural problems. Most people with dementia eventually require 24 hour care. Dementia often go on for many years—5, 10 or even 20—and are not usually the actual cause of death.

## Types of Dementia

- Alzheimer's disease is the commonest cause of dementia, accounting for about 60 percent of all cases.
- Among other types of dementia are vascular dementia, which is the second most common type of dementia. Vascular dementia results from brain damage due to tiny strokes.
- Lewy body dementia, which some people regard as a variant of Alzheimer's disease or Parkinson's disease. It takes its name from abnormal collections of protein, known as Lewy bodies, which occur in the nerve cells of the brain.
- Fronto-temporal dementia, for example Pick's disease in which there are striking changes in behavior before the memory problems appear. Pick's disease is a rare type of dementia. It shares various similarities with Alzheimer's disease (AD) but also differs from AD in a number of important respects.
- Huntington's disease, also sometimes called Huntington's chorea, which is characterized by jerky movements in addition to dementia. Huntington's disease is an inherited disease. If your mother or father had the disease, there is a one in two chance that you will also develop it.
- AIDS related dementia
- Dementia that sometimes occurs together with Parkinson's disease
- Creutzfeldt Jakob disease or CJD is an extremely rare type of dementia. CJD usually progresses very rapidly and is often fatal within a year.
- Dementia due to a brain tumor - One type of slow-growing brain tumour, known as a meningioma, sometime causes symptoms of dementia. Most brain tumours cause other kinds of symptoms such as headaches, loss of limb function, visual disturbance and loss of balance. In some cases, removal of a meningioma may result in recovery from dementia.
- Normal pressure hydrocephalus, due to a build up of fluid in the brain - Early symptoms of this type of dementia, include incontinence of urine and problems walking.
- Dementia due to an excessive intake of alcohol over an extended period of time, known as Korsakoff's syndrome, which develops because of vitamin B<sub>1</sub> deficiency.
- Dementias due to various treatable causes, including vitamin deficiency, hormone deficiency, and syphilis.



## **‘Training of Trainers’ in elderly and dementia care skills for nurses**

The ‘Training of Trainers’ in elderly and dementia care skills for nurses will be carried by the the Lanka Alzheimer’s Foundation in collaboration with Unity in Health (a charity based in the UK), Ministry of Health, Nutrition and Indigenous Affairs, National Institute of Mental Health, and WHO Sri Lanka.

The Ministry of Health will select 9 public health nurses and 11 community psychiatric nurses (2 from each province and 2 additional nurses from NIMH) attached to the public health service for the training programme. The 5 day programme will be held at the National Institute of Mental Health, Angoda from the 22nd to the 26th of July, 2019.

The objective of the programme is to equip and empower nurses to be trainers and to deliver the training to other nurses and health professionals and caregivers in their regional hospitals and communities.

## **The Master Trainers from Unity in Health (UiH) - UK**



Jo James, RN, MSc, PGC  
Trustee UiH

Jo James qualified as a registered general nurse in 1988 and completed a MSc in Medical Anthropology in 1997. She is a health care professional with a wide and varied portfolio of experience. Throughout her career, she has championed the development of excellent nursing care through education, understanding and professional accountability.

Currently working as the Lead Nurse for Dementia at Imperial College Healthcare NHS Trust, she initially specialised in Emergency Care and service redesign working as an Emergency Department Sister, Nurse Practitioner and Matron in charge of training as well as on a large scale service redesign and hospital rebuild project. Since 2008, she has specialised in the care of older people and people with dementia and the development of hospital services to improve standards of care.

Jo has been involved with service improvement in the field of dementia care both locally and nationally. She was a member of the Department of Health General Hospital Dementia Group, the RCN Transforming Hospital Care Steering Group and Strategic Clinical Network Leadership Group for Dementia in London. She is currently on the steering group for the RCN Older People’s Forum and a Special Advisor to the Care Quality Commission.

Jo has a strong interest in education and has been instrumental in the development of London wide Dementia Training materials and also delivering dementia training to hospital and care home staff. She was programme manager for the highly successful 12,000 trained in dementia project at UCLPartmenrs which was a finalist in the Health Service Journal awards.

Ho has publised owkr on a vcariety of subjects, ranging from regugee needs to dementia care and her most recent publication is a text book on Excellent Dementia Care in Hospital.



Neville De Silva  
BSc (Hons); MSc; PGCE  
Trustee UiH

Neville was born in Sri Lanka and qualified as a Mental Health professional in the UK, where he worked in the National Health Service (NHS).

At present Neville is involved in the field of Mindfulness Research Groups worldwide. He is a qualified and accredited Mindfulness Teacher Trainer with ‘Breathworks UK’, where he works as a Holistic Therapist. One of Neville’s many ambitions is to help develop Mindfulness Based Interventions (MBIs) in the Mental Health Sector.

Neville is passionate about helping people with Mental Health problems in their recovery process via many sources including the voluntary sector

# Living Well in Older Age

An information seminar was organised recently by English Nursing Care entitled 'Living well in Older Age.' English Nursing Care provides home nursing in the Colombo area under UK trained supervision.

The event was co sponsored by Healthnetbuy, and held at Lanka Hospital auditorium on 2<sup>nd</sup> March. As Richard Gould, Managing Director of English Nursing explained 'The purpose of the seminar was to provide useful information on services that are available to help support relatives in old age.'

Speakers included Mrs Fiona Eccles, UK Director of Nursing for English Nursing on how to practically manage relatives with illnesses at home; Mr Uvindu Gopallawa from Healthnetbuy on the importance of adherence to medication regimes;

Dr Lasith Obadaarachchi spoke on behalf of LAF about dementia and how the Foundation supports people living with dementia; and Dr Senani Ranaweera from the Sri Lanka Nutrition Association talked about the high unexpected incidences of malnutrition in older people and what can be done to combat this.

After refreshments there was a Question and Answer session which had a range of issues discussed particularly around dementia and the benefits or otherwise of various foods including probiotics and coconut oil in older people.

As Mrs Ivanka Fonseka, General Manager English Nursing explained, 'The issue of adequate community healthcare for the elderly is an important topic now for Sri Lanka. We intend to hold further information seminars to provide useful tools for families who wish to support their elders at home in the best way possible.'

For further information on future events please contact Miss Jessika Raj, English Nursing on 0114500117  
[www.englishnursing.com](http://www.englishnursing.com)

## Research— A Possible Alzheimer's Treatment with Clicks and Flashes? It worked on Mice By Pam Belluck ( New York Times 14/03/19 )

Could people's eyes and ears help fix the damage Alzheimer's disease does to the brain? Just by looking at flashing light and listening to flickering sound?

A new study led by a prominent M.I.T. neuroscientist offers tantalizing promise. It found that when mice engineered to exhibit Alzheimer's-like qualities were exposed to strobe lights and clicking sounds, important brain functions improved and toxic levels of Alzheimer's-related proteins diminished.

What's more, the rapid-fire soundtrack appeared to make mice better at cognitive and memory skills, like navigating mazes and recognizing objects.

Of course, mice are not people. And many drugs that have helped Alzheimer's-engineered mice haven't done much for people with Alzheimer's, which affects 44 million people worldwide, including 5.5 million Americans. Also, because the technique didn't have long-lasting effects — results faded about a week after the sensory stimulation was stopped - any therapy developed from the research might have to be repeated regularly.

Still, seeing that a noninvasive daily dose of light and sound could have such significant effects in mice give some experts reason for optimism.

"It's exciting, I think," said Dr. Lennart Mucke, director of the Gladstone Institute of Neurological Disease, who was not involved in the study. "Reading the paper made me quite enthusiastic about seeing this move forward into some well-crafted clinical trials."

The experiments were led by Li-Huei Tsai, director of MIT's Picower Institute for Learning and Memory. She and her colleagues showed that light and sound delivered to mice at a certain frequency — 40 hertz or 40 flashes or clicks per second — appears to synchronize the rhythm of the brain's gamma waves, which is disrupted in patients with Alzheimer's. Gamma waves are among several types of electrical brain waves believed to be involved in concentration, sleep, perception and movement.

Somehow - neither Dr. Tsai nor outside experts are quite sure how - 40 hertz produces a gamma-wave oscillation that appears to increase activation of cells called microglia, which perform trash-clearing and immune-regulating functions. The microglia became more efficient at chewing up the amyloid protein that forms toxic plaques in Alzheimer's.



Another Alzheimer's-related protein, tau, which forms tangles, also decreased. And in the sound experiments, brain blood vessels also worked better, further helping clear harmful proteins. Especially striking was that these effects occurred in brain areas active in memory formation, planning and decision-making, and that the mice became better at learning and remembering.

"The effects on cognitive function are pretty big," said Dr. Walter Koroshetz, director of the National Institute of Neurological Disorders and Stroke, which funds some of Dr. Tsai's work. He said the results of [the study, published Thursday in the journal Cell](#), are "definitely something that I don't think anybody could have predicted."

Enhancing or regulating electrical brain activity through techniques like surgically implanted electrodes is used to treat some other conditions, like Parkinson's and obsessive-compulsive disorder. And previous research has shown that the activity of gamma waves, the highest-frequency waves ranging from 25 to 140 hertz, decreases in the brains of patients with Alzheimer's.

Intrigued, Dr. Tsai began experimenting with light, and in 2016, she and colleagues showed, after trying different frequencies, that light flickering at 40 hertz, beamed at mice an hour daily for a week, decreased amyloid and tau and revved up microglia in the brain's visual cortex.

Aiming to reach other brain areas, she tried sound, settling on clicks because "your brain seems to be able to perceive clicks more than a tone," she said.

Her team found that 40 hertz clicks, broadcast from speakers over mouse enclosures, produced the same brain changes in the auditory cortex and the nearby hippocampus, an area active in forming memories that is damaged early in Alzheimer's. The mice also performed better at maze navigating and recognizing objects they had seen before. Light and sound combined magnified the brain effects and extended them to the prefrontal cortex, a key area for planning and executing tasks.

"it's stunning that the intervention had beneficial effects on so many different aspects of Alzheimer-like pathology," said Dr. Mucke, who is also a professor of neurology and neuroscience at University of California San Francisco. "On the other hand, it shouldn't be surprising that the brain is influenced by outside stimuli because what it was designed for was to adapt to a changing environment."

The results also dovetail with findings by Dr. Mucke and his colleagues, who have genetically altered brain cells called interneurons, which he likened to conductors of the brain's orchestra. The altered interneurons enhanced gamma rhythm activity, generating cognitive improvement in mice. "When there isn't proper brain rhythm, there is disharmony and everyone is sort of playing when they want to, a little like the tuning up of an orchestra," he said.

His colleagues are also developing a drug that would have similar effects. So there might be several ways to enhance gamma rhythms, he said.

Because the brain changes subsided somewhat after a week without the light or sound treatment, experts said it's likely that people would need such stimulation consistently, essentially a sensory version of a daily pill to control a chronic condition.

Dr. Tsai's team has tested light and sound on healthy people, using a four-by-three-foot light panel and high-quality stereo speakers, "so the sound is more tolerable to humans, because it's not melody, it's clicks," she said. Electroencephalogram measurements show the desired gamma-wave effect, she said, and "nobody complains about any discomfort or headache or anything."

They will soon start testing on people with mild Alzheimer's. Dr. Tsai and a co-author, Edward Boyden, co-director of the M.I.T. Center for Neurobiological Engineering, have also co-founded a company, Cognito Therapeutics, which is testing a goggles-like light-and-sound device on Alzheimer's patients, she said. Dr. Tsai said the company is not involved in her team's academic research, which was funded by several foundations and the National Institutes of Health.

Experts cautioned that people should wait for clinical trial results and shouldn't suddenly start illuminating their homes with disco strobes or pipe clicking sounds through their earbuds.

Still, said Dr. Koroshetz, sensory treatment is likely to be safe for most people.

"Can't think of any harm that can come out of this one," he said. And because Alzheimer's is so devastating, he added: "I think people would participate in studies, even if they require flashing lights for an hour and listening to a very quick drummer."

# Current Services:

- Raising Awareness and eradicating stigma
- Education on risk reduction
- Helpline +94 11 2667080
- Befriending/Counselling
- Memory Screening
- General Psychosocial Assessments
- Activity Centre
- Quarterly Newsletter
- Secretariat/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 need basis -

- 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

# The Board:

Lakmali Cabral, Lilani Jayasuriya (Treasurer), Yasmin Cader (Secretary), Priya Fernando,  
Beverley Mirando, Prof. Shehan Williams; Lorraine Yu (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

Details for a Monthly/Annual donation by Standing Order:

**Account number: 106110117418 Swift Code NDBSLKLX**

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

**The Lanka Alzheimer's Foundation relies on donations in order to sustain the services provided to persons with dementia and their family carers. The Foundation is a community based charity, which has not as yet received support from the international donor community or the public sector.**

**Your support will make a difference - Please give generously  
Thank you**