



ALZHEIMER'S AND RELATED DISORDERS SOCIETY OF INDIA (ARDSI)



**ANNUAL
REPORT
2020 - 2021**



ARDSI REMEMBER THOSE WHO CANNOT REMEMBER

ALZHEIMER'S & RELATED DISORDERS SOCIETY OF INDIA (ARDSI)

(Registered Under Travancore-Cochin Literary Scientific & Charitable Society, Registration Act No. 12 of 1955, S.N. ER 243/93, dated 26th May 1993)

ARDSI is the first AFRO-Asian National Alzheimer's Organisation to receive full membership in Alzheimer's Disease International (ADI).

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Chairperson Message

This has been an extraordinary year with the pandemic bringing new safety norms that now have become a way of life with travel being very restricted. This is the second Annual General Body Meeting we are holding virtually and for the first time, we are unable to hold the Annual ARDSI-CON as planned.

Persons with dementia and their families have been very badly affected by the various lockdowns with access to doctors and care services becoming difficult leading to the sudden deterioration in health of persons living with dementia adding to the stress experienced by caregivers due to prolonged isolation. We do not have statistics about fatalities in this group, but there is ample evidence that the number of deaths amongst the elderly was the highest.

In these challenging situations, I am happy to report that the national office of ARDSI and the chapters rose to the occasion by continuing to provide assistance support and performed well to continue services to families. The initial months after the total lockdown, most support was offered on phone or virtually and wherever possible, essentials were reached to those elderly who were living alone. Our day care services were shut for most of the year, while residential care facilities were functioning with all precautions being strictly followed.

World Alzheimer's Month in the midst of the peak of the pandemic in India gave rising numbers with different states going through various phases of lockdown. Yet, this did not deter ARDSI national office or its chapters from observing WAM and maximum publicity was given to the theme "Let's Talk about dementia".

Technology, the silver lining, helped with extensive use of Webinars, Facebook and other social media as well as television, radio and press to spread awareness on all aspects of dementia, the need for prevention and how to cope with COVID 19 that had severely impacted persons with dementia and their families. The sudden lockdown resulted in challenges of getting medical and caregiving help and difficulties in procuring essentials. But, our volunteers and staff rose to the occasion and provided all possible

assistance to families that they were catering to. The national office kick-started WAM activities with a webinar on Risk Reduction that had an overwhelming response and towards the end of the month, another webinar on Dementia Care Management and Impact of COVID-19 was held to disseminate information on how to cope with the situation and take precautionary measures.

The Chapters excelled in conducting a host of events, mostly using technology and a few programmes with in-person participation and adhering to all safe practices. The Kolkata chapter observed each day of the month with some activity on awareness, performance by school children and artists or by just sharing digital posters. The Bangalore chapter organised a 'United For Dementia' campaign and also launched a mobile app called DemKonnnect to support families. The Mumbai Chapter had innovative campaigns with poster series like COVID Contemplation and 'Be Their Memory, Be There For Them' and also released a touching film, 'A Call To Remember' besides a daily event throughout the month. The Hyderabad chapter held a host of webinars highlighting how to engage persons with dementia during the lockdown, policy planning and way forward.

The observations of all chapters of ARDSI were commendable from the Mizoram Chapter's television programme where a caregiver shared his experiences, Kottayam Chapter's fond remembrances of Dr. Jacob Roy, Mysuru Chapter's innumerable webinars and the memory walk, to the live call in Television programme by Trivandrum chapter. The various centres of the national office also held



a variety of activities using technology and social media. I had the privilege of being invited to do live show on Doordarshan commemorating World Alzheimer's Day and also a webinar conducted by the Press Information Bureau of Tamil Nadu.

The STRiDE research project is progressing well. Though there was a slight push back in the field studies due to the

lockdowns, preparations for the Work Package on Unpaid Care have made good headway. The analysis work on the Work Package on Stigma has been completed and will throw up some useful data. Excellent progress has been made in the development of vignettes and care pathways. I must mention that the entire research team working in unison has been the reason for the smooth and great progress of the project.

The Kerala State Initiative on Dementia project is proceeding well under these testing times. The residential care centre at Edavannakad is continuing without any interruptions with maximum precautions and, fortunately, the pandemic did not affect this centre. The day care centre under this scheme had to be suspended. A virtual meeting was held with the Director and officials in the Ministry of Social Justice and it was decided to convert the day care service to home-based care until the restrictions are removed.

The National training centre at Trivandrum had to be shut down as travel was not permitted. But, within no time, we shifted to the virtual mode of providing training and we have been conducting regular training programmes both for family and professional caregivers.

I must submit that financial commitments increased because of the necessity of purchase of medical equipment's like oxygen cylinders, PPEs, sanitizers, etc. And at the same time, our income decreased because persons were not attending the day care facilities or taking part in training programmes. But, rent for these premises is still being paid. So, it has been a challenging year even financially. But, thanks to the sincere efforts of our staff and the Governing Board Members, we were able to tide over the crisis.

The three-year grant from the Van Otterloo Foundation comes to a close this year. I should place on record the support and solidarity of those associated with the grant through regular zoom calls, motivating and encouraging us to carry on with our work. They have also kindly agreed to extend the grant for a further period of one year to help us bridge the gaps and sustain our activities.

Finally, let me conclude by conveying my appreciation to all members of the ARDSI family for the resilience shown and coming up with innovative and meaningful ways of providing solace and support to the families of persons living with dementia.

Meera Pattabiraman

ARDSI BENGALURU CHAPTER

Covid-19 posed several challenges to people with dementia as well as those working with dementia during the year 2020-21. With Day care centers closed and restrictions on elders' movements, family caregivers found it difficult to keep their wards engaged. The lack of awareness about this growing epidemic and the social stigma attached to it prevented the caregivers from seeking support. In India, with almost negligible support from the government, family members had to bear the stress of constant care and attention through the pandemic. Professional and trained caregivers are hard to find and institutional care support systems are also woefully lacking.

In spite of many hurdles, the Bangalore Chapter strived hard to create necessary awareness about dementia and build appropriate care systems for the patients and the caregivers. Due to COVID 19, we could not facilitate a meeting for the members of our society but planned various events to raise awareness and draw the attention of policy makers and the public to this emerging epidemic.

Subsidized Dementia care program aims to help under-privileged people with dementia by subsidizing the cost of medicines and dementia rehabilitation facility. The Chapter supported 16 patients during 2020-2021.

September is World Alzheimer's Month. Its impact is growing, but the stigmatisation and misinformation that surrounds dementia remains a global problem that requires global action. This year with Nightingales Medical Trust and we organized #UniteForDementia campaign to unite families of dementia patients, medical professionals, policy makers, researchers and all those who are concerned about dementia to build appropriate support systems/ programs for the patients and their families.

We had to limit our reach due to pandemic restrictions. Throughout the month series of events were planned to unite people for this cause. For the first time, We partnered with Red FM Bangalore for a 6-day campaign of Radio



World Alzheimer's Month
Bangalore | September 2020

#UniteForDementia



For more information and to register please log on to
www.unitefordementia.in



promotion on #Unite for Dementia# to take progressive steps of uniting all towards making Bangalore a dementia friendly city, the main framework for this year's campaign. We planned to #Unite through Music, #Unite through Dance, #Unite through Art, #Unite to Learn, #Unite to care and #Unite to Communicate.

September 21st, is observed as World Alzheimer's Day and programs are organized all over the world to raise awareness, remove the stigma and build appropriate support systems for dementia. A public event was held at UB city Mall, Bangalore where over 50 family carers, medical professionals, researchers, students, volunteers and media representatives gathered together to Unite for Dementia. Formation of a human chain with people holding placards and messages about Dementia and sharing of experiences by family carers was its highlight.

The Dementia Friends program is a global movement started by the Alzheimer's Society of England and Wales whose objective is to change the way the world thinks, acts and talks about dementia.

We added close to 365 Dementia Friends between April 2020 and March 2021. Due to the pandemic online sessions were conducted with RV Nursing College, Life

Science Department of Mount Carmel College, St Clare College and St Anne's College. The chapter also scheduled Dementia Friends Sessions for Deutsche Bank, Hear It Out, Volunteer for a Cause.

To reduce the spread of the virus during the pandemic, day care services were temporarily suspended in compliance with government regulations across cities. Having realised that the persons with dementia are more vulnerable to complications of COVID-19 infection due to comorbidities and face additional problems in accessing healthcare services a number of support Group meetings and webinars were organised. The sessions were informative, well appreciated and recorded 25-30 attendees.

An expert talk by Dr. Anitha was planned "On Understanding Dementia" which was an open forum of discussion for carers, students, Medical professionals and Psychologists to understand more about Dementia on World Alzheimer's Day. On 19th Jan 2021, an awareness talk on dementia by Ms. Wendy Mitchell, Alzheimer Society Ambassador from the UK on "So Much More To Live... Still". was arranged. Wendy was diagnosed with an early onset of Dementia after a stroke. Her never-give-up attitude and determination to live independently was clearly shown during the session as she shared her experience of living with Dementia. We had close to 30+ attendees and the session was appreciated by one and all.

Senior Psychologist, Ms. Sruthi Sivaraman master-trained in Training of Trainers, a dementia care skills training program conducted an in-house three-days training for 14 staff members at Nightingales Centre for Ageing and



Alzheimer's during 2020-21. The training was conducted from 6th June to 8th June and covered various topics like nature and impact of dementia, behavior and psychological symptoms, effective communication and meaningful engagement.

We are thankful to all our committee members, life members and volunteers who have given their time to relentlessly strive towards achieving the objectives. The journey continues as the Chapter strives to work towards a dementia friendly city in the upcoming year.

ARDSI DARBHANGA CHAPTER

Government protocol to be maintained during COVID resulted in suspension of normal classroom teaching in colleges. Our plans to prepare a medical directory of elderly living with varying degree of memory impairment proved a distant dream. Social distancing made it impossible. Members of the family seemed reluctant to permit outsiders to meet their parents and grandparents. Caregivers within family became more possessive of their elders having dementia. Under these compelling



circumstances, regular telephonic communication by the team members was the last resort. Online classes and webinars turned to be a viable alternative and virtual platforms became the preferred choice for academic discussions including those pertaining to elderly care.

After the webinar organized on June 26, 2020, a series of online lectures and interactive online meetings were arranged for encouraging students to pursue elder-centric courses that were offered and later were admitted in allied academic courses. Besides, the proposal received from MFAI, UK to implement webinar-based online course relating to dementia care was recommended for administrative approval by the University. Speaking on the occasion of class induction of P.G. Diploma in Geriatric Care Session 2021-22 on Feb 04, 2021 as invited guests, Prof. Dolly Sinha, Pro-Vice-Chancellor, Dr. M. Nehal, Professor of Zoology and Dr. G.S. Roy, Retd. Professor of Psychology appreciated the time-driven innovative course with potential to generate professional care providers for the elderly, more particularly, those in oldest old age group diagnosed with dementia.

ARDSI GUWAHATI CHAPTER

Presently having 51 Life Members, our goal is now to increase life members, with 9 life new life members already having being enrolled. Three EC Meeting were held in the year of 2020-2021.

The pandemic forced us to close the day care for the major part of 2020. However, team ARDSI Guwahati continued to be in contact with all its members through telephonic or video calls. Presently, taking advantage of therapy are three regular members and four members who take sessions at home. 78 memory assessments, mostly referred by neurologists and psychiatrists from Guwahati were, done in the Memory Clinic. Members now take therapy sessions at House no-10, Rukmini Nagarpath, Dispur Guwahati as our dementia daycare centre has shifted since December 2020.

Since the old age homes had been badly affected during such challenging times, a memory screening camp and distribution of food materials and medicines was done at Helping Hand Old Age Home on 25th January-2021.

A 5-day Dementia Care Skills (DCS) training program was conducted for 26 participants who came from different parts of Assam during February 23-27, 2021 that was aimed at students of Psychology, Social Work and professionals already working or interested in work in the area of dementia care. Experts who were actively part of this Training program viz., Dr. Ajaya Mahanta, Dr Ankumoni Saikia, Dr. Neelakshi Mahanta, Dr. Dipesh Bhagawati, Dr. Siddharth Das, Debastuti Baruah, Mr. Bhaskar Baishya with Mrs. Vidya Shenoy, ARDSI Secretary General, who joined in virtually for a session as well as was an evaluator for this DCS program.

An awareness meeting was organized at Maitri, an organization providing nursing attendants for elderly, on 13th March-2021. Ms. Debastuti Baruah interacted with all

the attendants and trained them on the basics of elder care and dementia care.

Another virtual training program was conducted for a new batch of nursing attendants of Maitri on 28th June 2021.

On World Alzheimer's Day 2020, mind stimulating activities were undertaken and medicines were distributed among people with dementia. Our Team personally visited them on 22nd September 2020 and handed packages and also spent some quality time with them.

Two webinars were conducted for caregivers of people with dementia in which Dr. Ajaya Mahanta discussed some important points on care during the pandemic followed by an interactive session with the caregivers and another where Dr. Ankumoni Saikia and Dr. Dipesh Bhagawati spoke on various aspects of dementia followed by an interactive round with the audience that was attended by all members of the chapter, medical professionals and public.

Like every year, an article by Dr. Ajaya Mahanta was published on World Alzheimer's Day, 21st September, in Amar Axom newspaper.

An internship program was held in which students from the disciplines of Psychology and Social work participated totalling to 11 students from different institution participated viz., two from Assam Don Bosco University, four from TISS-Guwahati, four from Guwahati University and one from Dibrugarh University.

ARDSI Guwahati Chapter is working on a new project of designing a mobile application for elderly that will help them have home visits of doctors, physiotherapists and psychologists

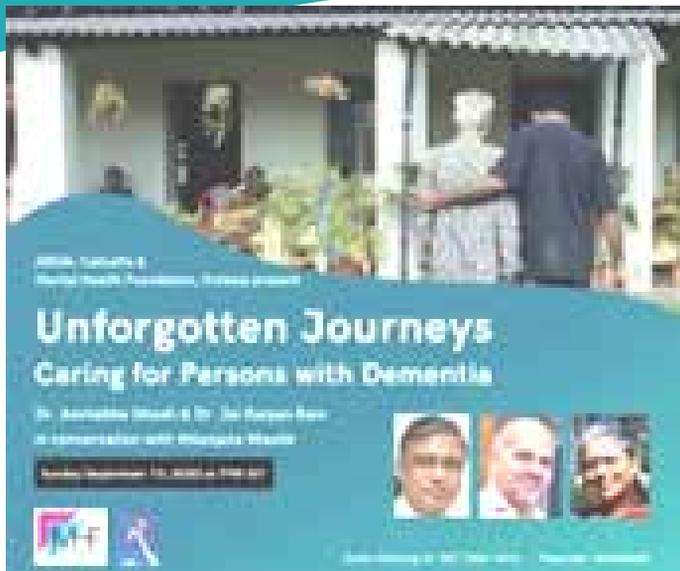
ARDSI KOLKATA CHAPTER

28 awareness programs were conducted through online platforms like Google Meet, Zoom & Facebook that reached around 10,500+ people from housing complexes to clubs, schools, colleges, government offices, consulates, hospitals, and social organizations.

- World Alzheimer's Month 2020 saw ARDSI Calcutta reach hundreds and thousands of people all over the city of Kolkata and in other parts of Bengal and India through online platforms like Zoom, Google Meet Face book and WhatsApp to raise awareness of dementia.
- 38 events were held from 1st of September to 30th of September that ranged from talks, posting digital information, and training family caregivers to using electronic media. Doctors and professionals were involved

in delivering the talks. Sambad Pratidin/Ei Somoy/The Telegraph/Outlook Magazine/News 18/The Huffington Post/The Hindu Business Line covered the events.

- 5 home visits & 16 office visits were conducted that reached family members with care plans & counseling.
- 29 Online Assessments were conducted.
- 27 memory clinics were conducted that treated 179 patients in our Chandannagore campus.
- 548 days home companionship service delivered at the home setting to 13 clients.
- 324 days of daycare service was delivered to 25 clients with activities that ranged from arts, crafts, music, food to everything that triggered all the senses- sight, hearing, smell, taste and touch.
- 13 family caregiver support meets were conducted to



share the caregiving journey
 • 5 Trainings were conducted in the year 2020-2021

TESTIMONIALS

“The limitation of dementia knowledge is a huge handicap. Interpretation of the ailment and dealing with it on day to day basis are poles apart. I count my blessings to have been referred to ARDSI Calcutta. Here, I developed a bank of knowledge and the guidance to fulfill the Care giver role with compassion and care. Thank You Nilanjana Ma’am for being the mentor and sharing to rediscover. I value the relationship and pray for a strong back to shoulder the journey ahead with smiles”!! Family Member “It is the occasion of our annual recognition of ARDSI’s vital presence in the lives of “those who cannot remember themselves”. From ARWIPL, please consider this a small gesture of gratitude for educating us in the care of those who we owe all that we are. On a personal note, being the primary caregiver to my mother living with advanced



dementia in her 90’s, I am indebted to the organization for teaching me not only how to care for her the best I can, but also myself as I do so”. Donor, Director, ARW IPL

ARDSI KOTTAYAM CHAPTER

Covid-19 pandemic helped us make use of web platforms convenient to promote and conduct our Chapter’s WAM 2020 programmes.

With the ADI theme of ‘Let us talk about Dementia’ being the focus this year, well-thought messages in English and Malayalam were widely circulated in social media so as to create more awareness on various sub-types of dementia, early onset dementia, features of dementia, risk reduction, carer support and more. References were taken from comprehensive document, Dementia in India 2020, edited by CT Sudhir Kumar, Dr. Mathew Varghese, Dr. KS Shaji, Dr. MKC Nair, Dr. Sridhar Vaitheswaran et al. We received maximum responses from the message ‘remember there is



a person and a personality behind the dementia'. Importance of creating dementia-friendly communities by identifying available resources in the community and linking them with persons who may need them would make it an ideal beginning with emphasis on approach of asset-based solutions and early onset dementia messages were also well received.

Two major sessions focused on improving awareness of dementia and reducing its risk Sessions were conducted in English and Malayalam, moderated by Dr. CT Sudhir Kumar on 19th September and by Dr. P Ninan Kurian on 20th September. Remembrances of Founder Chairman, ARDSI, late Dr. Jacob Roy was done by Dr. Mathew Kanamala and Mr. KC Varghese, felicitations by children of Dr. K Jacob Roy, Mr. Greg Kuriakose and Mrs. Michelle Mathews. WAD message was given by Dr. PK Ajith Kumar, Secretary, Kottayam Chapter, 'identification and assessment of Dementia' was presented by Dr. KS Rajani and Dr. Mathew Kanamala, 'Prevention of dementia' by Dr. P Ninan Kurian and Dr. CT Sudhir Kumar. Conducted in simple Malayalam encouraged more participation of 170 people with appreciation from Mr. Blessey famous national award winning film director of 'Thanmaatra' of our activities.

Dr. Mathew Kanamala addressed 100 higher secondary students of Little Angel's English Medium School, Chittar



on 'Introduction to Alzheimer's Disease and Related Old Age Challenges' with a writing competition on the best write-up on the said topic.

WAM programmes organized by Devraj Urs Medical College Kolar, Kerala Association of Professional Social Workers, St Joseph's College Moolamattam, Rajagiri College Kalamassery etc. had good participation and social media presence.

An online 10-hour introductory course in Dementia titled "Dementia and Alzheimer's Disease Understand, Care and Support" was conducted from November 14-28 with 45 delegates in attendance. Every month, either third or fourth Saturday, an online caregivers meeting was conducted with attendance from all over India.

ARDSI MIZORAM CHAPTER

To mark the World Alzheimer's Month, a song composed by the President, Dr. Vanneihluanga (whose mother lived with Alzheimer's) was released in memory of and included those who had passed away. From this year (2021) onwards, Alzheimer's awareness message is to be read out at the funeral of any member who died of Alzheimer's disease, whilst the Chapter's condolence wreath is placed on the coffin.

World Alzheimer's Day was observed on September 21, 2020 with a TV Talk Show by the Chapter's caregivers. As desired by the Registrar of Firms and Societies, Accounts of the Chapter need to be audited by the identified auditor of Account & Treasuries, Govt. of Mizoram. The Chapter's Annual Reports and Audited Accounts for three years were submitted as this will be practiced every year. The Secretary represented the Chapter by attended the online meeting of the Annual General Body of ARDSI National on 01.11.2020.

Two Targeted Intervention (TI) Mental health counselors sponsored by the Chapter attended Dementia Care Skills Training organised by ARDSI National Office. The MOU with NMHP for running the TI program was renewed. The Chapter's Office houses the Counselling Centre and a Monthly Report is submitted regularly to the NMHP. In the 3-Day Review Meeting-cum-Refresher Training for NMHP Staff, the Chapter President was called to give a report as an NGO TI (Targeted Intervention) under the NMHP and was awarded the Best TI Award.

Chapter's Governing Body members contributed to support two members in financial crisis due to the pandemic with Rs. 17000 each and another person with Alzheimer's was identified and supported with Rs.5000 with giving awareness and caregiving skills in their homes.

ARDSI MUMBAI CHAPTER

ARDSI Mumbai Chapter reorganised its function much to the disappointment of not only our Team but also our extended family at 'Smriti Vishvam'. So, to all of us COVID became a matter of Change to be brought about, Challenge to be met, of Concern to Correct with Compassion and creating new Opportunities that teach

and Value of and for people and with Introspection to Develop with Divinity.

We were just a call away..... COVID protocol brought about temporary closure of Universe of Memory. Thought impossible, ONLINE sessions was the new order of the day for all services with our 'family'



meeting the challenge with their focus improving! Guest sessions brought a new aspect of 'socialisation' and intergenerational bonding. Webinars were conducted on different aspects of dementia and care management, training sessions, counselling and support, celebrations to spread cheer, surprise distribution of gift packages and with family carers included in individual and group support sessions.

We used multiple social media platforms with regular media campaigns. World Alzheimer Month (WAM) had a daily dose of vitamin throughout September. Apart from sessions every day a media campaign with a caption, 'What I Learnt From My Family With Dementia' on social media, a four-posters' series, 'COVID Contemplation' and another, 'Be their Memory. Be there for them' and a successful 6-posters' campaign with a dictum, 'Remember to be COVID Positive' reflected inspirational messages using the acronym, COVID. A beautiful video, 'A Call To Remember' was released with great impact on its viewers. Different aspects of dementia, be it awareness, care skills, therapies or training were covered for educational institutions, corporates, hospitals and service sectors. On World Alzheimer's

Day, September 21, five virtual webinars were organised with UNESCO, Indian Academy of Neurology, Nagpur, Mithibai College, Nanvati Women's College and Drishti on dementia-related topics as care, its critical and ethical issues, awareness, environment with multidimensional perspectives.

With COVID protocol being relaxed, we immediately started home care services, much to the delight of 'families'. These will now continue as a regular facility. Home visits, demand for home care and clinical assessments, counselling and support requirements have increased considerably. We try our best to continue with also giving student support for their internships too.

We look forward to reuniting with our 'family' at our Dementia Daycare Centre, Smriti Vishvam Universe of Memory.



ARDSI NEW DELHI CHAPTER

ARDSI Delhi Chapter operations included day care center, helpline services, home counseling, referrals, conducting sensitization sessions in small and large forums including media platforms, providing medicines free of cost for poor patients and training for carers. Except for medicines being distributed free of cost to needy patients, help line services, home counseling (through telephone/ whatsapp/zoom calls) and enabling referrals, day care center, sensitization in forums and training activities had to be suspended due to COVID outbreak.



During the reporting period, ARDSI Delhi Chapter did 10 virtual homes counselling, attended to 1220 helpline calls and provided medicines to 7 poor patients. COVID outbreak impacted the in-person services that affected regular activities facing resource constraints. However, volunteers and staff members were active by reaching out to needy patients by arranging appointments with doctors. Doctors extended consultation over video calls, emails etc. and



attended to as many patients as possible without stopping their useful services.

President, Dr. Manjari Tripathi, participated in programs organized by BIG FM 92.7 (with Kurapati Nitin) and Doordarshan on Alzheimer's especially focusing the new drug released in the US to treat Alzheimer's disease including symptoms of the disease.

Two members viz., Wg. Cdr. YP Singh and Ms. Bina Berry of Delhi chapter also participated in a Superhero Spotlight series organized by ARDSI National office to share their personal experiences caring their dear ones affected by dementia. This talk was very well received and appreciated for its rich content with Dr. Manjari Tripathi, our expert, who ably handled the Q&A session.

ARDSI PATHANAMTHITTA CHAPTER

Awareness webinars were regularly conducted by eminent doctors in Pathanamthitta District included office bearers collaborating with NGOs, church denominations, educational institutions to spread more awareness.

Our domiciliary care unit headed by staff nurse Mrs. Thulasi Mohan gave support by visiting needy patients extended by telephonic communication. 11 patients were regularly and connections with 30 maintained as per request. Standard format data maintaining records to monitor and evaluate by Staff Nurse was done with feedback to caregivers and home nurses. Home Nursing unit headed by Mr. V.K. Mathew, Vice President of our chapter, along with committed nurses is working well. Dr. Prathibha, Government District Hospital, Dr. Kurien Oommen and Dr. Sam, Poyanil Hospital and Dr. S. Joseph, Muthoot Hospital Kozhencherry volunteered to improve quality care.

Mrs. K.N. Sarasamma, office-in-charge attends to calls from Pathanamthitta district, Alappuzha and Kollam coming

on our Help Line that operates on weekday from 10-4pm. Secretariat meetings are held regularly and office is handled by two staff.

WAM and WAD programmes scheduled included Beliver`S Church Medical College Hospital Thiruvalla on Sep 21st. Integrated dementia care services at the weekly Memory Clinic and residential Care Home named as `Believers NEST` was inaugurated by National Award-winning Film Director, Blessy, noted for "Thanmatra" on dementia. Pathanamthitta Chapter, Secretary Dr. Agith Thomas delivered keynote address with attendance by selected participants with media coverage.

Annual Elocution Competition normally held in memory of Founder, General Secretary Shri C. John Thomas Memorial Elocution Competition could not be conducted due to the pandemic.

Our Support group Mundiappaly is working well under Mrs. Annamma John, Joint Secretary with others members with awareness programmes and other care assistance.

ARDSI THIRUVANANTHAPURAM CHAPTER

We pay homage to our father figure and founder of Chapter Mr. TK Radhamonie and three other inmates who passed away.

Covid-19 protocol forced us to close down our Project, Snehasadanam temporarily till its reopening in June, 2020 with our determined team's constant evaluation and frequent brainstorming. However the inmates who had left the respite home mostly refused to return. The new Project Administrator, Mr. Jose Sebastian filled in for Smt. Shalie Abraham and Mr. Jose Joseph who tendered

their resignations. Financial crunch due to Covid did not stop us from paying salaries. Immense gratitude to Dr. Thomas Iype, Chief Patron and Dr. Robert Mathew, President helped overcome pandemic challenges and restrictions. The EC held 8 meetings as well its AGM on 11.9.2020. Appreciation to Prof N Sindhu, co-opted as EC Member in October is helping with social media skills and to Mr. Jose Joseph.

ARDSI-TVM Chapter is working on its own registration and new office bearers.

ARDSI VISAKHAPATNAM CHAPTER

Was registered as a Society on 15th Nov 2019. under the provisions of Societies Registration Act, Andhra Pradesh, with the mission of helping & remembering those who cannot remember and creating awareness in the society about dementia COVID-19 pandemic in Mar 2020, though had severely impacted the envisioned activities of ARDSI VIZAG, did not affect its vision to create public awareness as well inform of caregiving skills to those needing it. COVID 19 has limited the scope for conducting field activities like those conducted prior viz., an inaugural meet-cum-awareness session was held in Public Library,



Visakhapatnam, on 25th Jan 2020, collaboration with EISAI Pharmaceuticals India Pvt. Ltd, Visakhapatnam to spread awareness about dementia, an Awareness Walk, in association with Sneha Sandhya Age Care Foundation, an

NGO working towards providing Geriatric and Palliative care to the elderly and under privileged in the society, on the beach front of Vizag.

Dementia screening camps were held in old age homes in Visakhapatnam, in association with Sneha Sandhya Age Care Foundation during the month of Dec 2019. Awareness camps were organised for members of women self-help groups in Fishermen's colonies in Visakhapatnam during the month of Jan 2020.

Conducting memory screening camps on a regular basis, starting a day care centre for those living with dementia and imparting training for the care givers was planned to be launched in 2020 but were put on hold because of COVID 19.

Social media platforms were used to initiate dementia awareness campaign through Whatsapp by circulating an audio clipping pertaining to the experiences of a dementia caregiver, webinar / zoom awareness meets in World Alzheimer's Month. Provided memory first aid training to its members and volunteers through Memory First Aid International, radio talk shows through FM Channel in Vizag, public awareness drive through overhead LED public display boards at prime traffic junctions in Visakhapatnam in association with Sneha Sandhya Age Care Foundation and with the support of municipal administration of Visakhapatnam.

An article written by Dr. Mani Tolety, Joint-Secretary ARDSI Vizag, was published in The Pioneer during Sep 2020.

NATIONAL TRAINING CENTER FOR DEMENTIA CARE SKILLS, THIRUVANANTHAPURAM

ARDSI National Training Center organised Dementia Care Skills training programs for professionals including nursing staffs, social workers, medical professional, family members of persons with dementia and caregivers.

Due to Covid-19, online platform was used to conduct various courses. In the said year, the training center organized around 11 online certificate courses of short-term 5-day courses. The participants received their certificates by Speed post.

ARDSI has planned to organize a one-month online, that included three weeks of theory classes on virtual Zoom platform with one-week of practical sessions. This Geriatric Care course has focus on dementia. Two were successfully conducted. We also conducted webinars on dementia in collaboration with members of Lions Club to create awareness among general public.

ARDSI NATIONAL DCS REPORT

Dementia Care Skills - Training the Trainers Programme

April 2019 to March 2020

Introduction

There are about 5.29 million persons with dementia in India. These numbers are expected to double by 2030. The increased numbers of people with dementia will have a marked impact on the country's infrastructures and health-care systems that are ill-prepared and also on families and caregivers who are the main carers (Dementia India Report 2010).

Alzheimer's & Related Disorders Society of India (ARDSI) is a national voluntary organization dedicated to the care, support and research of dementia. Since 1992, it has been in the forefront to improve the welfare of persons with dementia and their families. ARDSI is committed to developing a literate and dementia friendly community in the country by training of manpower, through both short term and long term courses, as one of its most important components. It is creating a national program called "Train the Trainers" which begins with training the trainers followed by nurturing these trainers with the intent that the best of them become Master Trainers over time and support training for Care Workers as well as Family Carers.

This focus is in line with the Dementia Care Skills (DCS) Train-the-Trainers course Program, developed by Alzheimer's Disease International which aims to address the need to build sustainable capacity in the training of dementia care in developing countries. Therefore, ARDSI took it up with the ADI Asia Pacific Regional Office that plays a key role in the region, strengthening the capacity of its members through training and strengthening the associations. Background:

One of ARDSI's priorities is to strengthen all the Chapters by providing them with a standard framework for uniform programmes throughout India that includes Train-the-trainer and training for family caregivers and paid workers. The adoption of such a framework is to bring all the Chapters together and equip them to provide good quality training.

The starting point for the development of a national uniform training program began in late 2016 when ARDSI Chairperson Meera Pattabiraman attended an awareness programme during WAD held at Changi Hospital Singapore, in the company of Francis Wong, the then Director of the Asia Pacific Office who suggested ARDSI to start a national training program in the framework of ADI. Eventually a plan of action to develop the module was formulated after several Skype meetings between Asia Pacific office and ARDSI.

In early 2017 a work plan was formulated to realize the objective. From "Readiness" of the chapters to Designing the Module based on DCS and finally implementing the



training before a workshop to decide the outcomes it was successfully conducted.

Potentially, 10 certified ARDSI DCS Trainers were trained to impart training in their respective regions.

For the year 2019 - 2020, the following DCS training was conducted by 8 of the trainers. Details of the training below:

ARDSI Mumbai- Vishwa Modi

1. Dates conducted: February 29 & March 1, 2020.
- Co-facilitator: Nandini Devendra
2. Type of DCS: Professional Caregivers
3. Number of participants: 10

ARDSI Mysuru- Dr. S P Goswami

1. Dates conducted: August 23-25, 2019/ Co Facilitator- Sruthi Sivaraman
2. Type of DCS: Professional Caregivers - Speech Language Pathologist, Clinical psychologist, Social worker
3. Number of participants: 37

ARDSI Calcutta- Arpita Dutta

1. Dates conducted:
 - (i) September 28-29, 2019
 - (ii) November 9-12, 2019
 - (iii) February 15, 2020
2. Type of DCS -
 - (i) Family Caregivers (12 hrs.)
 - (ii) Professional Caregivers (18hrs)
 - (iii) Professional (9 hrs.)

Co-facilitators: Nivedita Saha, Ritodeep M, Snigdha M, Supriya C, Kabita G, Mahua B

3. Number of Participants -
 - (i) 18
 - (ii) 13
 - (iii) 12

ARDSI National Office- Ashly Jacob/ M J Sebastian

1. Dates conducted: November 4-6, 2019
2. Type of DCS: Professional Caregivers
3. Number of participants: 15

ARDSI Guwahati- Debastuti Baruah

1. Dates conducted: August 26, 2019.
2. Type of DCS: Professional Caregivers
3. Number of participants: 25

ARDSI Hyderabad- Shashidhar K

1. Dates: Oct 20-22, 2019
2. Type of DCS: Professional Caregivers
3. Number of participants: 10

1. Dates: Dec 16 -18, 2019

2. Type of DCS: Caregivers
3. Number of participants: 17 participants

ARDSI Bangalore- Sruthi Sivaraman

Training 1:

1. Dates: June 20-22, 2019
2. Type of DCS: Professional Caregivers (Psychologists and Social Workers)
3. Number of participants: 13

Training 2: Along with Dr. Goswami

1. Dates: August 24-26, 2019
2. Type of DCS: Professional Caregivers (Speech Language Pathologist, Clinical Psychologist, Social Workers)
3. Number of participants: 37

Training 3:

1. Dates: November 9-10, 2019
2. Type of DCS: Family Caregivers
3. Number of participants: 6

Details of dementia care skills training sessions, out of DCS purview, were also conducted by Mumbai Chapter in Ahmedabad and Mumbai as hereunder:

Ahmedabad

1. Dates: July 13-14, 2019
2. Category: Family Caregivers
3. Number of participants: 135

Mumbai

1. Dates: October 26-27, 2019
2. Category: Professional Caregivers
3. Number of participants: 35

DCS training from Delhi and Chennai is yet to start.

Wayforward

1. ARDSI shall continue to remain engaged in STRIDE project till 2021-22. In addition to the progress achieved during the last year with respect work packages three, seven and ten, work package four relating to aspects covering unpaid care givers shall be taken up to ascertain the status of economic burdens of unpaid carers through field study with the help of a qualified dedicated team from NIM-HANS. Similarly, mapping of stakeholders shall be taken up to disseminate the STRIDE project findings and recommendations for a National policy, action plan and allocation of resources.

2. The Van Otterloo Foundation project shall be continued in its third year where public policy advocacy with Government for a pro national policy and working with state health missions for utilizing funds meant for District Mental Health Programme by suggesting to set up memory clinics, enhancing treatment facilities, training etc., shall remain pursued.

3. By showcasing ARDSI national office services in terms of 24X7 services, a crowdfunding initiative shall be taken up to generate revenue to meet the deficit caused due to COVID-19 induced uncertainties.

4. Continuing with WAM activities during the ensuing year both through virtual modes and organizing informative webinars by pooling expert speakers with a view to disseminate authentic and up-to-date information on best practices.

5. Few new initiatives shall be implemented with possible support from few new donors after necessary due diligence.

6. KSID project shall be continued with same vigour, while it shall be scaled up to Kozhikode after getting approval from Social Welfare Board Kerala and Kerala Social Security Mission.

7. Continuing with ARDSI care services with due safeguards to ensure protection from COVID-19 induced threats to both residents and the carers.

8. Expanding the outreach of National training center with the help of technological interface and online short-term/capsule courses focusing dementia care skills.

9. Expanding ARDSI outreach through setting up of new chapters to cater to the unreached population.

10. Consolidating the positive experiences of institutionalizing services as publications.

11. Engage in socio-economic and therapeutic research projects to benefit people living with dementia and their family carers.

12. Continuously explore opportunities for convergence and collaboration by networking with alliances to ameliorate conditions of people living with dementia and focusing caregivers in keeping ARDSI services inclusive.

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20-21 NOVEMBER **2021**

VIRTUAL CONFERENCE

DEMENTIA CARE IN FAMILY & COMMUNITY

Building resilience & hope

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Sharing & Learning from ARDSI CHAPTERS



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WHO CANNOT REMEMBER
HYDERABAD DECCAN CHAPTER



ASHA HOSPITAL
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COUNSELLING & PSYCHOTHERAPY



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ALZHEIMER'S & RELATED DISORDERS SOCIETY OF INDIA (ARDSI)

ANNUAL REPORT 2020-2021

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