

DIALOGUE

Newsletter of Dementia India Alliance | July 2024



Dementia
IndiaAlliance

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www.dementia-india.org



Dear Friends,

Greetings from the Dementia India Alliance

Dementia, a neurodegenerative brain condition that affects millions of elderly in India and remains a hidden epidemic. The estimated dementia prevalence for people above the age of 60, in India, is 7.4%. There are, currently, almost 9 million Indians with dementia. It is estimated that in 2036 there will be 17 million afflicted Indians. The absence of a cure leaves persons struggling with severe memory loss, disorientation, and challenges in daily tasks, creating unrelenting hardship for themselves and their immediate families. The resulting physical, financial, and emotional toll is immense, significantly diminishing the quality of life for family caregivers whose lives, livelihoods, and relationships are severely compromised.

There is widespread ignorance and low awareness surrounding this condition leading to almost 90% of people never getting a diagnosis. The stigma attached to the disease, scarcity of experts, dearth of services, lack of trained professionals, and the low priority given to the disease by the government make the situation immensely challenging. Support services are often unavailable, inaccessible, unaffordable, and unsuited to meet the needs of people with dementia or their families.

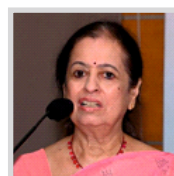
Tackling dementia and its challenges requires a strong national-level movement. Dementia India Alliance (DIA) is a not-for-profit family carer-centered national organization established with a Purpose to bring help and hope to persons with dementia and their family caregivers by bridging the gap between the need and support systems available.

In the short span of one year, we have achieved significant milestones including major awareness events as part of the Blue Button movement, educational workshops (with the support of Indian Oil) in different parts of the country, and regular support groups. The announcement of dementia as a public health priority by the Government of Karnataka was a landmark moment. We successfully launched two key services: the National Dementia Support Line and DemClinic. Celebrities like Dr Kiran Mazumdar Shaw, Mr Anil Kumble, and actress, Ms Revathi, endorsed our cause. Our association with NIMHANS, the Centre for Brain Research, the Association of Healthcare Providers (India), the Ministry of Social Justice and Empowerment, the Ministry of Health and Family Welfare, NABH, medical colleges, and service providers have strengthened.

As we complete one year, strategic planning is imperative to sustain our efforts and solidify the organization's foundation. We have initiated this newsletter to update our members, associates, and well-wishers updated on the current plans and activities at DIA.

We look forward to your continued support to bring help and hope to persons with dementia and their family caregivers.

Warm regards,



Dr Radha S Murthy
President



Mr Shyam Viswanathan
Secretary

Key Highlights

1. Building Support Systems for Persons with Dementia and Family Caregivers

A press meeting on 5th Sep 2023, DIA announced the launch of two key services.

National Dementia Support Line:

The services include information, guidance, promoting timely diagnosis and intervention through online memory screening services. Services provided through the Support Line are free of cost ensuring access to crucial assistance to all. The online memory screening aims to mitigate stigma and encourage senior citizens to get an assessment to promote early diagnosis.

The Support Line operates from 8am to 6pm, Monday through Saturday, offering services in English, Hindi, Tamil, Malayalam, Kannada, and Telugu. Trained psychologists and social workers address callers' needs, providing empathetic and informed assistance. **For those seeking guidance, support, or assistance related to dementia or memory-related issues, the National Dementia Support Line can be reached at 8585 990 990.**

Demclinic: Virtual Memory Clinic

www.demclinic.com

India's first comprehensive expert-led cognitive assessment platform for the elderly. The initiative is aimed at supporting families and persons with dementia through post-diagnostic care. There is a huge dearth of memory clinics, psychiatrists, geriatricians and neurologists in our country. This virtual platform helps those with dementia, and their families to get timely diagnosis and expert advice for post diagnosis clinical management. Twelve senior psychiatrists, neurologists and geriatricians are empanelled for the DemClinic and this service is offered at an affordable fee.

Currently, there is no known cure for dementia. DemClinic leverages telemedicine technology to provide easy access to diagnosis and care. This virtual platform features interactive videoconferencing with experts. The consultation include a detailed history and neuropsychological evaluation, advice on management and medication prescription. Periodic follow-ups and continuum of care are essential caveats of the service.

People can book an assessment by calling 8585 990 990 or logging into DemClinic. Clinical Experts wanting to empanel in Demclinic can also contact.

Testimonials from Family Carers

"Thank you for the support so far. We have been struggling to find a doctor for my parents in Ujjain. I called the Helpline and was referred to DemClinic. The services are very helpful, and the doctor is also great. I am able to consult with the doctor when required. Thank you for checking on my parents and for the guidance."

- Ms Raashida

"I am very thankful to DemClinic for facilitating dementia assessment for my father and being there every step of the way for initiating his treatment. I have already referred your valuable service to a few of my friends and one of them has started using your service for his mother. Overall very impressed with your service and the fact that everything is organized online without having to take the elderly patient to a physical clinic. Kudos and keep up the good work. Thank you all once again for your service and support."

- Mr Gurumurthy



2. Creating Awareness and Mitigating Stigma

World Alzheimer's Month: The Blue Button Movement

DIA organized the Blue Button Campaign during September 2023, World Alzheimer's Month, across seven cities – Bangalore, Hyderabad, Coimbatore, Chennai, Vizag, Delhi, and Kochi. The blue button is a symbol of awareness and support for people living with dementia. Around 1500 people participated in these events. Participants gathered to form a human chain symbolically resembling the blue button as a shield, a coat of arms unifying and encouraging people to recognize the impact of dementia, empathize, and take proactive steps to support. This multifaceted approach aimed not only to raise awareness but also to lay the foundation for compassionate action and a more informed society.



3. Working towards National Dementia Policy

Dementia now a Public Health Priority in Karnataka

A milestone was achieved by DIA in collaboration with NIMHANS when the Karnataka Health Minister, Shri Dinesh Gundu Rao, announced Dementia as a public health priority on the occasion of World Alzheimer's Day 2023. Following the declaration, the formulation and implementation of the Draft State Dementia Action Plan will be a collaborative effort led by the Department of Health and Family Welfare, Govt of Karnataka with Dementia India Alliance and NIMHANS.

We hope this sets a precedent for other states to develop their dementia action plans. DIA will advocate with state governments to establish state dementia policies, ultimately paving the way for a national dementia plan.



4. Community Outreach Programs

Workshops with the Support of Indian Oil Corporation Limited

DIA conducted six education workshops in Chennai, Visakhapatnam, Hyderabad, Bangalore, Kottayam, and Mumbai (sponsored by Indian Oil Corporation) and partnering with local organizations.

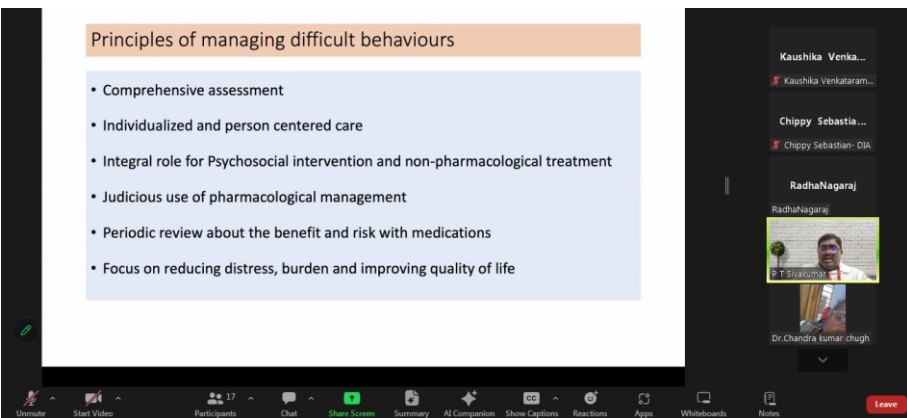
These events featured expert speakers, interactive sessions, and deliberations, attracting diverse participants including caregivers, healthcare professionals, and students. Each workshop had over 100 participants, who appreciated the informative content and the initiatives.

If you are interested in organizing events to create awareness and provide updated information on dementia care in your cities / towns, you can contact DIA for support and collaboration.



Two-Day Regional Conference on Psychosocial Issues

DIA along with the National Institute of Social Defence, and Nightingale Medical Trust in association with the Dept of Geriatrics, Amrita Institute of Medical Science and Research Centre organized a two-day regional-level conference on elderly issues psychosocial problems, and mental health issues in old age. 200 people attended the conference including family carers, students, community health workers and NGOs working in the space of aged care.



5. Caregiver Support Weekly Support Groups

From September 2023, weekly online and offline support group sessions were organized by DIA, in collaboration with NIMHANS, to provide caregivers with a platform for mutual support and guidance. Led by experienced medical professionals and psychologists, these sessions foster a supportive community where caregivers can come together to share experiences and receive expert advice. Each session is led by an expert in the field who facilitates discussions and provide guidance in the management of persons with dementia. So far 650 caregivers have benefitted through these sessions. **Family carers interested in joining our support network can contact DIA.**



6. Networking and Collaborations

Networking and collaborations with like-minded organizations are essential for the DIA to effectively promote the cause of dementia care. Through partnerships, we can extend our reach, strengthen our advocacy efforts, exchange, best practices, and provide comprehensive support to those affected by dementia and their family carers. DIA has taken active steps to collaborate by signing Memorandums of Understanding (MoUs) with key organizations.

a. MoU with NIMHANS

The National Institute of Mental Health and Neuro Sciences is a multidisciplinary institute for patient care and academic pursuits in the field of mental health and neurosciences. On 22nd January, an MoU was signed by NIMHANS and DIA. The collaboration is aimed at improving the overall quality of life of persons with dementia and their family caregivers through support services, outreach, advocacy, training, and research.



b. MOU with Vayah Vikas

Vayah Vikas is a not-for-profit organization based in Bengaluru focused on well-being of the elderly & offering opportunities for productive engagement so that they can build dignified lives. The MoU between DIA and Vayah Vikas focussed on awareness, advocacy, and support services for dementia diagnosis and care.

c. MoU with Dr Kiran Mazumdar Shaw

DIA has signed a MoU with Dr Kiran Mazumdar who has generously committed her financial support. This funding will be instrumental in promoting the cause of dementia through various initiatives, including the National Dementia Support Line, Demclinic, training programs, and related activities. **Family Foundations interested in supporting the cause of dementia can contact DIA.** The support will significantly enhance our efforts to raise awareness and provide crucial resources for dementia care.



d. Making Hospitals Dementia Friendly

To promote dementia-friendly hospitals, DIA has signed a MoU with the Association of Healthcare Providers India (AHPI). This initiative aims to raise awareness, advocate for better practices, and provide training to integrate dementia-friendly practices in hospitals. DIA and AHPI will work together to educate hospital administrators about the importance and benefits of making their facilities dementia-friendly. Additionally, DIA offers online dementia care training programs for various hospital staff, including doctors, nurses, nursing assistants, outpatient staff, and other personnel, along with Training of Trainers (ToT) sessions to ensure sustainability and scalability. Hospitals interested in becoming dementia friendly can contact DIA.

e. NABH Guidelines on Dementia-Friendly Hospitals

Dementia India Alliance (DIA) is collaborating with National Accreditation Board for Hospitals (NABH) and a group of experts to develop dementia-care accreditation norms. These will be integrated as an annexure into the 6th edition of the NABH Accreditation Standards for Hospitals, set to be released in 2024.

This initiative is vital for enhancing the quality of care provided to persons with dementia in hospitals across India. By establishing clear standards and guidelines, we aim to ensure that healthcare facilities are better equipped to address the unique needs of dementia patients, ultimately improving their overall well-being and quality of life.



f. Dementia Care in Old Age Homes

It is estimated that approximately 20% of the elderly residing in old age homes (OAHs) are affected by dementia, with around 90% of cases going undiagnosed. To address this significant gap in diagnosis and early intervention, DIA signed an MoU with the Ministry of Social Justice and Empowerment (MoSJE), Government of India on 07 May 2024 to promote the well-being of elderly living with Dementia in government-supported OAHs through free online memory screening and training of staff on dementia care management. Through this MoU DIA intends to cover more than 600 old-age homes across the country.



g. Knowledge Partnership

The Association of Senior Living India (ASLI) strives to outline guidelines, frameworks and policies in the ASSISTED LIVING space. ASLI creates guidelines to advance excellence in senior living in India. DIA is now a knowledge partner to ASLI to enhance its capacity in the field of dementia care.

h. Dementia-care Service Provider Group (DSPG)

The DSPG (a task-force under DIA) will focus on matters of common interest to dementia-care service providers. **Organizations providing dementia care interested in improving the quality of care and standards can contact DIA.**

i. Partnership with Public Sector Companies

SCOPE (Standing Conference of Public Enterprises) is an influential organization representing and advocating for the collective interests of all Public Sector Enterprises (PSEs) in India. DIA has engaged with SCOPE to extend our services to benefit PSE employees across the country. Additionally, we aim to raise awareness about dementia among PSU leaders, promoting a better understanding and proactive approach to dementia care within the public sector.

7. Creating a Cadre of Dementia Capable Caregivers

DemLearn offers "Training of Trainers" (ToT), a certified program for psychologists, social workers, nurses, and allied healthcare professionals in geriatric and dementia care. This three-day program equips participants with essential skills to train both formal and informal caregivers. We have held two successful ToT sessions, certifying individuals from diverse backgrounds across India. The initiative behind ToT is to empower trainers to train underprivileged youth in dementia care, creating career opportunities and providing family caregivers with well-trained support. Additionally, we continue to offer online caregiver training to support broader accessibility and reach. **If you are an organization / individual interested in becoming a trainer, please contact DIA.**



8. DEMCHAMPS: Young Champions for the Cause of Dementia

The DemChamp program is specifically designed for students. By actively involving students, DIA aims to not only raise awareness about dementia and eliminate the stigma surrounding the disease. This initiative is particularly beneficial for psychology, social work, and nursing students as it provides practical experience in working with persons with dementia, enhancing their understanding and empathy. This certification can enhance their resumes and career prospects in mental health. **Academic institutions / Students interested in promoting the cause can contact DIA.**



Our initiative with Shastra IIT Madras

DIA partnered with Shastra, the flagship festival of IIT Madras, to promote social awareness on dementia. The collaboration featured a competition aimed at developing technology and products for persons with dementia, with the goal of turning the winning product into a prototype with the help of the social innovations team, Sahaay. The event attracted 15 innovative product entries, and the top 3 innovations were awarded.

IIT MADRAS PRESENTS

25 YEARS OF SHAASTRA

SHAASTRA2024

3RD - 7TH JANUARY

SPOKES OF TIME

Presented by **CATERPILLAR**

Sponsored by **Chetak**

Upcoming Events

Conclave on Standards for Dementia Care: Regulations, Challenges and Recommended Solutions for India

DIA is organizing a national conclave on July 20th in Chennai to formulate draft recommendations on uniform minimum standards and regulations for facilities catering to persons with dementia in alignment with the Mental Health Care Act (MHCA) through deliberations among key stakeholders. The outcome of the conclave will be a comprehensive white paper with recommendations for both central and state governments. This white paper will be formally released during the International Dementia Care Conference scheduled for November 29-30, 2024.

DemCon'24

International Conference
Bengaluru

Dementia Care:
Reaching the Unreached

9:00am - 5:00pm | 29th & 30th Nov
JN Tata Auditorium
Indian Institute
of Science

DemCon '24: International Dementia Conference

DIA is organizing DemCon '24, an International Dementia Conference, in Bangalore on November 29th and 30th at the JN Tata Auditorium, IISc, Bangalore. DemCon '24 aims to deliberate on strategies for reaching the unreached in dementia care and explore avenues to bridge gaps in awareness, advocacy, diagnosis, research, support, and care. Over 800 delegates from different countries comprising family carers, health care professionals, service providers, policymakers, senior citizens, and students are expected to attend. At DemCon '24, we aim to go beyond theories and craft strategies and action plans to bridge gaps in dementia care. **For more information log on to www.demcon2024.com**

Celebrity Endorsements

DIA thanks Mr. Anil Kumble, Dr Kiran Mazumdar Shaw, and Ms. Revathi, distinguished figures in Indian cricket, Philanthropy, and Cinema respectively, who have graciously supported our endeavour by raising awareness about the often-ignored issue of dementia.



Join Hands in Making a Difference

As a national organization, we need your support to promote the cause of dementia. Your encouragement is crucial in bringing help and hope to persons with dementia and their family caregivers. Here are some ways you can join the journey:



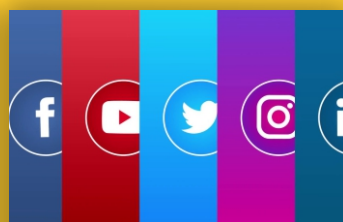
Volunteer

Your time and skills can make a significant difference.



Donate

Support our Initiatives and help us reach more families in need.



Follow us

Follow us on social media for updates and more.



Collaborate

Partner with us to improve Dementia care in India.

Become a Member

Individuals

Corporates

Non-Profit Organizations

Students



**Dementia
India
Alliance**

Dementia India Alliance

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