



Dakshama Health & Education

Your Voices Your Choices

STROKE PROJECT ANNUAL REPORT

Stroke Support Alliance
(Initiative by Dakshama Health & Education)

2021 EDITION



About DakshamA Health:

Strives to bring together patient and caregiver voices and make healthcare accessible, safe and within the reach of the person who needs it in order to bring a change in the way healthcare is perceived and delivered in the country.

Vision:

A world where people live a healthy and disease-free life through knowledge-based choices in an atmosphere of equality, equity and access.

Mission:

Empower patients and caregivers with the right knowledge, tools and forums to seek and access healthcare options that suit their needs and through their voices bring about a positive change in the healthcare environment.

1. Introduction:

Stroke is a leading cause of mortality and disability worldwide and the economic costs of treatment and post-stroke care are substantial. Every year, approximately 1.8 million people suffer from stroke, which is the second most common cause of death after coronary artery disease (CAD) globally. Stroke has become the 5th leading cause of death in 2016 from 12th cause in 1996 and claims 119-145 lives in every 100,000 population.

India's stroke burden is enormous and every year, 1.8 million people suffer stroke in India, but we have only about 2000 neurologists. The guidelines for Prevention and Management of Stroke issued by the Government of India in 2019 recommends setting up a stroke unit which includes physicians trained in stroke care. Additionally, this team comprises of nursing, physiotherapy, occupational therapy, speech therapy, and social workers.

The National stroke guidelines, 2019 are a welcome guide for specialists; however, the outcome of stroke is dependent on the patient reaching the hospital on time and well within the golden hours so that appropriate interventions can be undertaken. Initial research at the commencement of the project indicated that most patients loose precious time due to lack of awareness amongst themselves as well as family members on the warning signs of stroke.

National Stroke Guidelines, 2019 have undergone a recent revision as per discussions and meetings with specialists, the Ministry of Health and Family Welfare and the Directorate General of Health Services. The revised guidelines are expected to be released at the end of 2021. The updated guidelines will cover treatment alterations such as dose modifications and concrete standard protocols for delivering stroke care. While stakeholders from various aspects of healthcare have been consulted for the National Stroke Guidelines, conspicuously missing. Not having the voice would bereft the guidelines of an important perspective- “The lived experience” and the “real” experiences and challenges of people and family members living with stroke or having risk factors for stroke.

The Stroke project was conceived and delivered to increase awareness through participation of stroke survivors and family caregivers using a multipronged approach that included developing a website and using social media channels. It nurtured patient advocates to bring their voice into the policy discussion and address some of the gaps in the stroke management ecosystem.

Project Goal

Create a strong National Voice through Patient Leaders for Stroke Warriors and Caregivers

Project Objectives

Create a strong patient voice for supporting patients suffering from Stroke to improve their health outcomes and general well-being.

To educate patient groups about early signs and symptoms of Stroke and train them for timely diagnosis and treatment



2. Key outcomes of the project

Objective 1: Create a strong patients voice advocating for and supporting patients suffering from Stroke to improve their health outcomes and general well-being.

1. Project deliverables : Patient groups in four cities, 250 patients on board, 8 patient advocates



Mr. Varun
Sharma



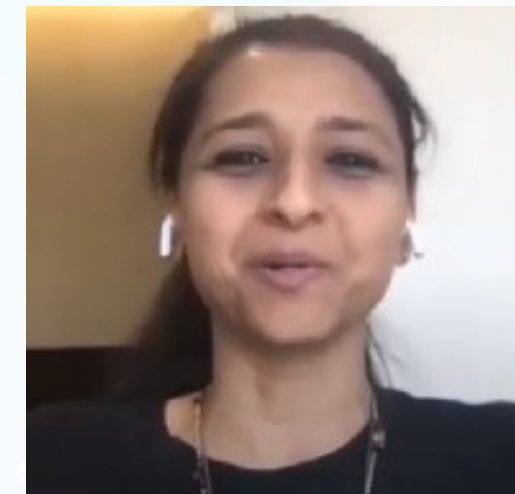
Mr. Kamran
Khan



Mr. Arjun
Bhavanasi



Mr. Jitendra
Varshney



Ms. Mansi
Jajodia



Ms. Geeta
Bhansali

Patient Advocates

Outreach Impact



Group with 260 stroke survivors
and caregivers



Stroke Support Alliance
234 followers



800+ webinar registrants



Stroke_support_alliance
150 followers

Following groups are working with us:

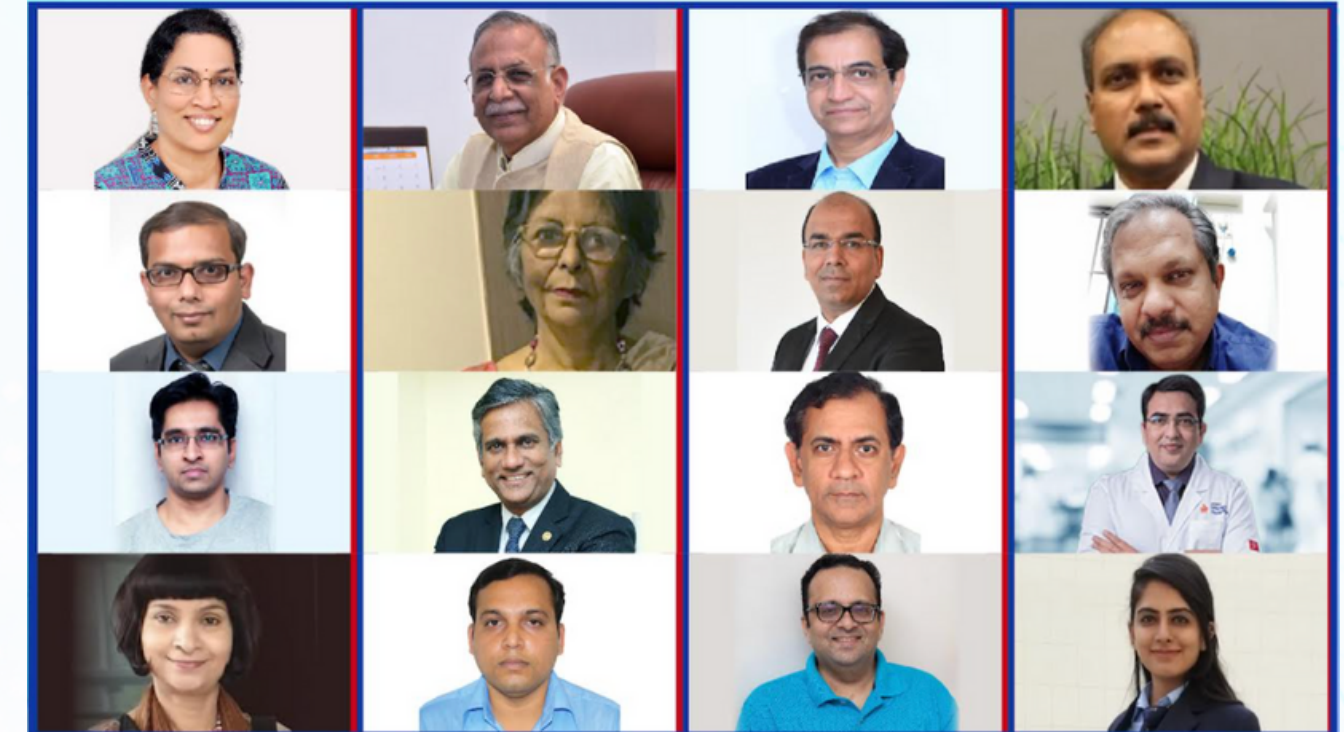
DELHI We Care Stroke foundation- Dr. Biplab Das & Stroke Support India- Hardeep Sodhi

MUMBAI Mumbai Stroke Society- Dr. Shirish Hastak

TELANGANA Second innings - Dr. Vijay Bathina

2. Outreach to specialists, survivors, and caregivers

- 20 webinars including rehab sessions with 6 survivor stories including 12 videos and 4 text stories
- 160 specialists including WHO- Dr. Pradeep Joshi, ICMR, NITI Ayog, NHA, Govt of Kerala, professional associations like ISA, IAN, AOCNR, physiotherapy associations, disability specialists



- Stakeholders were reached out to and mapped in four cities– Delhi, Mumbai, Chennai, and Hyderabad. The umbrella group was named Stroke Support Alliance and under this initiative, online meetings with stroke specialists, rehabilitation specialists, and stroke support organisations were conducted to enable outreach to stroke survivors. Around 160 government and private sector officials from a diverse set of educational and institutional backgrounds across public and private sectors, like health insurance, neurologists, neurosurgeons, NCD focal points, NPCDCS focal points from the four regions were reached out to, to seek their inputs on a policy analysis paper and recommendations for “National Stroke guidelines” from patients' perspective.
- Civil Society Steering Committee (CSSC) on Stroke: The Civil Society Steering Committee (CSSC) on Stroke was established as an advisory body of Stroke Support Alliance. The CSSC is a voluntary body and oversees the activities of the Stroke support Alliance providing insights and guidance to the patient body.
- An analysis of the National Stroke Guidelines 2019 was provided to the CSSC review and suggest recommendations to improve the National Stroke guidelines.
- Motivational stories from other survivors like cerebral palsy, aneurysm, Parkinson's

3. Outreach to hospitals

CHENNAI

MIOT international Hospital, Apollo Hospital, Greams Road , Sri Ramkrishna Hospital, KCMH hospital
KIMS Hospital, BSS Hospital, Sagar Hospitals, Christian Medical College Hospital Vellore

MUMBAI

Gleneagles Global Hospital, Kokilaben Dhirubhai Ambani Hospital and Medical Research Institute
King Edward Memorial Hospital Seth Gordhandas Sunderdas Medical College, Topiwala National
Medical College, B. Y. L. Nair Charitable Hospital, Tilak Municipal Medical College & Lokmanya Tilak
Municipal General Hospital, Sion Hospital, Fortis Hiranandani hospital vashi

DELHI

Fortis Flt. Lt. Rajan Dhall Hospital, Apollo Hospital, AIIMS Delhi , MAX Healthcare, Manipal Hospital,
Dwarka, Fortis hospital, Gurgaon, St Stephens Hospital, New Delhi

TELENGANA

Apollo Hospitals, Care Hospitals, Sunshine Hospitals, Nizam's Institute of Medical Sciences



4. Awarding scholarships:

4 scholarships were awarded to the winners on the occasion of World Stroke Day. This was viewed as one of the opportunities for the survivors and caregivers to upgrade their skills to enable them to lead a better life and meet the demands of the family. The scholarship will help survivors and their family members to explore learning opportunities in their career and in their field. Not only that, but it would also help them develop their own start-ups by enabling them to study through a variety of courses. Scholarships provided them with the motivation they needed and helped them regain their confidence.

- Ms. Akansha Sharma
- Mr. Arvind Chitoor
- Mr. Bhavesh Thakkar
- Mr. Mohan Kumar



Objective 2- To educate patient groups about early signs and symptoms of Stroke for timely diagnosis and treatment. Social media and communication



strokesupportalliance.org



[Strokesupportalliance](https://www.facebook.com/Strokesupportalliance)



[stroke_support_alliance](https://www.instagram.com/stroke_support_alliance)



chai pe
charcha

5 sessions with
patient advocates



Two newsletters
(bimonthly) published



[https://www.youtube.com/c
hannel/UCO_WQN7mKaEFla
il7OxwIaA](https://www.youtube.com/channel/UCO_WQN7mKaEFlail7OxwIaA)



Total posts on Facebook- 202, Post engagements- FB, twitter and LinkedIn- 10,000+

Post reach

Facebook and Twitter – 26465

LinkedIn – 11,053

Trending posts

WORLD STROKE DAY
EVERY STROKE MATTERS

28TH OCTOBER, 2021
04.30 PM ONWARDS

[REGISTER NOW](#)

KEYNOTE SPEAKER

Dr. Jeyaraj Pandian
President, Indian Stroke Association, Chair, Principal (Dean) and Professor of Neurology Christian Medical College
STROKE MANAGEMENT – GLOBAL BEST PRACTICES AND NEED FOR STRENGTHENING STROKE CARE IN INDIA
LAUNCH OF B E F A S T VIDEO BY STROKE SURVIVORS

Dr. Pradeep Joshi
Technical officer, NCD, WHO India
PATIENT VOICE IN POLICY- LEARNING FROM DIABETES COMPACT

[Click here to access](#)

Stroke Support Alliance

WELCOMES STROKE SURVIVORS AND CAREGIVERS
ONE ON ONE LIVE INTERACTION
ON STROKE REHABILITATION

WITH
Dr. DHARAM PANDEY
Head Of Department - Department of Physiotherapy & Rehabilitation Sciences at MANIPAL HOSPITALS, Delhi

12th June Saturday | 03:00 pm IST
Your queries will be ANSWERED LIVE

Submit your Queries to: tamanna.sachdeva@dakshamahealth.org or share it on our patient forum: <https://strokesupportalliance.org/patientforum/>

REGISTER FREE!

<https://bit.ly/3ptWFuw>

+91 81300 50439
<https://www.facebook.com/Strokesupportalliance> <http://www.strokesupportalliance.org/>

[Click here to access](#)

1. Development of IEC materials on stroke

Pamphlets of stroke

15 Pamphlets developed to raise awareness on stroke among the community/stroke survivors and their caregivers. These are also shared on our website under resources. [Click here to access.](#)

Booklet on stroke for survivors

Developed booklet for stroke survivors and caregivers in 4 languages. English, Hindi, Marathi and Tamil. [Click here to access.](#)

Podcast on stroke

Developed a series of podcasts on stroke which can help us in reaching out to new audiences broadcasted via Spotify. [Click here to access.](#)

Newsletter Stroke support Alliance

500 stroke survivors and caregivers as registered participants for our webinars. A bimonthly newsletter with patient stories, updates to treatment, activities etc. was circulated. [Click here to access](#)

Film on Stroke Awareness

Developed a short film on stroke awareness, BEFAST protocol with stroke survivors (6). The videos were recorded in Hindi and English language by the survivors.
English - [Click here to access](#)
Hindi - [Click here to access](#)

Resources on stroke

Developed resources for stroke survivors and caregivers. All the resources are shared on the website under the resources page: [Click here](#)

2. Advocacy with State and Central governments

We have conducted national, west, south, north regional consultations.

Regional /National Consultation	Date	No. of stakeholders
South regional consultation with JIPMER	28 AUG	8
West regional consultation with Mumbai stroke society	18 JUL	8
North regional consultation with Indian stroke association	18 SEP	7
National consultation in collaboration with Indian Stroke association	28 OCT	14

3. Letter to state and central governments

Letters were sent to IRDA, NHM, NHA and Directorate of Health requesting adoption of the recommendations presented during various consultation.

4. Letter to state governments by patient advocates

Patient advocates from four states have sent out a letter to the respective state governments requesting a common state directory for stroke-ready hospitals and rehabilitation centres.

- Mumbai: Ms. Geeta Bhansali
- Delhi: Mr. Kamran Khan
- From Chennai: Mr. Srivathsan Dharan
- From Hyderabad: Mr. Arjun Bhavanasi



5. Analysis of Insurance coverage for the treatment of stroke in India

Analysis of insurance coverage across the public and private sectors in India. In addition, we engaged four interns from MBA – finance stream, Regent Education and Research Foundation to undertake a financial risk analysis for patients with stroke. The document reviewed the current policy riders for stroke care. Stroke patients were interviewed in order to determine what benefits they were entitled to under their insurance policy. According to the study, stroke patients end up paying exorbitant rates for benefits that are limited to hospitalization. Rehabilitation and long-term care appear to be overlooked by insurance companies.

6. Participation and representation of Stroke Support Alliance in International Conference

Two speakers were invited from Stroke Support Alliance to represent their work at the AOCNR 2021 conference. The work was deeply appreciated and an invite to work closely with patient groups in Nepal, Bangladesh, Sri Lanka, has been extended to SSA.



7. Articles on stroke

Are post-stroke complications pushing young stroke survivors towards lowered quality of life and disability?

By EH News Bureau — On Nov 8, 2021

NEWS | QUEST BLOG



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98 | 0

Read Article

Dr Ratna Devi, CEO, Dakshama Health and Tamanna Sachdeva, Project Officer Policy, Dakshama Health talks about post-stroke complications

Stroke-cerebrovascular accident (CVA) and a non-communicable disease is the second leading cause of death worldwide with an annual mortality rate of about 5.5 million. 1 in 4 over the age of 25 will experience a stroke in their lifetime. According to the World Stroke Organization global fact sheet over 80 million people are currently living who have experienced a stroke globally. In addition to this 116 million years of healthy life is lost each year due to stroke related death and disabilities¹. According to the Global Burden of Disease Study 2019, stroke was ranked as the second most common causes of health loss or Disability Adjusted Life Years (DALYs) in the 50-74-year and over 75-years age groups and posed a significant burden in the 25-49 years of age group².

Low and middle income countries show an increase in stroke incidence and stroke related mortality. Stroke incidence in India is higher (194-215 per 100,000 population) in rural areas when compared to the national average (119-145 per 100,000 population), which is almost a 100 per cent increase (till 2016)³.

In India, 10-15% of strokes occur in people below the age of 40 years. It is believed that the average age of patients with stroke in developing countries is 15 years younger than that in developed countries. Nearly one-fifth of patients with first ever strokes admitted to hospitals are aged <40 Years⁴. Risk factors like hypertension, diabetes mellitus, smoking and alcoholism are on the increase in younger populations with changes in life style, industrialisation and poor dietary habits.

The acute episode of stroke is often followed with various complications. Some of them includes paralysis, difficulty in swallowing, weakness, incontinence depression and the inability to live an independent life. Young adults suffering from stroke have a larger bearing on the functioning of their family, employment, society, and country as they are in their economically most productive period. The impact on the employment status following a stroke can affect more than their ability to pay for their bills, affecting their sense of purpose and confidence, causing difficulties at work, or even being at risk of losing their job, due to disabilities resulting from stroke. For many, the loss of income comes with huge financial burden on their family. A preliminary analysis of 100 acute stroke cases (CT confirmed), using WHO STEP-wise Approach to Stroke Surveillance, Hastak, et al (2003) reported that at 28 days the overall case fatality rate was 9% and nearly 31% of survivors had severe neurologic disability/handicap whereas 13% had mild disability needing assistance. Only 47% of survivors were independent at the end of 28 days. Many stroke survivors get back to their work eventually, but some of them are not able to due to the disabilities that persist. Unfortunately, many of the survivors who has experienced stroke are the main breadwinners of their family making it difficult for them and their family to even manage their daily living, education, and cost of their long-term treatment or rehabilitation.

Financial burden along with the isolation following loss of employment, can severely affect a stroke survivor's mental health. This develops various anxiety, depression and anger issues. Along with the survivors it becomes equally challenging for the caregivers to cope up with the burden of being financially weak. It is therefore incredibly important that stroke survivors are given access not only to treatments and therapies but also opportunities that will help them socialize and bring them back into the community. Apart from this, inclusion of the stroke as one of the disability under Rights of Persons with Disabilities Act, 2016 must be taken into consideration. This will help the survivors to better manage their employment and financial burden under the benefits being entitled under the act.

"Are post-stroke complications pushing young stroke survivors towards lowered quality of life and disability?" –
In Express Healthcare

Author: Dr. Ratna Devi and Tamanna Sachdeva

[Read here](#)

Stroke is a leading cause of disability and death in India

Dr Jeyaraj D Pandian
10 Nov 2021 5:39 PM

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Recognising stroke symptoms are important since with each one-minute delay 1.2 million nerve cells are affected in the brain. (Photo credit: Getty Images)

News

- In India every year 1.7 million new strokes occur.
- There are two types of strokes, ischemic and hemorrhage.
- High blood pressure is the leading cause of both types of stroke.

Globally, stroke is the second leading cause of death and the third leading cause of disability. Whereas in India stroke is one of the leading causes of disability and death.

In developed countries, stroke occurs in the elderly population however in India, and other developing countries, stroke affects largely younger people. There is a major economic impact on the family particularly if the stroke survivor is the only earning member.

Also Read - Cervical Cancer Awareness Month: Regular testing is key; HPV vaccine for girls below 14 years must

In India every year 1.7 million new strokes occur. Every 40 seconds one Indian suffers a stroke and one dies of it every 4 months in India. There are two types of strokes – ischemic when there is a blockage to one of the brain arteries and hemorrhage, when one of the brain arteries ruptures and leaks. High blood pressure is the leading cause of both types of stroke. The other causes include high blood sugar, high cholesterol, smoking, heavy alcohol consumption, obesity, lack of exercise, air pollution, unhealthy food habits, heart disease, irregular heart rhythm and drug addiction.

Also Read - Explained: How full market approval of COVAXIN, Covishield may impact vaccine regime

Recognising stroke symptoms are important since with each one-minute delay 1.2 million nerve cells are affected in the brain. Stroke can be identified with the FAST acronym. F- sudden drooping of one side of Face; A- sudden weakness in one Arm; S- sudden disturbance in Speech; T- act fast. The patient should be taken by an ambulance or hired/own vehicle to a hospital with a CT Scan facility and a neurologist/physician.

Also Read - Coronavirus LIVE Updates: Delhi Lt Guv rejects Kejriwal's proposal to end weekend curfew, favours status quo, say reports

"Stroke is a leading cause of disability and death in India"
in News9 India

Author: by Dr. Jeyaraj Pandian

[Read here.](#)

Conclusion and Recommendation:

- Infrastructure and human resources: low-doctor population ratio, lack of trained medical professionals, lack of CT scan facilities, non-availability of lifesaving interventions like thrombolytics and well-managed ambulance services are lacking and need to be worked on.
- Care continuum pathways need to be developed and patient involvement at all levels of healthcare
- Inclusion of stroke under healthcare insurance: it should be recognized as a separate Neurology package under Ayushman Bharat-PMJAY. This will only assure that the beneficiaries have access to therapy for one of India's main causes of mortality. Rehabilitation aspects must be taken into consideration as well.
- Rehabilitation and palliative care that are restricted to private hospitals must be extended to the remote areas. Need to establish a skilled stroke rehabilitation workforce, which can be accomplished by providing them with accredited stroke rehabilitation training.
- We need to come out with a workable feasible model with for stroke management that can be considered as a benchmark to deliver stroke care services.
- Mapping out the patient's journey along with the difficulties they face should be taken as a forefront to shape the current national stroke guidelines. The patients and caregivers perspective along with the community healthcare workers and PHC physicians should be included.

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