

September is World Alzheimer's Month



World Alzheimer's Month is the international campaign every September to raise awareness and challenge the stigma that surrounds dementia. September 2019 will mark the 8th World Alzheimer's Month. World Alzheimer's Day is celebrated on 21st September each year. The impact of World Alzheimer's Month is growing, but the stigmatization and misinformation that surrounds dementia remains a global problem, that requires global action.

Policy makers need to take a growing interest in Alzheimer's disease and other dementias, which is seen as the main health and social care challenge of the 21st century. The best way to manage dementia at a country level is by developing national plans, comparable to nationwide management of HIV/AIDS or diabetes. There is no other disease area where the numbers are going up so rapidly.

There is believed to be close to 50 million people worldwide living with dementia in 2017. This number will almost double every 20 years, reaching 131.5 million in 2050. Much of the increase will be in developing countries. Already 58% of people with dementia live in low and middle income countries, but by 2050 this will rise to 68%. The fastest growth in the elderly population is taking place in China, India, and their south Asian and western Pacific neighbors.

Awareness and education, establishing memory clinics and other specific services for early diagnosis and treatment actions, training of specialists and health care staff, setting up programs to engage and stimulate people with dementia, and improving institutional care, are some of the areas that need attention.

Dates to Remember - September

7th (Saturday) - 5K Run -Taj Samudra North Lawn, Colombo at 4.30 p.m

28th (Saturday) - 5K Walk - Angsana Spa Garden, Cinnamon Grand, Colombo at 8.00 a.m

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Free Memory Screening

July - 05, 19

August - 02, 16

September - 06, 20

Appointments are limited.

Please call 2667080

to register.

AN APPROVED GOVERNMENT CHARITY
(GAZETTE NOTIFICATION NO. 1225)

Lanka Alzheimer's Foundation

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



A Carer's Story - by Praxie Anandarajah



My mother whom, we her 4 children fondly call 'Mumma' is the second parent in my family to be afflicted by dementia. Our father who passed away in 2006, also lived his last few years with dementia and was probably affected by it to a greater extent. During that period, it was my mother who cared for him. With no formal training or guidance on caring for people with dementia, she did a wonderful job of looking after our father. Maybe her long experience as a Year 1 teacher throughout her career instilled in her all the necessary skills to care for him with patience, love, respect and dignity. During that period, I never thought she herself would become a dementia sufferer within two years of my father's demise.

Mumma was always a happy, active and fun-loving person. At her ripe age of 97+, she is still mercifully quite healthy and needs little help with her daily routines. Age and dementia has certainly slowed her down and rendered her to be lot quieter. She spends most of her time either watching television, in prayers or resting on her own. Fortunately, she doesn't possess many of the behavioral disorders said to be common amongst persons with dementia and is easy to take care of. She seldom makes any demand or gets agitated.

Being a person who led an active life in the past, we had been looking for a place where we could take her at least once a week to give a break from the monotony of staying at home all the time. That is when I came to know in 2012 from Priya Fernando about the Lanka Alzheimer's Foundation's Activity Centre. Since then, 'Mumma' has been visiting the facility and she is probably now the oldest and the longest benefitting member of the community.

Though nowadays, she finds it increasingly difficult to get going to visit the Centre each Wednesday, I am amazed at how she brightens up immediately on arrival there. Mary, to many of her friends at the Centre, she enormously enjoys her visits and obviously loves the tender care extended by all the volunteers. The bright and open environment of the Centre must be also helping in no small measure to enliven the time spent at the Centre. With all my close family living overseas and unable to support in caring for my mother, Lanka Alzheimer Foundation has been a haven where I could leave my mother without a worry once a week. These visits not only help in invigorating Mumma, they also offer me invaluable respite

A visit by the medical students of the Kothalawala Defence University (KDU)

The Lanka Alzheimer's Foundation is the first non-government organization dedicated to advocating and addressing the needs of those diagnosed with cognitive impairment and dementia. On the 6th of May 2019, we visited the Foundation on a Monday morning for a lecture that was conducted on Dementia by Dr. Indika Mudalige. This visit was a part of the Psychiatry clinical training



After the conclusion of the lecture, the Founder and President of the LAF, Ms. Lorraine Yu, gathered all of us together. After a warm welcome, she narrated the story of the inception of the Foundation, the hardships faced along the journey to achieve its Mission and Vision. Ms. Yu continued to elaborate on the work of the Foundation and the services offered to persons diagnosed with dementia and their family carers.

Thereafter, we were given a tour of the Foundation. We had the opportunity to interact with clients and volunteers at the Activity Center and participate in the music and dance therapy and to get to know some of the clients who were having a very lively and amusing sing along.

We express our heartfelt gratitude to the Foundation for this partnership and permitting us to be a part of the experience and educating us about the importance of raising awareness, combatting stigma and the support needed for people with dementia.

From a volunteer's perspective - by Inesh Gooneratne



The chance to volunteer at the Lanka Alzheimer's Foundation was an opportunity I could not pass up. I was familiar with certain aspects of the disease as one of my relations suffers from severe dementia and my goal was to help those who were facing the same plight. Also since starting my journey through college, I realized how secluded and narrow my understanding of both the world and myself truly were. I made it a point to remedy this by educating myself through experiences such as this while being able to add value to a cause that is battling an issue that silently plagues our society. Moreover, this disease is complex in the sense that it asks us to question certain aspects of ourselves on a philosophical level. Questions such as who are we without our memories? how does that affect our identity? Through my time at the Foundation I hoped to get a better understanding of where to even begin to answer these questions.

Alzheimer's is a cruelly ironic disease as most clients, while unable to remember my name, could tell me numerous stories of their childhood. In fact one client told me stories of how, when she was just a school girl, she had ridden to around 18 train stations across Sri Lanka due to her father being an engineer in the railways. I was amazed with the accuracy with which she told me this. Talking to the clients, I came to terms with the fact that they repeated and recycled information or certain questions. One client repeatedly told me about how he got his doctorate from Sorbonne University in Paris as well as how his mother had blue eyes and fair skin.

I experienced the worst part of the disease when clients were deluded or had forgotten basic information such as whether someone was coming to pick them up. For example, one client who was previously a doctor told me that she had to go to work while another client stated that she needed to go home to take care of her mother. In addition to this I frequently had to reassure clients that someone was in fact coming to pick them up. It was honestly very sad to see these clients brought to tears as they were scared that they were abandoned. I had to make many an excuse, which ranged from the simple explanation that there was traffic to a more complex tale of running errands, until they were picked up. While many of these issues were prevalent, I do not wish to propagate a stereotype that entails that all dementia patients are like this. In fact, it's quite the contrary. Depending on the extent to which the disease had progressed in the client, I saw a spectrum of symptoms in the individuals. Some clients were so far along that I could not hold a conversation with them while some clients were so lucid that it was surprising that they had the disease. This reiterated in me the value of screening; if caught early with the use of a variety of therapies the disease's progress could be hindered.

A typical day at the Foundation could only be described as meticulous. This is thanks to the dedicated volunteers who ensure that each day follows a schedule of planned activities followed by a sing-a-long. The activities range from coloring a picture to doing a word and spelling activity using a projector to display images on the wall. Most of these activities were designed and carried out in such a way that it engaged clients by causing them to ask questions and interact with the volunteer staff. However, the real magic happens during the sing-a-long. Words fail to describe the difference in the client's moods, attitudes and faces once a song like "You Are My Sunshine" is played on the piano. The impact of music therapy truly struck me when one lady, who was in the advanced stages of the disease and unresponsive to my efforts to talk with her during the activities, literally came alive when the music was being played and even went on to sing. It's truly amazing to see the power that music holds on the human psyche as most of the clients, whilst unable to tell you what they ate in the morning, could recite whole poems and songs from long term memory.

However, behind all the psychology, neurology and science in general that underpin these therapies one factor is essential. The absence of which would render the therapies useless. The factor that I am referring to is the people that orchestrate the therapy. Through talking to the clients, a question that I frequently asked them was whether they were happy. The answer to which was a resounding 'Yes' was always followed by - "the people here are good". In fact, one client who loves to roam around and sing during the singing told me, "The only reason I get up and sing is because I love the people here". This statement is important as it highlights the reason that clients keep coming back each week. It is the reason that they smile, laugh and stay engaged during the activities. Ultimately it is the reason that slows the progression of the disease and gain those extra few seconds, minutes or hours with their loved ones while they are still lucid.

In conclusion I believe that the work being done at the Foundation is positively impacting many lives and until the cure for Alzheimer's is found, will be a beacon of hope in the fight against this dreadful disease.



People with dementia often have issues with sleep with their memory seemingly worse after a bad night. However, the evidence is unclear on whether poor sleep is a risk factor for dementia.

The relationship between dementia and sleep

Sleep and dementia is a complicated topic. Different types of dementia are associated with different sleep problems. Researchers are also not yet sure which way the interaction goes - whether poor sleep causes or exacerbates dementia or if dementia leads to poor sleep. Some researchers believe that both of these theories could be true, and the relationship could be circular.

On top of this, it is unclear what the mechanisms are that underlie these interactions. It is clear that more research is needed to understand this relationship; in particular research that observes large groups of affected people for very long periods of time.

Different types of sleep disorders

- **What are light sleep disorders?**

Light sleep disorders are often called rapid eye movement sleep behaviour disorder (RBD), and cause people to act out their dreams through moving or talking in their sleep.

Dementia with Lewy bodies and Parkinson's disease seem to be particularly associated with light sleep disorders and some studies have suggested that light sleep disorders are a very early indicator of these conditions, particularly in older men. Some researchers believe that the part of the brain that is damaged with dementia with Lewy bodies or Parkinson's disease also plays a role in light sleep, explaining why people with these conditions are particularly affected by light sleep disorders.

- **What are sleep-wake cycle disorders?**

The sleep-wake cycle is the 24 hour cycle that the body goes through each day, normally ensuring that we are active during the day and sleepy at night. When this cycle is altered it causes many unusual and disruptive sleep patterns. These include wakefulness at night and problems falling asleep and staying asleep, as well as drowsiness and napping during the day.

These sorts of sleep disturbances are associated with many kinds of dementia, most notably Alzheimer's disease. They also affect people with Parkinson's disease.

This has led to the suggestion that improving sleep quality may have the potential to delay progression of Alzheimer's. However, it is also possible that the changes to the sleep-wake cycle are caused by other changes in the brain, and do not have an impact on risk of Alzheimer's.

- **What is sleep disordered breathing?**

Sleep disordered breathing is when someone has difficulty breathing when they are asleep. This may be because of obstructions to the airway, making breathing harder work. Sleep disordered breathing is sometimes called sleep apnoea. People of all ages can be affected by sleep disordered breathing, but it is most common in older people and people with obesity. Some research has suggested that people who are affected by sleep disordered breathing may be at higher risk of cognitive decline or impairment. This is because sleep disordered breathing may cause damage to the brain due to changes of levels of oxygen and carbon dioxide in the blood. It may also change flow of blood to the brain.

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Treatments for poor sleep

Good quality sleep is linked to good health, including cognitive health. Researchers have also investigated whether there are effective treatments for poor sleep and whether these treatments can affect dementia risk. Some drug treatments for poor sleep, such as benzodiazepines, have been linked to an increased risk of dementia although the evidence behind this link is conflicting. Alzheimer's Society is funding a study into the effects of these drugs on dementia risk.

Many treatments that have been suggested to improve quality of sleep involve lifestyle changes. Regular sleep regimes, eating schedules and diets, exercise, and ensuring exposure to bright light in the morning are all ways that you can improve your sleep quality. However more research is needed to indicate whether these activities have an effect on risk of dementia or disease progression. There is more information in treatment of sleep disorders on the NHS website or you can speak to your GP.

A machine called continuous positive airway pressure (CPAP) has been shown to reduce the consequences of sleep apnoea by several studies. Before this treatment can be used, research is needed to indicate with more detail how to use it, for example how long the treatment should last and what lifestyle changes can be made to help.

There are also several drugs that have been trialed to improve sleep. Some doctors may prescribe melatonin, a hormone believed to be important in maintaining regular sleep-wake cycles. There is some evidence that this treatment does improve sleep quality in people with Alzheimer's disease and Parkinson's disease but so far evidence suggests melatonin does not affect risk of dementia or cognitive function.

A visit by the Soroptimist International Colombo

On the 15th May 2019, 8 members of Soroptimist International (SI) of Colombo visited The Lanka Alzheimer's Foundation (LAF). This visit was initiated by SI Member Beverley Mirando, to coincide with 'Mental Health Week' (13-19 May).

On arrival members were greeted by Ms Lorraine Yu, President of LAF. Ms Yu made a short, but an illuminating presentation which led to a discussion on the history of the Foundation, and the progress made.

The LAF building is purpose built. The members were led on a guided tour of the premises with its beautifully landscaped garden.

There were trained/dedicated volunteers in attendance, interacting with the clients at the Activity Centre (AC). The AC is open on Monday, Wednesday, and Friday from 9.a.m - 3.00.p.m. Services are offered on a no charge basis.

It is a meaningful project assisting those suffering from Alzheimer's and related dementias.



12 biggest risk factors for developing dementia as revealed by WHO

(by Sarah Knapton, *The Telegraph* 14th May 2019)

The 12 lifestyle choices and conditions which fuel dementia have been identified by the World Health Organization (WHO) in the most definitive list ever of how to avoid mental decline in later life. New guidelines based on analysis of decades of research found that physical inactivity, smoking, eating an unhealthy diet and drinking excessive alcohol significantly increased the threat of diseases like Alzheimer's. Medical conditions including diabetes, high blood pressure, high cholesterol and obesity also played a role in the development of cognitive decline and full-blown dementia.

"In the next 30 years, the number of people with dementia is expected to triple," said WHO Director-General Dr Tedros Adhanom Ghebreyesus. "We need to do everything we can to reduce our risk of dementia. The scientific evidence gathered for these guidelines confirm what we have suspected for some time, that what is good for our heart is also good for our brain."

Despite decades of research no drugs have been developed to halt or reverse the condition, meaning the only way to slow down or prevent the disease is through living a healthier life. Yet although dementia is now the UK's leading cause of death, only one third of adults recognise there is anything they can do to reduce their risk of the condition.

Under the new guidance, over 65s are advised to do at least 150 minutes of moderate exercise per week as well as muscle strengthening activity. Along with smoking and high blood pressure physical inactivity in middle age was found to be one of the biggest risk factors for developing dementia. The guidelines also included adoption of a Mediterranean or balanced diet which includes 400g of fruit and vegetables a day, less than 10 per cent of energy intake from sugar and less than 30 per cent from fat. However the WHO report said there was no evidence that dietary supplements such as B vitamins, antioxidants, omega-3 or ginkgo biloba helped stave off dementia. Instead experts encouraged people to partake in activities that exercise their brains, and get as much social interaction as possible.

Dr Carol Routledge, Director of Research at Alzheimer's Research UK, said: "With a rapidly ageing population in the UK and across the world, many people are keen to know the steps they can take to enjoy their later years in good health. "The findings clarify what we already know about dementia risk, including the value of physical activity and not smoking. Sadly, there will always be individuals who address many or all of these risk factors and still develop dementia.

"Genetic predisposition plays an important role in many people's risk of diseases like Alzheimer's, and while we cannot change the genes we inherit, taking the steps outlined in this report can still help to stack the odds in our favour."

Commenting on the research Robert Howard, professor of old age psychiatry, University College London, added: "The guidelines are based on a comprehensive and carefully conducted review of the published literature and are sensible but unsurprising. "Keep on doing the things that we know benefit overall physical and mental health, smoking cessation, reduce harmful alcohol drinking, treat hypertension, eat a healthy balanced diet and lose weight if you are obese."

12 Biggest Risk Factors:

- Smoking
- Excessive alcohol intake
- Unhealthy diet
- Hearing loss
- Social isolation
- Mental inactivity
- Obesity
- Diabetes
- High blood pressure
- High cholesterol
- Depression
- Physical inactivity

Carers - Looking after yourself



As a carer for a person living with dementia, you may experience a range of difficult emotions. Looking after yourself – and learning to deal with challenges – means you will be in a better position to continue to care for the person affected. The needs of the person you care for will often come before your own, and this can mean that you don't look after yourself properly. You might feel that it is not always possible to make time for yourself, but it is important for both you and the person with dementia. Looking after yourself – and learning to deal with challenges – means you will be in a better position to continue to care for the person with dementia. Keeping yourself healthy – physically, mentally and emotionally – can also help you to have a better relationship with them.

Your health and well-being

Caring can have a big impact on your mental and physical health and well-being. It is important to look after yourself well so that you can continue to care for the person with dementia.

Try to eat a well-balanced diet, with at least five portions of fruit and vegetables every day. A healthy diet will be beneficial for the person you care for too. Taking regular exercise is good for your health – both physical and mental. You could try going for a walk or taking up an exercise class, or doing a crossword for example. Whatever you choose should be fun and something that you want to do.

Try to get enough sleep. Sleep is very important as it helps the brain and body recover from fatigue. It can be difficult if the person you care for has disturbed nights. You may find it easier to sleep when the person you care for is sleeping, and may be able to take advantage of daytime naps.

If you have to help the person you care for to move around, be careful of your back. Speak to your GP for advice. See your GP on a regular basis to check up on your health.

If you are struggling to cope or feeling depressed, anxious or stressed, talk to your GP. There is help available, such as counselling or extra support services. These problems are easier to manage if you do something about them at an early stage.

Consider using technology to help you in your caring role. This could include using the internet to help with online banking to pay bills, or shopping online to buy groceries.

Taking a break

It can be difficult to find time for yourself when you are caring for a person with dementia. You may feel guilty about wanting time alone, but it is important for your own well-being. When you do manage to get time to yourself, you may want to use it to catch up with other tasks such as housework or managing finances. However, taking breaks and continuing to do things that you enjoy can help you manage your caring role. This could include having some 'time out' during the day to do a crossword or go for a coffee.

Many people find that taking the time to pursue things they enjoy helps them with their caring role. By taking regular breaks you may find yourself better able to support yourself and the person you care for. Time apart can also be good for both of you and can make you both feel better.

You don't have to take long breaks from caring, but a short time to enjoy yourself could make a lot of difference. Try to make time for something you enjoy every day, whether it is on your own or with the person you care for. By having a break, the person with dementia may also get to experience new things and have a change from their routine. Types of break might include:

- taking the time to sit down and have a cup of tea, read the paper, listen to music, or go for a walk
- going out for a coffee or drink. meeting a friend or going shopping
- pursuing interests, hobbies and activities that you find enjoyable
- having a short holiday, whether it is a few days or a week.

“World governments still failing to tackle the increasing growth of dementia”- Alzheimer’s Disease International (ADI)

A news report by ADI reveals that, on the second anniversary of the World Health Organization (WHO)'s Global action plan on the public health response to dementia 2017-2025, only 18 percent of WHO Member States have national dementia plans, a shortfall of 120 plans.

Geneva, 21 May 2019 – World governments are failing to address the dementia crisis according to a new report out today from Alzheimer’s Disease International (ADI). On the two-year anniversary of the World Health Organization (WHO)’s Global action plan on the public health response to dementia 2017-2025, the primary target to have 146 of the 194 Member States develop a national response plan to dementia, is falling further behind.

Globally only 31 national plans exist, including just 26 WHO Member States, while up to 34 are in development. In the last two years only two countries (Chile and Qatar) have created plans, meaning at the current rate the 2025 target will not be reached.

“Two years on from the commitment made by 194 countries at the World Health Assembly, the pace of progress is still too slow. World governments must recognise the crisis we’re facing now and proactively work to ensure they’re prepared for the dementia emergency at a national level,” said Paola Barbarino, CEO of ADI. “Some governments are doing well, creating, funding, deploying and monitoring plans that are world leading and can inspire other, including Japan, South Korea, England and Scotland, but it is not enough. National plans on dementia take time to develop and are essential in achieving the tangible actions required to improve the lives of people with dementia, their families and care partners.

“We are seeing development in key areas like risk reduction research, however, the search for disease modifying treatments continues to be underfunded and the application of better care interventions remains elusive. In the meantime millions of people living with dementia and their families are under terrible strain.”

The recommendations come from a report by ADI, which was released at its official side event to the 72nd World Health Assembly, “Why we all need to do more: Examining the seven action areas of the Global action plan on dementia” on May 21 in Geneva. In 2017, the WHO adopted the Global action plan on the public health response to dementia 2017-2025 at the 70th World Health Assembly. The first target in the Global action plan is for 75 per cent of WHO’s 194 Member States to have developed or updated national policies, strategies, plans or frameworks for dementia by 2025.

08 Warning signs of Dementia

- Show difficulties with language
- Experience significant memory loss
- Be disorientated in time
- Become lost in familiar places
- Display difficulty making decisions
- Lack initiative and motivation
- Show signs of aggression and depression
- Show a loss in interests and hobbies

If you are experiencing these symptoms or know of someone who is, talk to a doctor or call us on (11) 2667080 and make an appointment for a Free Memory Screening

The silent epidemic: Dementia's global impact

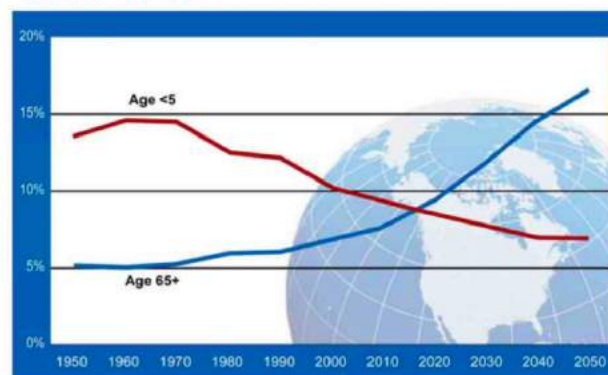
Nearly 50 million people globally are living with dementia. The condition strikes so often, so arbitrarily, and with such little warning that many have dubbed it the Silent Epidemic. Most of us are familiar with the most common type of dementia, Alzheimer's disease. Other common forms of dementia are less known but equally destructive: vascular dementia, frontotemporal disorders, and Lewy body dementia, the form of dementia Robin Williams was diagnosed with after his death.

At an individual level, dementia affects everyone it touches: the person diagnosed, their loved ones, caregivers, family, and friends. At the global level, dementia takes an equally exacting toll. This article is the beginning in a series of articles focused on this devastating condition.

The number of people with dementia is expected to double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050. The main driver of these increases is demographic change. People in rich and poor countries alike are living longer and longer lives. At present, the global population of people 60 and older is growing faster than any other age group. The number of people over the age of 60 is expected to more than double by 2050 and more than triple by 2100. While dementia is not caused by aging, it is much more prevalent among older individuals compared to the young.

Across the board, countries and communities must begin to bear an increasingly heavy burden of costs for dementia care and treatment. Dementia is a complicated disorder and providing high quality, integrated, and affordable care is a challenge for any country. Because of these challenges, people living with dementia often receive fragmented and uncoordinated care that does not properly address their needs or the needs of friends and family who care for them. Even the initial step to treatment – diagnosis – is out of reach for most. The vast majority of individuals with dementia have not been diagnosed or, like Robin Williams, they have been incorrectly diagnosed and the dementia is only properly diagnosed posthumously.

Young Children and Older People as a Percentage of Global Population: 1950-2050



Identification Bracelets - "Get them home safe"

A patient with cognitive impairment who wanders outside alone can easily become confused, injured and even die from exposure to harsh weather and other safety risks. The survival rate drops dramatically from 93% in the first 12 hours to 33% in 24 hours

An identification bracelet can help a loved one with dementia get home safe.

Hypoallergenic, Waterproof, Tamperproof ID bracelets

are available at

The Lanka Alzheimer's Foundation

Inquiries Call 0112667080/ 82

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

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

The Board:

Lakmali Cabral, Yasmin Cader (Secretary), Priya Fernando, Lilani Jayasuriya (Treasurer),
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**PLEASE SUPPORT THE WORK OF THE FOUNDATION
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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 NDBSLK LX

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