Chairperson's Message

The silver jubilee year of ARDSI started with a hugely successful awareness campaign ‘Ormakkootam’ in Kerala. Conducted under the aegis of the Kerala State Initiative on Dementia, the weeklong event was held in all the districts of Kerala by staging the play ‘Achan’ by Sri. Shivaji Guruvayur and his troupe. It was a beautiful and moving drama of an elderly person being cared for by his servant. The valedictory function in Trivandrum was graced by Smt. Shylaja Teacher, Minister of Health and Family & Social Welfare. I would like to commend our staff in Kerala led by Maj Gopalakrishnan who meticulously planned and executed this campaign to create a dementia friendly Kerala.

This issue of the newsletter is a special edition dedicated for younger persons with dementia. In India, this topic is totally neglected, even though the challenges faced by the young spouses and children are unimaginable. Unlike the problems faced by adult/middle aged children and family members, when a person in late thirties or forties develops dementia, the family is devastated. Both from the social and financial perspectives, the problems are magnified and there is also loss of income which complicates the situation. So, there is the urgent need to create awareness provide support and specialized services for this category of younger persons with dementia and their families.

ARDSI was well represented at the International Conference on services to the elderly held at Hyderabad on 23rd and 24th February, organized by Heritage Foundation. Dr. Nori Graham from U.K. was one of the key speakers who conducted an interactive session for family members which was much appreciated. The World Health Organization has been mandated to present the draft Global Action Plan on public health response to dementia 2017-2025 at its meeting in May. This will include the existing strategies/plans regarding dementia from all over the world. Our Ministry of Health too will have to submit their plans/proposals. So, the ARDSI National Office considers that this is the most opportune time to advocate with the central government for a national plan and sincere efforts have been initiated by setting up committees and gearing up spade work to bring out a manifesto. The World Dementia Council has transitioned to a Charitable Trust under the Charity Commission of England and Wales and it is my pleasure to inform you that I have been elected to the 5 Member Board of Trustees at the meeting in Paris in February 2017.
The Kolkata chapter is very busy with the preparations for the Dementia International Conference which will also be ARDSI’s 21st Annual Conference. Plans are also on to hold a training workshop prior to the conference. Nilanjana Maulik, Secretary of the Kolkata Chapter will be coordinating this workshop and I request all chapters to extend your full cooperation to make this a successful one.

From the Editors’ Desk

Let us start by thanking everyone who contributed to this special issue focusing on people with young onset dementia; the professionals and the carers. Although dementia is more prevalent among elderly, it significantly affects the younger population as well. Dementia is generally considered young onset when the symptoms start before the age of 65, in fact the symptoms may even start in their 40s or 50s. Sometimes it is also called early onset dementia or working age dementia. This type of dementia strikes when people are at the peak of their productive life with progression in their careers, raising children and supporting their parents. They are generally physically healthy and socially active. The symptoms are often wrongly attributed to stress and even the diagnoses by specialists may be conflicting. The condition is relatively rare, difficult to diagnose and the awareness poor but the burden on caregivers large and impact huge. Hence the often quoted figure of young onset dementia being around four percent of total number of people with dementia is probably a less accurate and under estimation of prevalence. Being perceived as a rare condition it is being neglected as well. Difficulty in acceptance of dementia as a diagnosis in a young person by the family adds to the delay in looking for help.

The genetic predisposition is generally higher than late onset and progression generally faster. However the proportion of reversible and treatable causes are believed to be higher among the early onset group and hence the importance of a thorough work up and diagnosis. People with learning disability and Down’s syndrome are at a high risk.

As there is no cure, prevention and risk reduction strategies are important. Judicious use of medication and psycho social inputs are extremely important. The needs of caregivers may be different from those caring for elderly with dementia. A multidisciplinary treatment approach is essential. The families are young and need support of employers. Carers often find it difficult to engage in any campaign efforts in the middle of their heavy and demanding caring role. The role of family members tend to change with the onset of dementia. The young, active and productive person becomes someone to be cared for while the spouse and children become the carers. Early diagnosis helps in seeking support early. Special emphasis on support of families of those affected often consisting of young spouses and children need to be considered. Psychosocial stressors of young carers are often neglected. Their education, leisure, vocation and future are often affected by their caring role. There should be special attention of the governments and voluntary organizations towards young carers.

Organizing services for people with young onset dementia is challenging even in developed countries. Specialists should be sensitive to the possibility of young onset cognitive impairment to prevent delay in the diagnosis. Once diagnosis is made it is the governmental and societal responsibility to ensure a proper infrastructure for support of people with dementia and their families. Special attention should be given to sensitize the employers to support the employee who has dementia by looking into the possibility of any role change within the organization, use of assistive technology and long term financial support. These would be essential components of a dementia friendly community (DFC).

We thank all the contributors of this special Issue and urge more young people to be patrons of our ARDSI Newsletter for better impact and outcome.
ARDSI NEWS

All India Institute of Speech and Hearing (AIISH), Mysore in collaboration with Department of Psychiatry, MMCRI, Mysuru, Department of Psychiatry, JSS Medical College, Mysuru and Foundation for Research and Advocacy in Mental Health (FRAME), Mysuru organized the ARDSI XXth Annual Conference from 10-11 December, 2016 at Mysore, Karnataka, India. The conference created a forum for clinicians, researchers, academicians and stakeholders to provide a platform for shared learning and better understanding of neuro-cognitive disorders and its impact on quality of life for older adults and their caregivers. This conference identified and discussed areas of research in assessment and management of persons with dementia and related neuro-cognitive Disorders. Further, it helped to build a network of clinicians and researchers from the USA, Australia, UK, Canada and India across various disciplines with shared interest in ageing to improve services for the aged in India.

The conference was inaugurated by Dr. Martin Prince, Professor of Epidemiology Psychiatry, Co-Director, Centre for Global Mental Health, King’s College, London. The chief guest for the inaugural program was Dr.B.Krishnamurthy, Director, Mysore Medical College & Research Institute. Smt.Meera Pattabhiraman, Chairperson, ARDSI, Dr. Jacob Roy, Honorary Vice President, ADI & Dr.Hanumanthachar Joshi, Chairman, ARDSI, Mysuru Chapter were the guests of honour. Dr.S.P.Goswami, Professor and Head, Department of Speech-Language Pathology welcomed the dignitaries and the delegates. Dr. S.R.Savithri, Director, AIISH presided over the function. A total of 291 delegates who attended the conference from different parts of India, UK, Canada, Norway & USA. The participants included Speech-Language Pathologists, psychiatrists, neurologists, clinical psychologists, social workers, physicians, pharmacists, students, care givers and other professionals. The conference was coordinated by Dr. S.P.Goswami, Professor & Head, Department of Speech-Language Pathology, AIISH, Mysuru. Overall the delegates appreciated the conference in terms of the topics delivered by the speakers and arrangements made by the organisers.

Factsheet - Young Onset Dementia.

- Early onset Alzheimer’s Disease (around 30%)
- Vascular Dementia (around 20%)
- Fronto temporal Dementia (around 10%)
- Behavioural variant- significant changes in personality and behaviour
- Language variant- significant speech/or language impairment
- Lewy Body Dementia (around 10%)
- Along with other symptoms fluctuating cognitive functions, difficulties in body movements and visual hallucinations usually prominent.
- Alcohol related Dementia (around 10%)
- With abstinence and support possibly partial or full recovery or less likelihood of progression.
- Other rare causes (around 10%)
- Huntington’s dementia-Cognitive impairment in people with Huntington’s disease
- Posterior Cortical Atrophy-Generally starts with problems of vision eg. Difficulty recognising faces and objects in pictures, problems with literacy and numeracy etc.
- CJD rare condition caused by infectious proteins called prions
- Dementia in Parkinson’s disease
- HIV AIDS related dementia

Note: The figures quoted are approximate from multiple sources

Early Onset Alzheimer’s Dementia- an Overview

Dr Kalyan Seelam, originally from Andhra Pradesh; he is currently a Consultant Psychiatrist specialized in memory disorders and old age mental health and also a Medical Clinical lead in the National Health Service, United Kingdom

Alzheimer’s dementia accounts for nearly a third of the early onset dementias. Age is usually considered as the biggest risk factor for developing Alzheimer’s dementias however in the early onset Alzheimer’s dementias they can be strong genetic linkage – familial Alzheimer’s dementia. It is not clear as to why these people get the disease at a younger age than
Multidisciplinary team. Delaying the progression of the disease as opposed to curing treatment options for Alzheimer's dementia are limited and carried out through a comprehensive medical evaluation by a thorough history taking, cognitive examination, neurological services for people affected by this illness. Accurate diagnosis, management and provision of appropriate other financial commitments.

Some of the symptoms of Early Onset Dementia include:

- Increased forgetfulness
- Forgetting recent conversations & events,
- Forgetting messages or repeating information.
- Increased confusion in unfamiliar surroundings
- Disorientation to place and time.
- Changes in one’s personality and behaviour,
- Lack of interest, feeling low in mood, losing confidence.
- Difficulties in recognizing objects, words & judging distances.
- Difficulty in communication (use of vocabularies)

When visual problems become more predominant the disease may be called posterior cortical atrophy. Early onset Alzheimer’s dementias can present significant challenges in diagnosis, management and provision of appropriate services for people affected by this illness. Accurate diagnoses of early onset Alzheimer’s dementia include: thorough history taking, cognitive examination, neurological examination, carrying out various blood tests to rule out any other physical causes, scan of the brain. These are usually carried out through a comprehensive medical evaluation by a doctor who specialises in Alzheimer’s dementia.

Treatment options for Alzheimer’s dementia are limited and the currently available treatments are mainly geared at delaying the progression of the disease as opposed to curing the illness. The emphasis is more around supporting the patients and their family to cope with the illness by providing psycho education and ensuring that appropriate resources are made available at various stages of the illness by a multidisciplinary team.

Recognizing and Classifying Early & Late Onset Alzheimer’s Disease.

Dr. Vikas Menon, Associate Professor, Dept. of Psychiatry, Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Puducherry-605006

Most people with dementia before the age of 65 years may be having Alzheimer’s disease (AD). However, many families often mention tales of their doctors not considering the possibility of AD as the patients were quite young. It is important that families and clinicians are tuned to this possibility as early identification can forewarn the patient’s support network apart from facilitating therapeutic changes in the family and environmental context.

Dementia refers to a global deterioration in higher mental functions and therefore, typically affects more than one cognitive domain. The first signs of an early onset Alzheimer’s disease are very similar to late onset AD. For details, please refer (http://www.alz.org/10-signs-symptoms-alzheimers-dementia.asp). The mistake that is often made is explaining the symptoms based on stressful events and other recent happenings when these may in fact be a marker for early onset AD. If any of the symptoms are present and there are deficits in activities of daily living such as self-care/work or interpersonal interactions, it is a clear signal that the patient needs further evaluation by a neurologist/psychiatrist. When compared to late onset AD, language and visuospatial dysfunction are as common in early onset AD while some studies report neurological symptoms and psychiatric symptoms as less common.

Delineating prominent memory deficits is central to the distinction between various types of young onset dementias such as fronto-temporal lobar degeneration and early onset AD. Silveri (2007) has noted, while the former is characterized by prominent personality changes and gait disturbances that may even antedate the memory disturbances, memory is not impaired as prominently as in AD.

Other important diagnostic possibilities to be considered include dementia associated with Parkinson’s disease, Huntington’s disease, major depression or bipolar disorder, thyroid disorder, drug abuse, infections of the central nervous system, head trauma, hydrocephalus or brain tumors. Even if the symptoms are due to AD, there may still be treatable causes such as hypothyroidism that are contributing to the problem. Hence, a thorough medical history and examination (both neurologic and psychiatric) coupled with laboratory work-up and cerebral imaging is part of the assessment protocol.
Whether the pathology of early onset AD differs from late onset AD and to what extent it may justify grouping the two together as one disease entity are questions that remain unanswered. On carefully reviewing the evidence, there seems to be a case for viewing early onset AD, at the very least, as a sub-group of AD with possibly different neurobiological correlates and treatment targets that can potentially modify disease process.

In brief, early onset Alzheimer’s disease shares many clinical features and neuropsychological hallmarks with late onset AD. A growing body of evidence indicates that early onset AD may represent a distinct sub-group and this needs further research to identify newer putative treatment targets. The role of the family, who may act as initial gatekeepers, in identifying and bringing such people to clinical attention deserves special mention.

“Ich hab mich verloren”
Ramani Sundaram, Team Lead- Research & Development, Nightingales Medical Trust, Bangalore

This remark in German brought to light a challenging neurodegenerative disease which now has become an epidemic. On 26 November 1901, Ms. Auguste Deter was examined by Dr. Alois Alzheimer. She sat on her bed with a helpless expression and when asked to write her name, she wrote, “Ich hab mich verloren”, which means, “I have lost myself” which succinctly portrays what a person with dementia goes through. The main risk factor for dementia is increasing age. By the age of 65 the proportion of people affected is 1 in 20, increasing to 1 in 5 by the age of 85 years. Although dementia mostly affects older people, it can occur in younger people aged 65 years or less where it is described as young-onset dementia or early-onset dementia. The prevalence of Young-onset dementia (YOD) is relatively low. However it might be an underestimate as the diagnosis usually gets established much later. Few common types of YOD that has been observed are Posterior cortical atrophy, Alzheimer’s disease, vascular dementia and fronto temporal dementia (FTD); FTD is more common in younger people.

Communicating the diagnosis of dementia to the family is a challenging task; it becomes even more challenging when it is early onset. Younger people are more likely to still be working when they are diagnosed. Many will have significant financial commitments. Families usually comprise of old parents, young children and the spouse who has a herculean task of managing the elderly, children and the disease. Carers play an absolutely vital role in the care and support of people with YOD. It is a long journey where they have to hope for the best and plan for the worst. Most of the times, it becomes extremely overwhelming for the spouse to deal with the situation and emotional turmoil for the children to accept the condition. Their lives undergo a paradigm shift from hopes, dreams, and retirement plans to a strenuous journey of caring. Along with the challenges comes fear of inheriting the disease. Most rare forms of Young onset Dementia are more likely to be genetically inherited forms. Questions from caregiver that I usually face are “Will I also get dementia”. Now that is very tricky to answer. Most of the times, I don’t have any explanation to provide to the family members.

Research has shown that lifestyle and vascular risk factors such as hypertension, diabetes mellitus, cholesterol and cardiovascular disease play a significant role in the etiology of dementia. Over the past decades there has been considerable research into developing treatments for dementia. However, in spite of these efforts there is no curative treatment for dementia yet. Epidemiological research has indicated that modifiable risk factors and preventive interventions can reduce the risk of developing the disease.

Drugs prescribed for dementia slow down deterioration but cannot stop the progression. The option left is prevention or risk reduction. There is ample evidence that the onset of dementia can be delayed through risk reduction programs which tackle risk factors such as vascular conditions, lifestyle and depression. Research indicates that these activities can reduce risk to some extent; however, there are no proven prevention techniques for dementia. I have patients with dementia who are highly educated, multilingual, and maintained an active lifestyle. This questions our knowledge about the brain and its function! I am hopeful that with growing scientific knowledge, a cure for dementia is not too far away in the future.

52 year old male, brought to memory clinic for assessment. He was searching something ....I started the assessment by asking his name and where he is what is the date as per the test of orientation. He performed well on all those questions...but something was not all right. The inappropriate crying and laughing... started taking the history from son, the person has 4 brothers and all were suffering from Alzheimer’s. Mother had Parkinson’s. It just made me think whether this person also has AD (Genetic?). I started taking the history but it was not the probable AD type perhaps it was more of FTD type. It all started with Behavioral problems five years back and since then there has been gradual decline in memory as well says the son who is 17.
Social challenges of young onset dementia By Babu Varghese, Previously with ARDSI, currently a Volunteer with Alzheimer’s Australia.

“…. please do not think that I am suffering. I am not suffering. I am struggling. Struggling to be part of things, to stay connected to whom I was once. So, ‘live in the moment’ I tell myself. It’s really all I can do, live in the moment...” Lisa Genova- ‘Still Alice’

There is an increasing global focus on Early Onset Dementia (EOD) with its significant impact on people with dementia and their families. Although the prevalence of EOD is not as high as that of late onset, it poses multiple social challenges for the person and their family. These issues and challenges can greatly contribute to the negative impact of dementia.

Younger onset dementia appears at an early stage in a person’s life, when they are physically and socially active. At the time of diagnosis, they may be in full time employment, and actively raising the family, physically strong and healthy, but they lose their self-esteem and dignity, independence, and get into extreme social isolation due to restriction of daily activities. It is hard to see our dear ones change before us and become a stranger. Apart from the person suffering, all members of the families are affected directly or indirectly as their routines are restricted by looking after the person with dementia. Most often the younger caregiver especially the spouse forgets to live their own life and just live the life of their dear ones. Due to the high dependence of the person with dementia on them, their freedom is curtailed and life paralyzed.

A spouse who takes on the caring role of the person with dementia may also have the responsibility of raising the children and managing finances. Taking up multiple roles at a crucial time is really strenuous. Children also react in a variety of ways when they have to take up unexpected roles at a young age. It may be difficult for them to notice inappropriate behavioural changes in their loved ones and cope with them while they are growing up. These young caregivers are more likely to have longer duration of caregiving which can adversely affect their physical and mental health. Many times family and caregivers are unable to accept the diagnosis and cope with unusual behaviours. This can bring serious changes in the family and social relationships too. With this demanding caring role, they can lose contact with their work colleagues and friends and even relatives may begin to distance from them.

Diagnosis of dementia at younger age can also bring significant financial challenges due to unplanned loss of income if the person with dementia was earning. Sometimes the younger caregiver also loses their job to care fulltime, which in turn trigger the financial tension amidst increasing expenses of care. Attitude of the community is another important area. It can be difficult for other people in the society to accept that a young person can have dementia, especially when no obvious physical changes are seen.

People may come up with various explanations which are often unhelpful or express sympathy towards the family and the person, which is often painful. Even if there is no cure for dementia whether young or old, there is so much we can do to improve the quality of life of those with younger onset dementia through awareness in the wider community. We should understand that life goes on even after a diagnosis of dementia and those with dementia still feel things deeply and want to be treated by people around them just as before the diagnosis.

Caregiver Narratives
My Life Around Bush By Anupama Suresh, Caregiver

My husband at his age of 42, started having early-onset of Dementia. It took more than seven years for us to understand what was happening. As his wife, I used to be in tears every day and night for three months continuously, so was our only daughter who was then doing her degree course and had a very tough time in managing various issues. We were not aware of the name Alzheimer’s disease. We did not even have a vague idea, about how bad and scary our lives would be, going forward.

It was August 2011 when I visited NIMHANS where after all the screening tests, MRI and other tests my husband was diagnosed to have Frontal lobe dementia. By then he was completely unable to remember the dates and started complaining that he was unable to work. He being a banker, had a tough time, at work. He used to travel daily by local bus. I had to arrange transport (auto rickshaw) to take my husband to work and bring him back safely. Even this did not help me for long. It was January 2013 when the auto rickshaw man went to pick him from the bank, my husband was not in his seat. We had to rush around in search of him. I was lucky enough to find him in the regular bus stop from where he used to take the bus. By then he had completely forgotten his daily routines such as how he was traveling, whom he was meeting, where he was going etc and the bank requested that he resigns his job.

Then Nightingales dementia day care came to my rescue. We had to think of alternate option, which was hiring a driver for our car to take my husband to the day care and bring him
back. Once dementia started affecting our daily lives in terms of frequent disorientation, forgetting how to carry out everyday tasks, not being able to perform at work, large scale medical intervention was necessary. This meant more expenses, responsibilities, burden and stress. Acceptance came gradually after multiple failed treatments and worsening situations. Eventually, he had difficulties talking; understanding and thinking capabilities started deteriorating; anger and restlessness started playing a major role. Moral assurance of his abilities played a major role. Our daughter is his priority and securing her future, his greatest concern. Each time she started assuring him that his monetary support helped her with a particular task, this gave him some relief and maintaining a good social environment for a person like him was a difficult task.

It was September 2015, the Centre Manager of Day care started informing me that he keeps screaming that he will jump off from the floor if the door is not opened to go home. He was turning very restless and agitated. One horrible night he had changed completely, became extremely challenging to handle and had to be admitted into a hospital which had made my life even worse. He was in ICU with high sedatives for a week. Being alone I could not see him suffer. He was brought from the hospital and admitted into a residential care center as I could not manage him as his right side of body was paralyzed. After the above episode, I did not have a choice other than putting him into residential care centre - 75 kms away from Bangalore for 1.5 years.

His present condition is such that - speech is 0%, eye sight 10%, walking balance 10%, day to day routine -0% , on diapers from the day I brought him out from the hospital. The food has to be fed by the caregivers. He is passing through the Baby stage (In FTD one will go back to childhood cycle). He keeps biting fingers continuously-causing to drool and fingers damaged. Through personal experience as a care giver, I have doubted myself and my decisions many times. The experience caused me mental and physical stress. Turning to be the sole breadwinner of the family and the primary caregiver was challenging. I grew mentally stronger and my experience through these 15 years now helps me guide others to accept, cope, learn and grow out of the stigma of mental disability.

**Beautiful lady Sujata- By Samir Kumar Chatterjee, Caregiver**

*Write up facilitated by ARDSI, Kolkata.*

My doctor was proud to say that advances in knowledge and diagnostics have made it possible today to identify persons with early-onset dementia much sooner, just like my wife Sujata Chatterjee who was detected with FTD (fronto temporal dementia) at age 51. But, little was I told about the support needs of the family caregivers of these persons. That unmet support needs have resulted in huge difficulty in my caregiving journey. In my journey, it’s the emotional impacts inherent to the caregiving situation that needed most attention.

After diagnosis I was overburdened with grieving and absorbing the shock, rather than coping with her symptoms. During the first year, I watched changes occurring very fast. She was losing her things constantly, which frustrated me. By the end of the first year, I began finding items in odd places. The milk carton would be in the clothes cupboard, or her undergarments in the kitchen cabinets. She would be rearranging her clothes in the wardrobe every hour. Her physical health was still intact and so she had much energy to move around and about. In the third year of her disease I had to resign from my job to become a full-time caregiver for her. Today, she no longer can dress herself. I have to be in the room to pick out her clothes and help put them on. She also forgets where to put her dirty clothes, even though they’ve had the same basket for 30 years.

The hardest thing to accept for me is to see her change from a beautiful, well dressed and articulate lady to a person we often call Wagabond. And, how ironic given the meaning of her name (in Sanskrit, meaning beauty) that her parents had given her and that she portrayed so well until the disease hit her. One of the ways I manage this stage of my life is through a support group with other caregivers. I was apprehensive about this at first but have learned that it makes all the difference. Two things I learned from this support group were to remember: making time to take care for myself and remaining positive and patient with my wife. However, the most important thing that I lost sight of and wish someone alerted me was the support my two young teenagers needed, to cope with their emotions along with myself. I felt they had their own busy life with studies and friends and so their mother’s condition did not affect them as much as it did to me. I was wrong. I was surprised to learn one day when they were invited to join the support group to share their thoughts and they cried, shouted and blamed all for forgetting them. They said, young people like them needed support, if not more support to cope. I urge associations representing people with dementia to design good programs to involve and support young carers with younger parents with dementia.

**Being an Artist’s Spouse**

**Acknowledgement: ARDSI Kolkata**

An artist, reserved, intuitive, intellectual with a fine sense of humour and musical sense, warm-hearted and steady as a bulwark. That was my husband for whom I willingly gave up my unmarried status. Being an artist’s spouse is a difficult one because you are always a first runner-up in his life. But on the whole we had a good life together and that is what I remember when it was my turn to become his anchor. When he was well, I had never bothered about being practical;
banks, finances etc as they were his department. Afterwards, I had to learn it all by myself and now I’m managing. Every morning when I wake him up, his smile gives me hope. A good day. Some warmth seems to transfer to me. He still has a beautiful smile. I know all the twitches of his face muscles. They speak to me clearly, though he has lost his speech. But he comprehends everything and so I’ve become a chatterbox now. Sometimes it’s amazing how I can pull any rabbit (topic) out of my hat (memory box)! My reward is the twinkle in his eyes and the smile. I pride myself in being the only one who can make him smile.

Care-giving, like any other task, is not easy. It requires attention. You have to put your whole self into even saying ‘Good morning’. Anything half-hearted is easily caught out! So when I’m with him, I try to be there without the cell phone, books or other things that distract me. The days I don’t invite trouble. He thrives on music so that is something we are always surrounded with. It is as if we are living on a houseboat in a lake of music. I have learnt how to change his moods with music or to suit the music to his moods. Sometimes we just share the rhythm together. Old songs and old films bring on smiles and I feel good when he shares a knowing smile with me. It’s as if I’ve been invited into his world that is slowly becoming silent despite our attempts.

Our daughters, who refuse to acknowledge that their father is growing old, never fails to lighten up his mood with their warm hugs and loving words. Our older daughter pulls his leg often and he responds. Even now they gang up against me but now I don’t get angry at all! Rather, wait for that rare word or two from him.

Always a handsome man, my daughter’s praise about his looks never fails to make him happy. The man who was least bothered with Looks and what he wore (he got married in a pair of jeans and kurta and a slightly torn pair of sandals) is now pleased if we say, “You look so good in this today!” Naturally I find myself buying new clothes for him on and off.

The rare moments when he appreciates my attempts to keep him happy and safe are now the most treasured moments of our life together. I would like to remember these and forget the punches he delivers during his bad aggressive phases. I keep talking to him and sharing my joys and sorrows with him just as I have always done. I think he understands because of the right expressions at the right time. On all important decisions, I try to share and take his opinion as before though knowing fully well that I will have to take the final decision.

All this and yet nothing significant. Doubts assail me often. Have I done the right thing by him? Even during a recent dark phase when he turned violent and I was feeling really disgusted with life and him, something told me that this will pass. I had to change doctors, medicines and life style. In such times, the only person whom I can always rely on is our counselor, Nilanjana Maulik. Doctors have sometimes not responded to calls and messages but not her. For a caregiver, her observation, advice and suggestions are extremely helpful. What I admire in her is her forthrightness. She is someone who is not afraid to call a spade a spade and that is what makes me rely on her absolutely. She is like a lighthouse and for a caregiver like me her presence in ARDSI, Kolkata is the best support I can have.

Learn to Accept the Way It Is- By Veteran Wg Cdr DP Sabharwal, Caregiver

She was grown-up when I first met her. At 23, she was a smart and beautiful young girl with a post-graduate degree under her belt. I won’t refer to her either as a lady or a woman since these titles were reserved only for those who were married and wore sarees. The unmarried ones, wearing salwar-kameez, were simply called girls in that part of India where I grew-up. She was sweet to talk to, and a good company to have and to spend time with. She was perfect at household work and turned out to be an excellent mother who brought up two sons in the most perfect manner. She was always calm, composed and cooperative and listened to any advice or suggestion. Never ever, she objected to anything vehemently or opposed anything without any solid reason. All this started changing as she grew in years and by the age of 55, she started behaving as never before.

She would no more listen to reasonable talk and would refuse to obey anything whatsoever. She won’t open her mouth to have the morsel of food to be put in her mouth. She would close her mouth and not allow her teeth to be brushed and would refuse to sit on the pot when taken to the washroom after she had indicated that she wanted to relieve herself. She won’t sit quite for even a minute when there were guests in the house who had come to meet her. She would lock her arms and would not allow for the shirt or the blouse to be changed...and so on. She would keep muttering and uttering non-decipherable words for hours together. She would butt-in and try to interrupt anybody and everybody when they were talking. To put it mildly, she would not listen to anything. By now, you would have guessed, the girl and the lady in question is my wife!

 Needless to say, she was behaving like a small child who generally is stubborn, obstinate, inflexible and unmanageable; and would not listen to any command or instructions. To begin with, I was patient as one is generally with a child, but then as the days changed to months, my patience started dwindling. I started becoming tense, irritated, irksome, and exasperated. This added mental tiredness and exhaustion to the already physically taxed body.
I started looking for help and guidance, which came in the form of a sentence which read, ‘An Alzheimer patient does appear and behaves like a child, but the similarity ends there. A child's brain grows and develops with the passage of time, but that of an Alzheimer patient's diminishes with every passing day. Therefore to expect any reasonable behavior would be foolish.’ The sentence changed my life and me. I became more reasonable, less demanding and least expecting. Calmness descended on me though the daily grind became more and more difficult as I accepted the reality that ‘she would not listen, because she is in no condition to listen.’ I have to accept her the way she behaves and have to tune myself to her way of life. The four years after this realization have passed-off rather comfortably. My advice to all caregivers is simple: Just accept the way he/she is. Don't expect or try to change the patient. He or she can't, but you can; and there lies the peace and comfort for you, a thing, which is always in short supply for the caregivers!

**ARDSI HYDERABAD DECCAN- Raising History of the Chapter**

Established in November 2008, ARDSI Hyderabad Deccan was begun by neurologist and dementia expert Dr Suvarna Alladi and leading psychiatrist Dr K Chandrasekhar along with Ms Rukhsana Ansari, Ms Bala Tripura Sundari and Shashidhar K – all carers. Registered as a society in August 2009 (Registration No: 561/900/2009), since inception ARDSI Hyd-Deccan has been extensively involved in information dissemination, publishing brochures and an array of services such as support groups, patient and family counselling, running of day-care and home visit services, dementia training workshops, etc in and around Hyderabad. ARDSI-Hyd Deccan has developed partnerships with several leading hospitals such as Nizam's Institute of Medical Sciences (NIMS), Asha Hospitals, Yashoda Hospitals, and several non-profit organizations like Pain Relief and Palliative Care Society of India, HelpAge and COVA among others. It has been awarded the AP State Award for institutions working for spreading knowledge and information in the field of ageing (Alzheimer's and other dementias) for the year 2010. The Chapter runs a full time dementia Day-care and Memory clinic at the Zeba Bashiruddin Centre for Healthy Aging, which is one of the first of its kind in the city. The activity centre provides daily structured programs in a community setting with activities, health related, rehabilitation services and person-centred cognitive stimulating activities for persons with dementia.

Since the origin ARDSI Hyderabad Deccan has conducted events to promote dementia awareness in the society through various media. To date, 44 public awareness programs, 62 care-givers sessions, over 600 family counselling sessions, over 2000 dementia assessments at various memory clinics and over 200 home visits for dementia counselling have been successfully conducted.

To date 19 training programs have been conducted covering various aspects of dementia and dementia care. This includes one month Certificate Course in Basic Issues in Geriatric Care in 2010, Bedside Attendants Training in 2009, one day workshop for physicians in 2010 which was attended by over 100 medics, teaching course in cognitive neurology, multiple one day sensitization for caregivers and NISD training programmes. Internship programs are offered for graduate and post-graduate students who are interested in understanding the different dimensions to dementia care.

The Chapter has enthusiastically celebrated World Alzheimer’s month each year. Memory walks received overwhelming response from Hyderabad city. On occasion of WAM 2013, the international award-winning documentary on Alzheimer’s dementia ‘Bicycle Spoon Apple’ was screened. It also features the services offered at the Memory Clinic, Department of Neurology, NIMS Hyderabad, as part of
different medical organisations throughout the world dealing with dementia. In 2014 a world-class puppet show “The Lady in the Mirror” story written by psychologist Amulya Rajan captured the multitude of challenges families face, and how they cope with them.

As part of WAD-2015 celebrations, in association with Sanskar screened an award-winning movie on dementia ‘Astu- so be it’ by Padmashree Mohan Agashe. In 2015 the global leadership team of Neuroscience Franchise constituting Dr Alexandre Joyeux, Franchise Head Neuroscience, Novartis Pharma, Switzerland and Dr Deniz Simsek, Associate Director, Health Economics & Outcomes Research (HEOR) – Neuroscience, Novartis Pharma, Switzerland visited the ARDSI-Hyderabad Deccan activity centre for a session with ARDSI- Hyderabad Deccan executive member Dr Jaydip Ray Chaudhuri and ARDSI-Hyderabad Deccan psychologists. Speaking of the latest events, a painting competition and art exhibition was conducted in September 2016. Memory Ride, a bicycle ride was conducted to spread the awareness of dementia, in association with Cycling India. A three month Music therapy was observed at the day care for people with dementia and their caregivers by Ms Nina Cherla. The Chapter also has an ongoing study on the effects of person-centered plan on people with dementia and caregivers.

‘Ormakoottam’ – Dementia Awareness Campaign In Kerala

Directorate of Social Justice (DSJ) jointly with Kerala Social Security Mission (KSSM) and ARDSI executed Dementia Awareness Campaign titled ‘Ormakoottam’ (gathering of memories) which started from Kasargod on 27 January and included the drama ‘Achan’ (father). The inaugural function was presided over by Smt. Beefathima Ibrahim, Chairperson Kasargod Municipality. Hon. Kasargod MLA, Sri NA Nellikkunnu inaugurated the function. Mr. Devidas, Dy. Dist Collector (RR), delivered the key note address. Mrs. Meera Pattabiraman, Chairperson, ARDSI presented a brief report on KSID Project – ‘Smruthipadham’ which is in progress in collaboration with DSJ, KSSM and ARDSI since 25th Sep 2014. The Chairperson reported on the work so far which includes a full time dementia care centre at Edavanakkad in Ernakulam district,a dementia day care centre at Kunnamkulam in Thrissur District and about the three proposed dementia care centres at Thiruvananthapuram (Vakkam), Alappuzha (Cherthala) and Kozhikode (Velimadukunnu) during the current financial year. The Chairperson noted that Ormakkoottam campaign is a novel attempt at creating awareness by staging a drama ‘Achchan’ with the aim of encouraging Keralites to become dementia friendly.

The campaign comprising ARDSI staff led by Major Gopalakrishnan KP (Rtd), National Coordinator and the drama troupe travelled through all the 14 Districts of Kerala. Hon. Kasargod MLA flagged off the campaign

The valedictory function of Ormakkoottam was organized in Thiruvananthapuram on 2nd February 2017. Smt. Shylaja Teacher, Hon. Minister for Health, Family Welfare and Social Justice was the Chief Guest to formally inaugurate the function in the presence of several distinguished guests, hosts and a wonderful gathering of audience including NSS Students from local colleges.Mrs. Anupama TV, IAS, Director DSJ welcomed everyone. Hon. Minister in her inaugural address congratulated ARDSI for the successful organization of Ormakkoottam. She specifically mentioned about conducting a survey in the society by utilizing the services of Anganwadi Teachers/Asha workers who have direct contact with all families in their area to assess the number of people living with dementia and to generate reliable statistics for planning and execution of result oriented schemes. Adv VK Prasanth, Mayor Thiruvananthapuram Corporation did the presidential address. Chairperson, ARDSI stressed the need to start Memory clinics in all government District and Medical College Hospitals. ‘Achan’ drama written and enacted by Sri Sivaji Guruvayur has sent a clear message to the society that people living with dementia require full support and love from everyone particularly from close relatives and their family care givers. Dr Mohammed Asheel, Ex. Director, KSSM spoke about his experience in developed countries where elderly people living with dementia are very well looked after by the government. Smt. Sundari, Asst. Director, Social Justice mentioned about efforts to start a dementia care centre in Thiruvananthapuram district by end of Feb 2017 who also delivered the vote of thanks.Prof. Robert Mathew, President ARDSI TM Chapter graced the occasion with his presence. Mrs. Meera Pattabiraman, Chairperson and Mrs. Vidya Shenoy, Secretary General, ARDSI jointly released the ARDSI Silver Jubilee logo.
K Chittilappilly Foundation (KCF) Awards for Excellence in Social Service 2015-2016

In response to KCF press advertisement inviting nominations for Awards for Excellence in Social Service for the year 2015-2016 ARDSI submitted a nomination describing service rendered by the organization in the field of dementia, its recognition at national and international levels (ADI and WHO) and numerous achievements to its credit since its inception in 1992.

Taking into consideration the exemplary work done by the organization in the field of dementia, ARDSI was short listed for the awards by KCF selection committee and was extended a special invitation to attend the award presentation. On behalf of the ARDSI Chairperson, Mr Thomas Cherian, Treasurer received a certificate of appreciation in the form of a memento from KCF Chairman Sri Kochouseph Chittilappilly in a well-organized function at The Renai Hotel, Kochi on Tuesday 21st March 2017.

Dementia: Together towards a new era

Alzheimer’s Disease International (ADI) and Alzheimer’s Association Japan (AAJ) would like to invite you to attend the 32nd International Conference of Alzheimer’s Disease International which will bring together all with an interest in dementia from around the world.

32nd International Conference of Alzheimer’s Disease International

26 - 20 April 2017
Kyoto, Japan
Kyoto International Conference Centre

www.adi2017.org
INTERNATIONAL CONFERENCE ON ‘ADVANCES IN DEMENTIA’ & XXIst NATIONAL CONFERENCE OF ARDSI

on
22nd, 23rd & 24th September, 2017
At The Gateway Hotel, Kolkata

Organized by ARDSI Calcutta Chapter
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Avail early bird registrations up to June 30th 2017

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