Quarterly Issue - Vol. 219

July-September 2021

Virtual Walk Await details Memorable Steps 2021 in September

ca Alzheimer's Foundation

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Message from the President

THE FATHER wins Oscars

Sir Anthony Hopkins wins another Oscar in 'THE FATHER' at 83 years, portraying a person with dementia. The film not only highlights the struggles of a person with dementia but also that of his daughter Anne played by Olivia Colman, who too was nominated as best supporting actress for her acting.

This epic film is described thus: "Anthony Hopkins is 80, mischievous, living defiantly alone and rejecting the carers that his daughter, Anne, encouragingly introduces. Yet help is also becoming a necessity for Anne; she can't make daily visits



anymore and Anthony's grip on reality is unraveling. As we experience the ebb and flow of his memory, how much of his own identity and past can Anthony cling to? How does Anne cope as she grieves the loss of her father, while he still lives and breathes before her? THE FATHER warmly embraces real life, through loving reflection upon the vibrant human condition; heartbreaking and uncompromisingly poignant - a movie that nestles in the truth of our own lives."

We hope that many of us will get the opportunity to see this film. "This is a film of immeasurable power which everyone should experience once. It explores the frailties of being human, in a society which increasingly values youth over experience", one reviewer has said.

We wish fervently that the film will once again open the eyes of many who need to awaken to the reality of dementia. It should push governments to prepare and support dementia as a public health priority. It makes a case for more awareness, understanding, acceptance and involvement in everyone on dementia related matters.

Prof Shehan Williams



"September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. World Alzheimer's day - is celebrated annually on 21st September"

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Free Memory Screening

2021					
July	-	16th	30th		
August	-	6th	20th		
September	-	3rd	17th		
Appointments are limited.					
Please call the Helpline 2667080					

A Carer's Story - by Tasneem

Reflections on time spent at the Lanka Alzheimer's Foundation

My father has been visiting the Lanka Alzheimer's Foundation (LAF) since 2013.

We first learnt about the Centre through friends, when my father started showing signs of memory loss. He has been visiting the Centre once a week since then, until the lockdowns started in 2020 due to the pandemic.

His experience has been nothing but positive and is something he and our family have been very grateful for.

Over the years, my father's visit to the Centre has become the highlight of his week. A combination of the activities organized and the interaction with the volunteers is what he enjoys the most. The creative sessions, musical events and physical activities have been stimulating and entertaining. The volunteers must also be specially commended for the caring and joyful social environment created at the Centre.

He brings home his art and craft work each week which is also a conversation starter with the family.

The Centre is a great space and well maintained. With lots of natural light, greenery and open spaces, it makes for a welcoming and comfortable space to visit each week. Over time, we have seen a significant improvement in my father's general mood, attention span and memory.

We attribute some of these improvements to the time spent at the Centre.

We have really appreciated the Foundation's efforts to engage the family by sharing photographs of the special occasions they have organized, including the annual Christmas party, birthdays and other holidays.

The memory screening test which is held at the center has also been very helpful to my father and the family in understanding his condition and progress.

During the last year and a half, although the pandemic has affected us all in multiple ways, the toll it has taken on elderly people has been significant and is less talked about.

My father has dearly missed his weekly visits to the Foundation and the social interaction with the volunteers. The Foundation's efforts during this time to reach out and support their patrons has been invaluable. We have received thoughtfully planned activity sheets along with guidance on how to conduct the activities in a home setting. We have also received regular phone calls from the volunteers to check on how my father is doing which has been much appreciated.

My father looks forward to continuing his weekly visits once the pandemic is under control and the Centre reopens.

Thank You

A patient with cognitive impairment who wanders outside alone can easily become confused, injured and get lost.

An identification bracelet can help a loved one with dementia to get back home safely.



Hypoallergenic and Tamperproof ID bracelets are now available at

The Lanka Alzheimer's Foundation

Inquiries Call 0112667080 /82

From a Volunteer's Perspective

For the past few years, it has been my privilege to volunteer at the Lanka Alzheimer's Foundation. The Foundation was set up by the meticulous and extremely hard working Mrs. Lorraine Yu. Her selfless work over many years resulted in what today is a ray of sunlight in the lives of many who are afflicted with Alzheimer's Disease, as well as their carers.

On entering the Activity Centre gates, you can't help but feel a sense of peace and calm. The gardens are beautifully manicured, there are always flowers blooming, and the building is warm and welcoming. The perfect surroundings for both the clients, who are often agitated when they come in, and for the volunteers.

For us volunteers, the needs of the client are paramount. We plan our activities carefully, from singing, dancing, percussion, and simple games, to yoga, tea and biscuit breaks, and a delicious lunch. We try to include activities in which most clients can participate, but follow a person centric approach as well, so that no client is forced into any activity.



There is probably not a single one of us who hasn't had to deal with a client who is having a bad day, but we do so with love and understanding, so that the carers can have some precious time off, knowing that their loved ones are safe with us.

Needless to say, as a result of this close and personal interaction, the volunteers form very close bonds with the clients as well as with one another.

For me, personally, volunteering at the LAF has enriched my life in more ways than I can say. I have learned a lot about this debilitating disease, and I am full of admiration for the carers who look after those suffering from it.

Not only has volunteering taught me patience, but I have also made deep and enduring friendships with some marvelous people, who are more than happy to give of themselves and of their time.

The Pandemic has been hard on many of our clients, for whom the day at the Centre was the only outing for the week.

The volunteers tried to help out by sending activity packs and music videos, so that the clients could have some welcome diversion. We still follow up regularly with calls to the clients and their carers, checking in and hoping that all is well with them. It is particularly heartwarming when clients tell us they are waiting for the Centre to reopen.

Here's hoping and praying that we can reopen the Centre soon.

By Alnaas Esufally



CALL OUR HELP LINE 2667080

Monday to Friday | 9am-5pm

For information on dementia and dementia care management

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News - Alzheimer's Disease International (ADI)

On 7th June 2021, the United States Food & Drug Administration (FDA) approved the first disease modifying treatment for Alzheimer's disease and Mild Cognitive Impairment (MCI) related to Alzheimer's disease. It is also the first new dementia drug treatment to reach the US market in almost 20 years.

Details of the availability of the treatment, which takes the form on an infusion, is awaited. The FDA also said that Biogen must conduct a post-approval clinical trial to verify the drug's clinical benefit. It will be sold under the brand name **Aduhelm.**

A confirmatory diagnosis of Alzheimer's disease is key to ascertaining if **aducanumab** is a treatment option for individuals. Diagnosis itself can be a barrier, currently requiring a PET scan and/or a cerebrospinal fluid (CSF) test, alongside memory tests and careful clinical assessment. Biogen has also filed for approval in Europe, Australia, Brazil, Canada, Japan and Switzerland.

Chris Lynch, Acting Chief Executive of ADI, commented on the FDA's decision:

"We have been awaiting news on a drug treatment breakthrough for Alzheimer's disease for almost 20 years and warmly welcome this news. This is indeed a momentous day for the entire dementia community. This treatment can be beneficial at the early stages of Alzheimer's disease and MCI (Mild Cognitive Impairment) related to Alzheimer's disease but importantly, we are now confident in what will no doubt result in fur-ther research investment into many more treatments, covering the broad spectrum of dementia, bringing confidence and further innovation to the sector".

"We are incredibly indebted to the many research participants and their families around the world who contribute so much to advance research on the causes and treatments of Alzheimer's disease. With more than 50 million people living with dementia today, and forecasts set to triple, this announcement is most welcome and timely."

The FDA approval raises important questions about rollout and availability plans, approval in other regions and countries, access and eligibility, payers and reimbursement and health system readiness.

More information can be found on www.alzint.org

ADI issues strong statement

On 25th May 2021, during the 74th World Health Assembly, held from 24th May to 1st June 2021, ADI submitted a statement to the World Health Organisation (WHO) and its member states, highlighting the **disproportionate impact of COVID-19 on those living with dementia and their carers**. It calls for member states to recognize and act to ensure that older people and those living with dementia are at the forefront of recovery and future preparedness plans.

ADI also hosted a side event to launch the Report "From Plan to Impact IV". This report calls for governments not to deprioritise dementia or progress on their national dementia action plans due to the pandemic.

ADI Membership Committee 2021

We congratulate One of our Board members, who has been appointed to the ADI Membership Committee 2021

- * Meera Pattabiraman, India (Chair representing Asia Pacific)
- * Beverly Mirando, Sri Lanka (Asia Pacific)
- * Dale Goldhawk, Canada (North America)
- * Noemi Medina, Argentina (Latin America)
- * Elizabeth Mutunga, Kenya (Africa)
- * Ameenah Sorefan, Mauritius (Africa)
- * George Karam, Lebanon (Middle East)
- * Jesus Rodrigo, Spain (Europe)
- * Lorene Gilly, France (Europe)

"Reduced Sleep is a risk factor for dementia"

If you are trying to get by on about six hours or less of sleep a night during the workweek, you're setting up your brain for future failure, according to a new study.

Sleeping less than six hours a night in middle age can increase your dementia risk, a long-term study has found.

After following nearly 8,000 people for 25 years, the study found a higher dementia risk with a "sleep duration of six hours or less at age 50 and 60" as compared to those who slept seven hours a night.

In addition, persistent short sleep duration between the ages of 50, 60 and 70 was also associated with a "30% increased dementia risk" independent of "sociodemographic, behavioural, cardiometabolic, and mental health factors" including depression, the study said.

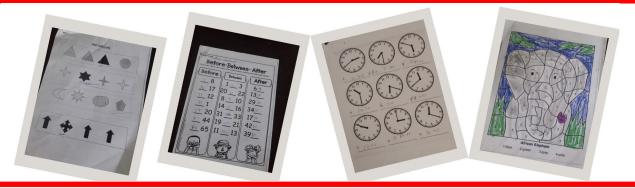
"Sleep is important for normal brain function and is also thought to be important for clearing toxic proteins that build up in dementias from the brain," said Tara Spires-Jones, who is deputy director of the Centre for Discovery Brain Sciences at The University of Edinburgh in Scotland, in a statement. Spires-Jones was not involved in the study.

"What is the message for us all? Evidence of sleep disturbance can occur a long time before the onset of other clinical evidence of dementia," said Tom Dening, who heads the Centre for Dementia at the Institute of Mental Health at the University of Nottingham in the UK.

"However, this study cannot establish cause and effect," said Denning, who was not involved in the study. "Maybe it is simply a very early sign of the dementia that is to come, but it is also quite likely that poor sleep is not good for the brain and leaves it vulnerable to neurodegenerative conditions like Alzheimer's disease."

Https://www.cnn.com/2021/04/20/health/sleep-dementia-risk-study-wellness/index.html

Creative work done by LAF clients while at home during the pandemic



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FINGERS - A multidomain intervention model to prevent and reduce Dementia



The Alzheimer's Disease International (ADI) has predicted that by 2030, there will be over 82 million people living with dementia, globally. With staggering numbers like such, there is an urgent need to find preventive interventions in order to slow the progression and prevent or delay the onset of dementia and its related disorders.

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) was the first large, long-term randomized controlled trial (RCT) demonstrating that a multi-domain lifestyle intervention can improve the overall cognitive function in older adults from the general population who are at a greater risk of developing dementia and other disorders that cause dementia¹.

The results of this study showed that by providing interventions across diet, exercise, cognitive training, socializing and vascular risk monitoring, a multi-domain intervention improved or maintained cognitive functioning; global cognition showed a 25% improvement and processing speed and memory had a 150% and 40% improvement respectively. This model shows that early treatment in a multi-domain manner, has positive long-term effects in at-risk elderly people.

Newer results from this study have demonstrated that with COVID-19, 34% of the older adults reported a decrease in physical activity, 21% reported more feelings of loneliness and 15% felt that their memory had been getting worse during the pandemic. Finnish older persons generally reported less negative changes in lifestyles and behaviors during the pandemic than expected. Older people and those living alone seemed more susceptible to negative changes. It is important to consider how coping strategies may compare with other countries to identify factors that may help older individuals to maintain healthy lifestyles during future waves of COVID-19.

With the success of FINGERS, the world-wide FINGERS network or WW-FINGERS network was launched in an effort to test the adaptability, generalizability and sustainability of this intervention method amongst different populations across the world as well as compare coping strategies and methods of treatment². At present, there are over 30 countries from all continents that are a part of the WW-FINGERS network with Latin America trailblazing ahead.

Even though the COVID-19 pandemic significantly dampened many people's plans, the WW-FINGERS study has been able to go on as planned as researchers have adapted effectively by adopting the E-FINGERS method. This brought about new avenues of research by adopting new methods of gathering data through an online method rather than the traditional face to face method.

With the results from these studies, it is hoped that we can completely prevent or control dementia altogether by adopting a healthy lifestyle and using disease modifying drugs. In order to do such a study in Sri Lanka and be identified as a part of the WW-FINGER network, the infrastructure should be put in place, tools of assessment should be acquired and the community would have to support such an endeavor. In the future, it is our hope that we join the WW-FINGERS network and advocate on behalf of those Sri Lankans who suffer with dementia.

References:

- 1. 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 (FINGER): a randomised controlled trial. *Lancet* 2015; **385**: 2255–63.
- 2. Kivipelto MMangialasche FSnyder H et al. World-Wide FINGERS Network: A global approach to risk reduction and prevention of dementia. Alzheimer's and Dementia (2020) 16(7) 1078-1094.

Questions about dementia?

CALL OUR HELP LINE

2667080

Monday to Friday | 9am – 5pm

For information on dementia and dementia care management

Maintaining positive friendships

Maintaining positive, warm and trusting friendships might be the key to a slower decline in memory and cognitive functioning.

'SuperAgers' who are 80 years of age and older who have cognitive ability at least as good as people in their 50s or 60s, reported having more satisfying, high-quality relationships compared to their cognitively average, same-age peers, a study reports.

Previous 'SuperAger' research at the Cognitive Neurology and Alzheimer's Disease Center (CNADC) at Northwestern University Feinberg School of Medicine has focused on the biological differences in SuperAgers, such as discovering that the cortex in their brain is actually larger than their cognitively average, same-age peers.

"You don't have to be the life of the party, but this study supports the theory that maintaining strong social networks seems to be linked to slower cognitive decline," a senior author Emily Rogalski, associate professor at Northwestern's CNADC has said.

Participants answered a 42-item questionnaire called the Ryff Psychological Well-Being Scale, which is a widely used measure of psychological well-being. The scale examines six aspects of psychological well-being: autonomy, positive relations with others, environmental mastery, personal growth, purpose in life and self-acceptance. 'SuperAgers' scored a median overall score of 40 in positive relations with others while the control group scored 36, a statistically significant difference,

Other research studies have reported a decline in social networks in people with Alzheimer's disease and Mild Cognitive Impairment (MCI), and previous literature has shown psychological well-being in older age to be associated with reduced risk of developing Alzheimer's dementia.

"It's not as simple as saying if you have a strong social network, you'll never get Alzheimer's disease," Rogalski has said. "But if there is a list of healthy choices one can make, such as eating a certain diet and not smoking, maintaining strong social networks may be an important one on that list. None of these things by themselves guarantee you don't get the disease, but they may still have health benefits."

Tree Planting - Sinhala/Tamil New Year

This activity was done by some of the Board Members and staff on 16th April 2021 at LAF.







"There is one thing Alzheimers cannot take away, and that is love. Love is not a memory, it's a feeling that resides in your heart and soul."



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Current Services

- Raising awareness and eradicating stigma
- Education on risk reduction
- Education on care management
- Helpline +94 11 2667080
- Memory screening / assessments done twice a month on Fridays
- Activity Centre
- **Caregiver Support Group (CSG)**

The CSG meetings are conducted as needed.

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

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

Collaboration:

- Sensitise medical students of the Kelaniya University & the Kotelawala Defence University on non-pharmacological approaches to Dementia.
- Practical training for students of the speech therapy unit of the Kelaniya University.

The Board

Lakmali Cabral (Secretary), 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 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