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# DELIVERING HOPE !

Newsletter of Stroke Support India

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Stroke Support India

Delivering **HOPE**

Web : [strokesupport.in](http://strokesupport.in)

Raising Stroke Awareness and  
Supporting Stroke Survivors  
and their Families

## Recovery.....

It will be challenging.....

It will also be worth it.

It will take time....

But keep on striving and fighting.

When you feel alone in your struggles...

Try to help others who are struggling...

even if only by words !

Your loved ones may not understand....

But try explaining best you can anyways...

You will have good days and bad days...

But the bad days will get fewer.

Your problems will not magically go away...

But they will be more and more manageable..

You might not feel different at first...

But slowly yet surely, you will be

Healthier....

Happier.....

Stronger...

and Recovered

And, most of all...

be more grateful for this wonderful life !

Who knows, you may inspire others on the Journey !

So, Stroke Warriors - keep on fighting !

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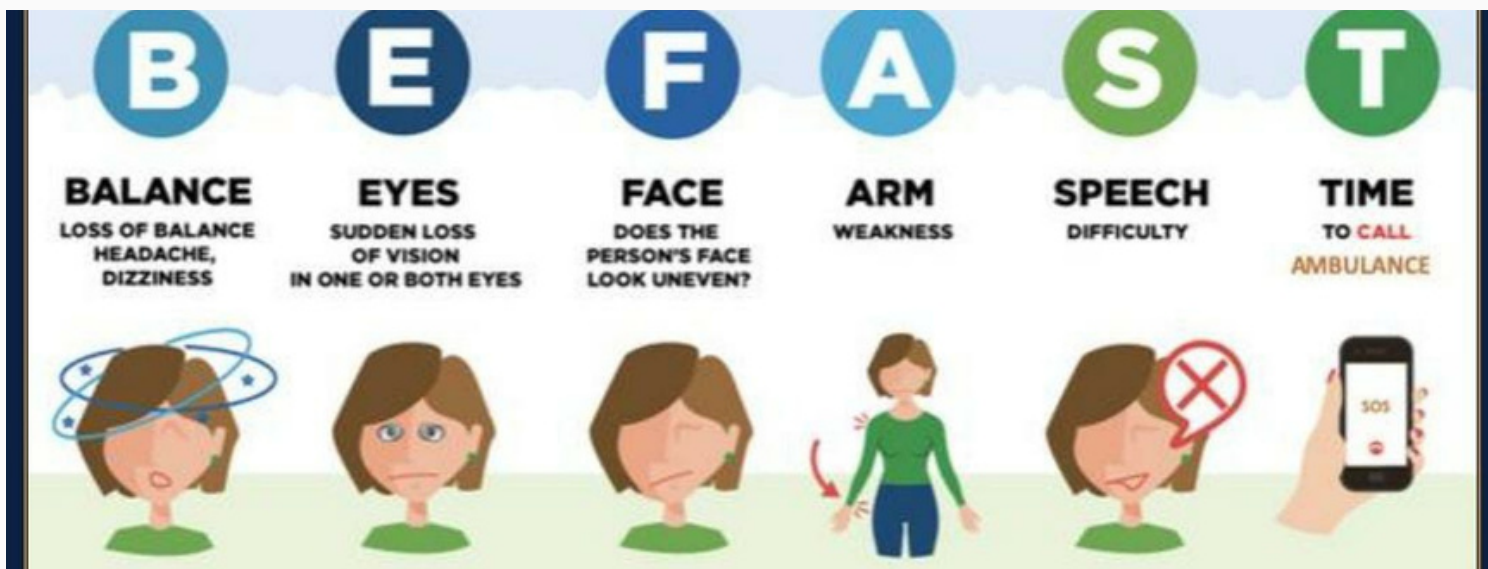
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OR CLICK TO [HTTPS://STROKESUPPORT.IN/ADD !](https://strokesupport.in/add)**

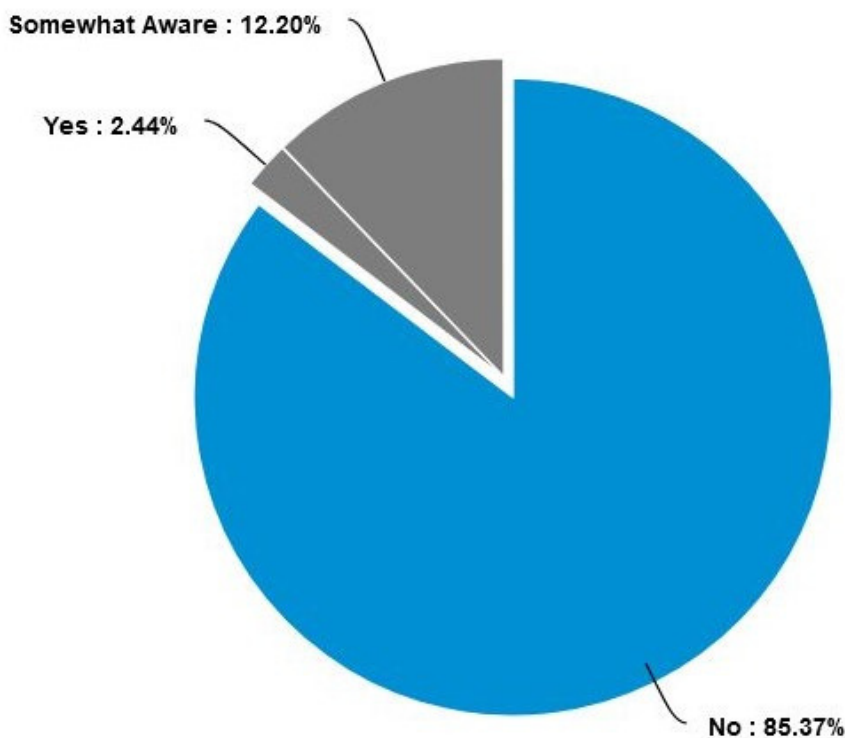
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**ALWAYS REMEMBER AND TELL OTHERS THE MOST COMMON SYMPTOMS OF STROKE AS SHOWN ABOVE ! For more elaboration please see <https://strokesupport.in/be-fast>**

Stroke Support India is having an ongoing Survey on Time taken to reach proper stroke treatment and its impact on outcome of stroke. All stroke affected/ family caregivers may participate via :

<https://strokesupport.in/r/time> . Here answer to one question (as of end March 2022) : " Were you aware of stroke when it happened to you " ? .



As can be seen, stroke awareness remains a huge challenge. And stroke is a disease where awareness significantly impacts response time and consequently outcome ! So be aware and tell others too !



# My Stroke Journey

BY- APARNA BHATACHARJEE



## MY LIFE BEFORE STROKE

I had been working in the corporate world since the last 17- 18 years. I enjoyed every minute of it. Deadlines & targets gave me a different high. My last stint was with a global travel company in which I handled International Partnerships between countries, which gave me a chance to travel the world.

Personally - I am fun loving & a highly positive person. I strongly believe in being happy & spreading happiness & compassion around. As I grew up, this quality in me grew stronger, which led me to join various social causes - I was part of Dignity Foundation (for senior citizens). I was actively involved in education for underprivileged street children. In fact right now also (after stroke) I'm part of Eklavya Bindaas Bol project which encourages vernacular medium students to speak in English, become confident socially, give interviews & bag corporate world jobs.

Inspite of my hectic schedule I ensured I lead a healthy lifestyle. I exercised 3-4 times a week. I also ensured I stuck to a healthy diet...

## MY STROKE INCIDENT-

12th October 2020 - It was just another day...A Sunday...My regular glass of water first thing in the morning felt heavier... immediately panic gripped me & I went running to my mom saying something is wrong...in 2 mins all was okay with me & we were a happy family once again checking each others blood pressure & having fun...None of us realized I went through a stroke...

Later that day I went about doing my usual chores...went to our other house for Diwali cleaning...after doing all the work I went for my usual evening walk...one hour of brisk walking..I realized something was not right...So that evening itself I called my General Physician & told him that something was awry...He told me to see him the next day...

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**“Whatever we plant in our subconscious mind and nourish with repetition and emotion will one day become a reality.”**

- Earl Nightingale

**“You will never know how much you can accomplish until you try. Never stop trying. Your miracle will come in undefined moments.”**

-Lailah Gifty Akita, an inspirational writer

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Aparna's Journey, Continued...

The next morning my GP called me to say not to come & that my appointment has been canceled because entire Mumbai had gone through a major power failure. I still insisted he see me, to which he finally agreed. His clinic is in one of those ancient British architectural buildings in Churchgate with huge staircases. Since the lift was not working, I climbed 5 floors with full energy, absolutely fine !

He examined me... took my vital stats which were all fine... gave me a tablet (Meganeuron) & said go home. He also said just get a spinal x-ray done.

On the way back, my brother who was with me said - let's go to our family doctor since he knows our family since childhood. No one in my family has had a stroke. The family doctor too physically checked me, took my vital stats...gave me a tablet (Thelmakind) and told me to go home. At that time my BP was 150/100 and blood sugar was 98....

Thereafter we went on to get my spinal x-ray done, thinking let's not keep this pending. But on the way to the hospital my right hand just froze and became completely cold. I realized something was not normal. Anyway I went onto the hospital only to be told that machine is not available. I called my GP frantically who unfortunately was not available at that time.

Post that we decided to go to another hospital for the test ( 2nd hospital). I seem to have recovered and could walk up to the 2nd hospital. By that time my GP called back & asked me to get CT scan of brain as well done, which I did. Another test asked by him ( serum creatinine) could not be done as the hospital said it needs to be done on empty stomach.

We decided to get an MRI done as well. But as Covid was at its peak, getting it done was a problem. Finally, at a 3rd hospital I could get it done which also did not reveal anything, yet they advised admission as a matter of abundant caution. This was almost 36 - 40 hours after the initial symptoms.

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“If my mind can conceive it, if my heart can believe it, then I can achieve it.”

- Muhammad Ali

***2021 was the beginning of the second year post stroke for me. I achieved a few moments which seemed too difficult to do at one time. I interacted with and joined groups of various stroke warriors across the globe which helped me realize that I am not alone with this history. These were the most important of the many positives that happened in 2021. The negatives include having my first seizure post stroke due which needed new medicines, and losing my job because of disability. But I am looking forward to recovering well and am sure will have better and more positives in 2022 !***



- Stroke Warrior  
Prateek Luthra



Aparna's Journey, Continued...

I had walked up to the MRI machine and got admitted on my feet. For the next 3 days in the hospital I was actually able to do squats & lunges & my usual exercises. I was even going to the bathroom on my own. All my reports were coming clean. On the 4th day, the doctor gave me some medicines via drip. But that did not seem to help as almost immediately thereafter my right side slumped and my balance was lost. I became worse, so much so that I became totally dependent.. I stayed in the hospital for 13 days.

#### **AT DISCHARGE -**

Physical state - I was discharged on a wheelchair. Mental state - Calm & waiting to get back to normal & beat the hell out of this sickness

#### **MY LIFE AFTER STROKE -**

Physically - I am much much better now since I started my physiotherapy from the next day itself & continue doing so...I am almost fully independent now..

**Family support** - is a must. Since I'm not married I live with my mom & brother, who thankfully treated me NORMAL since the day I came home from hospital. This was the BEST thing they could have done. It pushed me to becoming normal faster.

**My current lifestyle** - remains the same (except watching movies in theaters which I love). It is more healthy now with tons of exercises & diets.

**My outlook on life now** - Stroke has definitely changed my outlook towards life. I am much more calmer. I've become extra sensitive towards others. Patience has increased. I'm more of a listener. More self aware (almost on the footsteps of Dalai Lama..haha).

**My few tips to caregivers** - Be patient with us. Give us time. We ourselves don't know what hit us. We are much more vulnerable than you think, but don't want to show it. So give each stroke survivor it's time to recover because as we all know every stroke is different!!

**To my fellow survivors-** Simply believe in the fact that this situation is going to change & IT WILL CHANGE. Follow a discipline even if it is for 10 mins. Have the courage to accept what has happened. The earlier you accept the better & faster for your recovery. Thank your physiotherapist, caregivers, family because they are going through an equally hard time like you.

**Remember- You are a masterpiece in making. Quitters never win and winners never quit !**

**“You don't  
have to  
see the  
whole  
staircase...  
just take  
the first  
step !”**

- Dr. Martin Luther King



## Our Stroke Journey

BY- SHRUTHI FOR GURURAJ

I am writing about the progress of Mr Guru after stroke since he has Brocas Aphasia after a stroke in October 2017.

My husband was 42, a senior manager in a Software firm in Bengaluru when he suffered an ischaemic stroke. There were no symptoms prior to stroke. I understood that it was a middle cerebral artery infarct. This was followed by midline shift of the brain due to oedema. Subsequently decompressive craniotomy was performed 48 hours after stroke.

Guru came home after 15 days in hospital. He had lost his speech entirely and he had suffered right hemiplegia.

**We were well aware that we will be facing new challenges , new realities, that we will have to accept and adjust to new normals. We were also aware that we will be facing the unknown. We started our new life with grit and determination.**

### Our family:

We are a nuclear family. Our daughters were in 5th and 2nd standard at the time of the event.

### Journey towards recovery:

Physiotherapy and speech therapy were started immediately after we came home. He was first taught to turn around in bed, get up and sit, put small steps. His feeding tube was removed after a month. **I explained what had happened to him. He accepted with grace and indicated in sign language that he will not give up.** He was mentally prepared for the next surgery. Cranioplasty was performed within 3 months after stroke. During this continuous therapy, Gururaj has progressed from being dependent for everything to handling daily chores independently. He also challenges himself with small activities. Physiotherapist is guiding to help improve the hand function and gait pattern. Currently he can lift his right hand. Over the years he is improving in his strength also he is able to do different types of activities.

We realized the importance of sensory function / sensation. Both speech and physiotherapists have guided us in this regard. It also important to understand the underlying cause of stroke. It is more important to take necessary steps to prevent the same.



“Our  
greatest  
glory is  
not in  
never  
falling ,  
but in  
getting up  
each time  
we fall ...

-Confucius

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## Our Stroke Journey

Shruthi & Gururaj's Journey...Contd...

Corona virus pandemic has affected us in different ways. Although the changes brought about by pandemic was difficult to handle, we tried our best to overcome the same.

### **Our efforts to improve speech :**

First of all, the speech therapist taught us mouth exercises , which in turn helped to improve sensory function and breathing. Our first speech therapist started training with pronouncing individual sounds like “a”, “b” , “c,” “d” etc. Initially spelling individual sounds felt like a herculean task both for Guru and for me (to help him understand how to pronounce a particular sound was very difficult for me.) In fact that part of the journey was most tedious and exhaustive. He used to get tired by spelling a single sound. Mouth exercises also helped to produce individual sounds.

**Sometimes its good that we know that we have no other options but to face it or fight it out.** We knew we had to come out of that phase and move a step forward. He progressed to 2 letter, then 3 letter words. Then he was trained to speak small sentence. **The major breakthrough in speech was through melodic intonation therapy.** One day when my father was chanting shloka, Guru sang a few words with him. We informed the speech therapist immediately. He advised and trained us to use the melodic intonation therapy to progress further. Second year **appeared as plateau** to us. We decide not to give up and put in more efforts. From third year onwards after stroke , I can find improvement in the way he responds, clarity of words, improvement in cognition, understanding and sentence making ability. Now he is able to ask us questions in a single word or a small sentence. We are working towards improving all the above said factors.

**Regular practice and repetition has proven to show improvement.** I have often observed that Guru says new words, also tries to say sentences while speaking over the phone and while trying to build a conversation with others.

Contd. P 8

Stroke  
Warriors  
- develop  
the  
attitude  
of :

" If It's  
Going  
to Be,  
It's up  
to Me"



## Our Stroke Journey

Shruthi & Gururaj's Journey...Contd...

### Alternative therapies :

Ayurveda panchakarma and other relevant treatment's as suggested by Vaidya has helped in improvement. Acupuncture, colour therapy, seed therapy, varma therapy were going on simultaneously with physiotherapy. With pranic healing , I observed that he became emotionally stronger and his decision making skills became quick.

### What helped us face the situation:

Mr Guru is a person with a positive mindset, calm , understanding and quickly adapts to changes. He is self motivated and a fighter in true spirit. All these qualities have helped us in this journey. We always had a simple lifestyle and appreciated every small thing around us. Our sense of gratitude has taken us a step further in life. Our children , although quite young at that time have resonated the same feelings through out these years. Though we faced innumerable challenges, especially more due to aphasia – all these qualities have helped us sail through the toughest of situations.

**Understanding the principles of neuroplasticity, relearning and brain rewiring has motivated us to put our best efforts.** We have always felt along the way that the divine blessings are always with us.


Being active through out the day by engaging in different types of activities has helped to gain and maintain the strength. **Participating / attending various types of events and involving in outdoor activities (Social rehabilitation) has helped in better recovery.**

We read lot of inspirational stories , see many inspirational videos with children. It keeps all of us motivated together as a family. I have realised that **involving the family members in small tasks, daily chores together with stroke affected sensitizes to each other's needs and feelings.** It also ensures that daily activities of all the family members and the stroke affected is going on smoothly.

I feel it is necessary to take breaks when we feel tired or do not want to do anything on a particular day. We do some new activities when we feel a need for change.

“The  
time  
to be  
happy  
is now.  
The  
place  
to be  
happy  
is  
here.”





# PSYCHOLOGICAL ISSUES AFTER STROKE: UNEXPLORED AREA OF REHABILITATION

BY- DR. FORUM SHAH ( PT)



After stroke effects are not only pertaining to neurological, musculoskeletal or any other physical impairments but also it carries several psychological and mental issues to not only stroke survivors but also to their care givers and family members.

In present times, physical rehabilitation is a central component to help the stroke survivors to manage difficulties they may face in activities of daily living and maximizing their participation in society. A psychosocial model of rehab is frequently relied on. This model focuses on impairments along with psychosocial health of the individual. As psychological care is a multidisciplinary area of care not only stroke survivors but their family members, care givers, medical staff, psychological counselors well play major roles.

Here are some key points for administrating psychological care for stroke survivors:

- Everyday assessment of patients mood and anxiety level on a very basic level can be done by the people around so that he can be managed accordingly.
- Raising Awareness of psychological issues among stroke survivors, family and care givers are very essential particularly in a country like ours where this issue is not addressed.
- Active listening from patients, care givers and family perspective about their emotional state, difficulties faced in day to day activities is of utmost important to carry out further rehab.
- Providing advice and information for adjustment, modification, goal setting and problem solving.
- Support can be sought from support groups, individuals who have survived stroke, people who are working in this field who can help to boost up confidence and enhance psychological wellbeing.
- Group activities or sessions can be carried out for all the individuals for educating them for what can be done to improve psychological status.
- Resources and educational material can be provided to the stroke survivors and family members along with care givers.
- It is important to ask for feedback and continues follow up should be taken after attending the sessions or about the materials to see for improvement and reduce drop outs.
- Customized protocol should be made for each and every patient looking at his goals so that his problems can be addressed. Motivational tools such as appreciation and even rewards may be used to help towards improvement and goal achievement.

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- Rehab professionals should use strengths and interest of patients in any aspect to support his weakness and involve in him actively in rehab during the session.
- Explaining to the survivor and family members the mechanism of injury with the process of recovery, its impact and implications can help him to cope up with his after stroke psychological effects, and also help towards acceptance of the situation when needed. These can help greatly the survivor becoming self-dependent as much as possible.
- It is important to help survivor to integrate a new sense of self and align this with the old self before stroke. This can be useful to reconstruct new image of the individual and integrate it into day to day life. It is useful to explore discrepancy between pre-injury state and after brain injury state and goal achievement should be realistic and achievable.

In summing up, addressing psychological issues and needs after stroke should be done upfront. Such needs should be assessed and addressed as an essential part towards stroke recovery. This can play a strong role in physical rehabilitation and in improving the functional status of the stroke survivor.

***“Psychological care is less about ‘fixing’ and more about understanding and offering timely support”-Dr.Posy Knights***

*Dr. Forum Shah (PT) is an active member of our Stroke Support Group, and a practicing physiotherapist at Valsad (Gujarat). She has done Masters of Physiotherapy in Neurological Sciences with special interest in Cerebral Palsy, Stroke and Parkinson's disease.*



## Some Happenings...

- **Why is stroke awareness important .. A Video Presentation in Bangla .**  
Link : <https://youtu.be/zAArA37evPQ>
- **Physiotherapy Session with Dr. Forum ( Fourth )**  
Link : [https://youtu.be/Sum\\_h5zKejE](https://youtu.be/Sum_h5zKejE)
- **Speech Practice Session with Shruthi (Second )**  
Link : <https://youtu.be/aZPGWjePnBw>
- **Pranic Healing with Ms Nagalatha P. and Dr. Prithviraj P.**  
Link : <https://youtu.be/la3d31MHly8>
- **Aquatic Therapy- Chat with Dr. Brinda Merchant (PT)**  
Link : <https://youtu.be/vWi4Y5v-Wys>

## and some Plans !

Similar and other activities are planned in future as well, including offline And most hearteningly, all are done by voluntary help and participation of the members of Stroke Support India.

Join our Support Groups to be informed of other events and participate/help where you can !

“Just keep going. Everybody gets better if they keep at it.”

- Ted Williams

**Please forward this Newsletter to any it may benefit. Thank you !  
All feedback, suggestions and help welcome.  
E-mail to : [strokeindia@gmail.com](mailto:strokeindia@gmail.com)**