

# **Dementia India Alliance**

## **Annual Report 2023-2024**

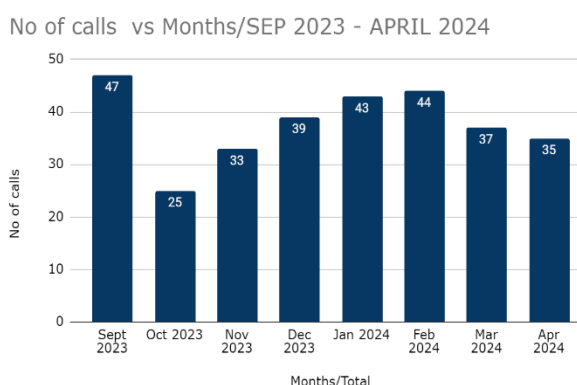
Dementia India Alliance (DIA) is a not-for-profit family carer-centered national organization established under the Societies Act, with a primary focus to provide Help and Hope to persons with dementia and their families. DIA stands at the forefront of the fight against dementia, aiming to improve the overall well-being of affected individuals through compassionate care and support.

DIA is dedicated to providing essential services which not only benefit those directly impacted by dementia but also provide much-needed relief and hope to their family caregivers. These are:

### **1. National Dementia Support Line – 8585 990 990**

The Support Line operates from 8:00 am to 6:00 pm, Monday through Saturday. It provides services in six different languages: English, Hindi, Tamil, Malayalam, Kannada, and Telugu. The Support Line offers information, guidance, support, and memory screening to individuals and families without any charge.

Between May 2023 and May 2024, the Support Line received a total of 331 calls from people seeking assistance and support. These calls came from individuals and families looking for support to care for their loved ones. The Support Line aims to continue providing assistance and support to those in need within the community.



### **2. DemClinic – [www.demclinic.com](http://www.demclinic.com)**

This comprehensive expert-led online memory assessment platform is designed to assist the elderly, particularly those with dementia, by providing early screening, diagnosis and support.

- Memory screenings: Assessing memory function to identify any potential issues in memory and cognition.
- Cognitive assessments: Evaluating the cognitive abilities of elderly individuals to understand their mental health status.
- New clinical consultations: Providing consultations with experts to address any concerns or changes in cognitive health, leading to early diagnosis.
- Post-diagnostic care: Offering assistance and guidance to families and individuals after receiving a dementia diagnosis.

As of May 2023-May 2024, the platform has served a cumulative total of 58 individuals and families, providing them with valuable support and guidance in managing

dementia and cognitive health issues. DemClinic has been able to enhance the quality of life for the elderly and their families by offering specialised care and assistance tailored to their cognitive health needs.

3. **Support Groups** – From May 2023-2024 18 periodic support group sessions were organized to provide caregivers with a platform for mutual support and guidance. Led by experienced medical professionals and psychologists, these sessions aim to foster a supportive community where caregivers can come together to share experiences and receive expert advice. The support group sessions are conducted either online or offline, allowing caregivers to participate from the comfort of their own homes, or in person, depending on their preference.

4. **Dementia Awareness and Screening Events**

a. **World Alzheimer’s Day, 21<sup>st</sup> September 2023, Bengaluru:** A milestone success was achieved when the Health Minister of Karnataka, Shri Gundu Rao announced Dementia as a Health Priority on World Alzheimer’s day. DIA along with NIMHANS and Government of Karnataka have worked out a draft action plan for approval and implementation. The event was organized by DIA along with NIMHANS and was held at NIMHANS convention centre and was well represented by Government officials,



NIMHANS' team of doctors, medical students, and elders from Nightingales Medical Trust, DIA's team and Media.



b. **Blue Button Movement, 23<sup>rd</sup> September 2023, Bengaluru:** DIA, in collaboration with Nightingales Medical Trust organised the Blue Button Movement at Sankey Tank, Bengaluru. The Blue Button carries a deep symbolism for those affected by Dementia. The ability to button one's own clothes is a sign of independence. The loss of this ability is an early indicator of the onset of Dementia. The Blue Button marks this poignant moment when loved ones shift from caregivers to care receivers. The interconnected threads in the Button represent the Alliance, coming together for hope and support. The Blue Button movement is a component of DIA's broader initiative to foster inclusivity within our society. The Chief Guest, Dr. Ashwathnarayan C.N., who serves as the MLA for the Malleshwaram Assembly Constituency and former Deputy Chief Minister, along with our guest of honour, Ms. Surabhi Santosh, a renowned Indian actress, model, classical dancer, and lawyer, played a pivotal role



in launching the Blue Button movement.

## Difficulty in buttoning clothes could be sign of dementia: Doc

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### STUDENTS & EDUCATORS JOIN CAUSE

**Bengaluru:** Do you find it tough to button your clothes? It could be an early indicator of dementia onset, say experts. "The degeneration in parietal and temporal lobes of the brain can cause inability to perform learned motor tasks such as buttoning one's shirt, locking/unlocking the door or operating a phone or remote," explained Dr Ganjan Kulkarni, consultant neuropsychiatrist, Nightingales Centre for Ageing and Alzheimer's, Bengaluru. "There is a high probability that it is a sign of dementia," he added.

Several educational institutions in the city have joined hands with Dementia India Alliance, For Amnesia Arif, a final-year physiotherapy student at Acharya Institute of Health Sciences, helping patients is a way of adding more meaning to her life. "Some people with dementia develop muscle atrophy, into paralysis and movement problems. We help them stay more active and encourage hand and finger movements. Some may be on wheelchairs. We teach them wheelchair-mobility activities," she said. "Patients with dementia benefit from simple building-

block activities and solving puzzles," said Tanusee VL, head of department of psychology at Maharani Laxshmi Amrarni College for Women. "As many as 30 psychology students from our college have joined the Blue Button Movement," said Tanusee, adding they will visit hospitals and clinics and offer psychological and emotional support to dementia patients.

represent the coming together (of people) to support those with dementia and their caregivers, she said, adding, "I hope this marks the beginning of the Blue Button Movement for dementia."

Former minister and Malleswaram MLA C N Ashwath Narayan attended the event, which saw hundreds of people create a human chain as a gesture of sympathy and support for patients and their caregivers.



To raise awareness about dementia and reduce stigma, Dementia India Alliance, which is focused on supporting dementia patients and their caregivers, in collaboration with Nightingales Medical Trust, organised the Blue Button Movement here on Saturday. The movement is part of the organisation's efforts to create an inclusive society, said Dr Radha S Murthy, president, DIA. The blue button

### BLUE BUTTON MOVEMENT

carries deep symbolism for those affected by dementia. We dedicate it to them. The button serves as a unifying symbol that encourages people to recognise the impact of dementia, empathise and take protective steps to raise awareness and provide support," said Dr Murthy. The interwoven threads in the button

## 170 unite in 'Blue Button' rally for World Alzheimer's Day

**BENGALURU, DHNS:** Around 170 people participated in the Blue Button Movement at Sankey Tank on Saturday, to observe World Alzheimer's Day.

The event, organised by the non-profit Dementia India Alliance (DIA), in collaboration with Nightingales Medical Trust, involved participants forming a human chain resembling a blue button like a shield, encouraging people to recognise the impact of dementia and take proactive steps to offer support.

Malleswaram MLA C N Ashwath Narayan said at the event, "As life expectancy increases, we all have to do our bit to spread awareness

about dementia and the need for support services."

DIA president Dr Radha S Murthy said, "While the person with dementia experiences the condition, it is the family that bears the greatest impact. The Blue Button is dedicated to all who are affected by dementia."

Placards and informative pamphlets were distributed to the participants, mainly caregivers, senior citizens, healthcare professionals and students.

Those seeking guidance related to dementia or memory-related issues can contact DIA's National Dementia Support Line at 8585990990.



Malleswaram MLA C N Ashwath Narayan, along with volunteers, gather in a 'D' shape formation during the "Together for Dementia" event, which was held at Sankey Tank on Saturday. DH PHOTO/B K JANARDHAN

The Blue Button movement was also organized at Vizag, Coimbatore and Delhi on World Alzheimer's Day, 21<sup>st</sup> September 2023.





c. **Community Health Screening, 25<sup>th</sup> February 2024, Sheshadripuram:** Lions International District 31F, Lions Club of Bangalore Vijayanagar, in collaboration with NIMHANS (National Institute of Mental Health and Neurosciences) and Dementia India Alliance (DIA), organised a community health initiative at Seshadripuram College. The event aimed to raise

awareness about dementia and promote early screening among seniors to ensure active ageing.

d. **Free Memory Screening for Retired Police Officers, 24<sup>th</sup> March 2024:** Lions International organised a free memory screening event tailored for retired police officers. The event aimed to provide screenings to enhance awareness of memory health among this demographic and promote membership in the Lions Dementia Initiative and Awareness (DIA). The event attracted 70 retired police officers. A total of 51 memory screenings were conducted during the event. These screenings involved assessments to evaluate memory function and detect any potential issues.



5. **DemChamps:** The DemChamps program is a program where students can learn about dementia. From February to April, DIA has registered 116 students to become DemChamps. These 116 students have signed up to learn about dementia and be a part of the movement to help those affected by it. This is an important step towards creating a more understanding and caring society for those living with dementia.

## 6. Dementia Care Workshops:

a. **Chennai, 25<sup>th</sup> Nov 2023:** The Workshop aimed to enhance understanding and management strategies for dementia among caregivers, healthcare professionals, and senior citizens. Organised by DIA and sponsored by The Indian Oil Corporation, with partners including Heritage Foundation and Madras School of Social Work, the workshop saw 85 attendees. There were presentations on various caregiving interventions, and pharmacological and non-pharmacological management strategies, along with small group discussions on dementia care stages.

b. **Vishakapatnam, 3<sup>rd</sup> December 2023:** Titled "Caring for Dementia across the Spectrum - Effective Management Strategies for Different Stages", this workshop was held at Hotel Best Western Plus Tejvivaan, Visakhapatnam. Organised in association with Sneha Sandhya Age Care Foundation, the event featured key speakers Dr. K Venkateswarlu and Dr. N N Raju. The workshop saw attendance from 82 participants, including caregivers, medical professionals, and NGO members. The event aimed to share effective strategies for managing dementia across its various stages.



d. **Bengaluru, 16<sup>th</sup> December 2023:** NMT, NIMHANS, and Apollo Hospitals, along with DIA focused on understanding the needs of caregivers and professionals. The event, attended by 118 people, included sessions by expert clinicians on effective dementia care management strategies.

## Free Workshop On Dementia

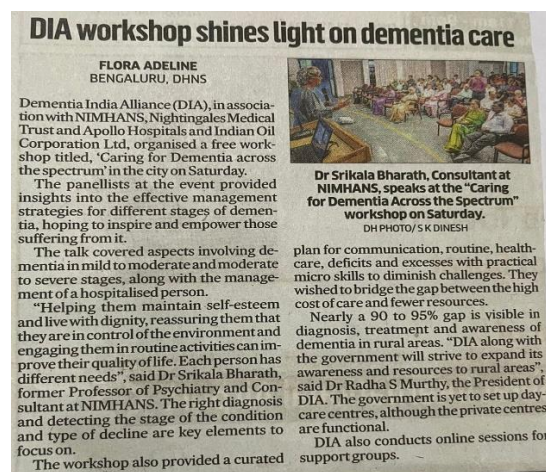
CHENNAI : Dementia is a neurodegenerative disease, and is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life. There are, currently almost 90 lakhs Indians with dementia. With no cure in sight - and with symptoms such as severe memory loss, disorientation, wandering and getting lost, difficulty in performing familiar tasks, limited social skills, challenging behaviours, and chronic dependency - persons with dementia and their immediate family face unmitigated suffering. This causes enormous physical, financial, and emotional burdens and poor

quality of life for the family carers.

However, early diagnosis and effective treatment offers some hope for reducing the impact of the illness. Proper care plan is very crucial and needs to be worked out in order to manage the persons living with dementia at different stages.

Dementia India Alliance (DIA), is a not-for-profit, family caregiver centric national organization. DIA actively engages in community outreach programs, conducts educational workshops and organize awareness campaigns - to promote early detection and encourage timely interventions.

c. **Hyderabad, 9<sup>th</sup> December, 2023:** DIA partnered with Kshetra Assisted Living for this workshop and had 118 attendees, mainly paramedical, nursing, and psychology students. Expert clinicians delivered sessions on various dementia-related topics, followed by an interactive Q&A.



- e. **Mumbai, 6<sup>th</sup> April 2024:** This Dementia Care Workshop aimed to educate participants about dementia and empower them with practical caregiving strategies. Partnered with Silver Innings, the event garnered significant pre-event publicity through emails, social media, and press releases, resulting in 113 registrations.

7. **Health Care Conference, 12<sup>th</sup> January 2024, Kottayam:** Let's Talk About Dementia – The health care conference jointly organised by Dementia India Alliance (DIA) and Indian Oil Corporation in association with IPCAI was conducted at Chaithanya Pastoral Institute, Thellakom, Kottayam. Smt. V. Vigneshwari IAS, District Collector, Kottayam inaugurated the conference and various eminent personalities enlightened the conference with their presence and sharing of knowledge. A total of 110 participants including students and professionals attended the conference.



8. **DemLearn Training of Trainers:** From February 29<sup>th</sup> to March 2<sup>nd</sup> DIA and Nightingales Medical Trust organised the DemLearn programme, aimed at training participants on dementia. Several institutions took part in this initiative. The programme primarily focused on training the trainers through a structured module-based approach. In total 27 participants attended the programme.



9. **Online Training Program for Doctors on Dementia:** Six doctors from Athulya, Chennai on 10/04/2024 participated in an online training program. The program covered various aspects of dementia to enhance the doctors' understanding and skills in dealing with patients suffering from this condition.
10. **Other Awareness Events:** Dementia India Alliance (DIA) has been actively engaged in raising awareness about dementia from May 2023-2024. Through various events and initiatives, namely:

- a. Kristu Jayanti College with 81 participants
- b. Talk on Dementia at Montfort College with 104 participants
- c. Session at Jal Vayu Vihar
- d. Orientation in Dementia at Christ University for 30 MSc Sociology students
- e. St Joseph's Skill Academy with 25 participants
- f. 61 students of Shishu Mandir

## Overall Impact

- Number of people benefited by the National Support Line: 331
- Number of people who utilized DemClinic: 58 individuals and families
- Number of workshops: 6
- Number of support groups: 18
- Number of memberships: 518
  - Individual members – 394
  - Institutional member - 2
  - Corporate members – 7
  - Number of DemChamps – 116
- MOUs
  - BLDE(Deemed to be University)
  - Kshetra Assisted Living and Dementia Care Facility
  - Rajagiri College of Social Sciences
  - Sneha Age Care
  - Renaissance Pvt Ltd
  - The National Institute of Mental Health and Neuro Sciences (NIMHANS)



- Ministry of Social Justice and Empowerment, Government of India





### Upcoming Events-

- 20th July 2024 -Conclave in Chennai: Dementia Care Regulations— Challenges and Solutions
- 29th & 30th Nov 2024 DemCon 2024 - International Dementia Conference at IISc Bangalore

### Other Notable Events in 2023-24

- 1st press meet 5th Sept 2023



- IPCAI National Award, received from Collector of Kottayam, 12<sup>th</sup> Jan 2024



- Meeting with BIOCON Founder, Ms. Kiran Mazumdar Shaw

