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DELIVERING HOPE !

Newsletter of Stroke Support India

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One day you will
tell your story
of how you've
overcome what
you're going
through now,
and it will become
part of someone
else's survival
guide. ♡

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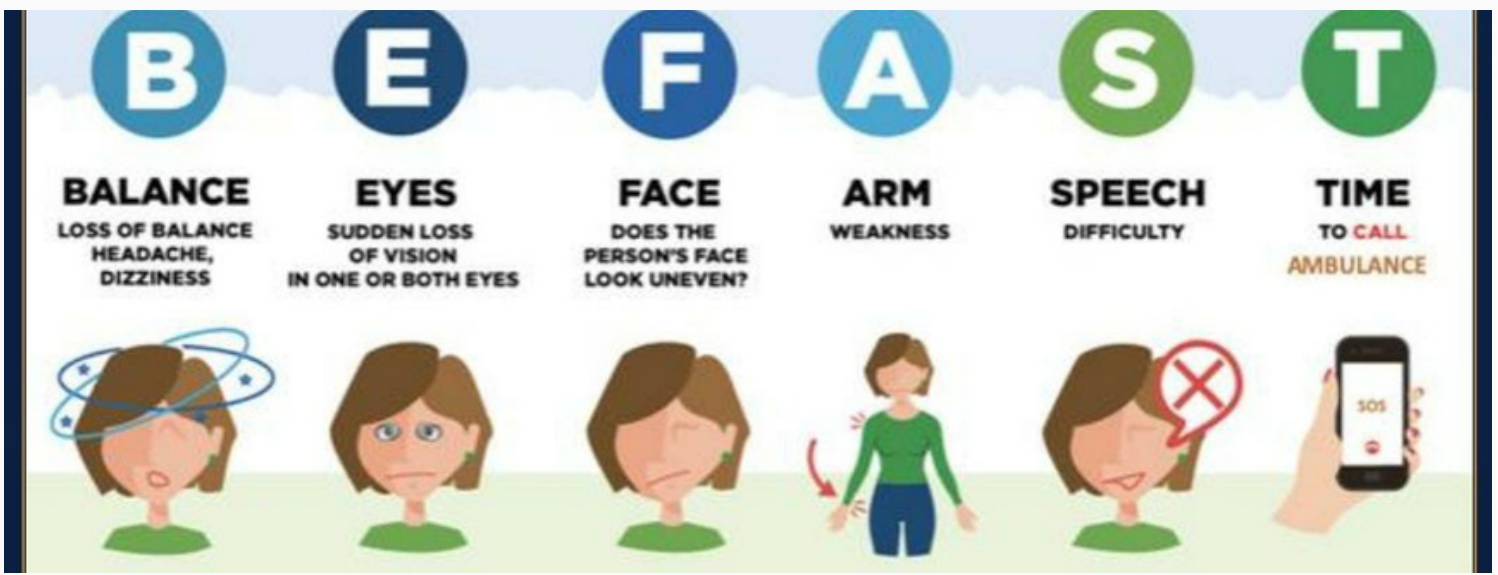
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ALWAYS REMEMBER AND TELL OTHERS THE MOST COMMON SYMPTOMS OF STROKE AS SHOWN ABOVE ! For more elaboration please see <https://strokesupport.in/be-fast>

On Aphasia - a Short Introduction



- Aphasia is a communication disorder that affects someone's ability to speak or understand speech. It may also impact how they understand written words and their ability to read and to write. However, their intellect usually remains intact.
- Aphasia happens due to damage to speech and language zones of the brain, which may be caused by stroke as well.
- Appropriate therapy, along with strong practice may lead to good improvements as evidenced by many people, including on our Support Groups

We are developing a separate group for the Aphasia affected, their caregivers, and experts. All can join via <https://strokesupport.in/add> .

June is Aphasia Awareness month. See our chat on Aphasia at https://youtu.be/rYDw_Mher8Y and share with others too !

My Stroke Journey- Discovering and Accepting a new Me !

BY- SREEKANTH KESAVA

For a very long time after my stroke (almost 3 years) I struggled with my state. Not that I was not able to accept what had happened, I had crossed that hump, but what it had made me become.

I used to be very active before the stroke. Physically doing things and active generally. I used to play a lot of sports in my younger days - and was good at it, or so I believed.



Suddenly becoming bed ridden and being unable to do anything was a lot to deal with. I used to love foods and to cook. Being unable to do either was the insult on top of the injury!

Sometime back (a few months ago I guess) it dawned on me that that the root cause of this misery was that fellow. Comparing everything with him.

He died long ago - well and truly! I wouldn't say I was born that day fully, but this new me came to life.

I didn't start with a blank slate, I still had a mind, a mindset, an IQ. A personality overall.

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About Sreekanth

Sreekanth had a massive basilar stroke on 6th Feb. 2019. He was 43 years old at the time and leading a normal, healthy lifestyle. Presently he has minimal movements on left hand side, and none on the right. He can't speak and feeding is via PEG tube. But he can type using some movements in his left hand. And that has liberated him from the cage ! He writes wonderfully well, and these were some of his thoughts he is truly a great inspiration and exemplifies that where there is a will, there is a way !



My Stroke Journey- Discovering and Accepting a new Me !

BY- SREEKANTH KESAVA

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But I was a completely new person !

I was lucky enough that I came alive with many of those faculties and abilities. In many many cases, even the personality of the new person is so very unpredictable.

It made me realise I was not really disabled per se. I was just here with these new set of abilities. Some of them, if I am lucky, will get a little better over time even.

It is a subtle change in the thinking but does a huge change to the mindset overall.

I would assume it is the same case with all life changing situations (accidents, natural calamities, man-made disasters, etc). It probably helps to remove the memory of the earlier person to remove the shackles from the mind.

Likewise for a stroke affected, and especially for carers and family and loved ones - simply because that person is no longer present.

Who is present is a completely different person - with a different set of abilities and personality. Many times, that person will also not be familiar with his/her own new self and struggling with it as well.

It will probably help to forget the earlier person and personality and make peace with reality and adapt to the new person - with new abilities and personality. Of course all the times making all possible efforts to be the "best" new person one can be.





My Stroke Journey- Finding Purpose and becoming a Better Me !

BY- WILLSON GAEKWAD

I am a stroke survivor and warrior for last about one and half years.

It was on 19th November 2020 at 3:00 PM when life intervened with an event which, I am determined, will make me a better person. And indeed it even already has.

Before stroke life was busy. I was a sincere though not studious student. But I did try me level best. I am reminded of my teacher Ms Vijaya who wrote in my class X " Autograph Book " that ' Education is the only thing that you can never lose, and that you can have as much as you want to ".

From school to college - I studied to become a Masters in Microbiology , with research in Nanotechnology. Alongwith I did my LLB with a focus on labor laws. With a Diploma in Medical Technology I was working very hard to achieve my " goals" .. but to be frank I was not sure about precisely what they were.

That changed after my stroke. I know that I have to live a purposeful life for my children and also for society in which we all exist. Due to my stroke only I came across Stroke Support India group where, interacting with my fellow brothers and sisters on similar journey as mine my sense of purpose has only grown stronger.

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Miracles start to happen when you give as much- or more- energy to your dreams as you do to your fears...



My Stroke Journey- Finding Purpose and becoming a Better Me !

BY- WILLSON GAEKWAD

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Let me take you to the day of how stroke happened, what was I doing prior and how am I coping with some challenges. In January 2020 all was well . I was busy with my legal practice in various courts across Mumbai. In February 2020 my father , mother and brother went to my native place to attend marriage of my cousin on Valentine Day , that is, 14th Feb. 2020 .

There my dad, very healthy even at 90 years of age (was the first body builder of Ahmednagar and had never taken any medicine even for a single rupee) suffered a cardiac arrest ! I received a phone call at about 7. 00 AM that he is being taken to hospital and as I spoke with the Doctor he told me he can't do much and declared him dead. The news shattered me and I rushed to Ahmednagar. That was the most fateful day of my life.

Then the lockdown started in March 2020 and I could come back to Mumbai only by September 2020. Even then, all courts were closed, so were the schools. Students studied via Zoom and people were working only 2-3 days a week.

On 18th November 2020 I had my bath at about 8:00 AM. Then my little son Joel went for a wash and I was playing with him (as I used to bathe him then). Suddenly I slipped at the bathroom door and fell down hard. I could not break my fall and suffered a hard knock on the head.

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Sometimes, all that matters is that you are still trying.....



My Stroke Journey- Finding Purpose and becoming a Better Me !

BY- WILLSON GAEKWAD

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But still I got up after about 1-1.5 minutes, was feeling OK and told so to my mom, wife and brother who had rushed to see what had happened. My Mom put some turmeric on my head. Still through the day I had some strange feelings but could not pin them down. At about 1:00 PM my wife took me to a hospital where the Doctor checked my BP and as it was high advised me to get admitted. But that needed a Covid 19 test . I was told I may be admitted in the general ward till the test results came in. But I felt that was risky given the Covid situation and so came home.

At home the whole day I was generally fine. The next day 19th Nov. 2020 I slept well till 11, had my bath and breakfast and since there was no work to be done went back to sleep.

But I woke up suddenly at 2:30 PM with a strong feeling of nausea and vomited even before reaching the bathroom. Being a microbiologist with some idea of medical situations I felt something was serious and immediately alerted my wife and brother that I wanted to go to the hospital.

Wearing only a half pants and T-shirt I tried to walk but it was difficult...I leaned on my wife's shoulder but as I was coming down the stairs (we live on the first floor) I could feel my legs becoming heavy. I could hardly walk.

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Two Things you are always in control of : Your attitude and your efforts....



My Stroke Journey- Finding Purpose and becoming a Better Me !

BY- WILLSON GAEKWAD

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Somehow I was put into a cab and rushed immediately to the nearest hospital. I was losing my consciousness and getting double vision . We reached the hospital within 5 minutes I think and next thing I remember is waking up in the ICU. At that time , my right side was completely paralyzed and my vision and voice were also affected. Even the next day I could hardly speak. That day the doctor explained to me and my family about my condition. Understandably we all were devastated. All my friends, relatives and of course family started praying for me.

After about a week in ICU I was shifted to a room and after a further stay of one more week I was discharged. Completely bedridden, a condition I remained in for the next 4 months. Completely dependent upon wife even for my daily activities. I could not even go to the lavatory !

But I thanked God all the time for the second chance. So did my family. I started sitting , then coming down from bed, then walking around in the house.Gaining confidence, I started walking in our garden. The grace of God had been upon me and He helped me to walk. Then the walking was extended for about an hour and slowly it kept on increasing. Physiotherapy, Speech and Occupational Therapy has lead to improvements and I am immensely grateful to God and all those who helped.

Even today I have a lot of issues. Balance , loss of peripheral vision, tremor in hands are some of the main ones. I am an advocate and arguing in courts, writing applications etc. is all challenging.

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My Stroke Journey- Finding Purpose and becoming a Better Me !

BY- WILLSON GAEKWAD

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Yet I have never been more determined. I take this stroke as a positive event that has made me stronger in all aspects (yes finance is an issue but I will cope, I am sure !) My faith in God is stronger and I always thank Him for this second chance. I firmly believe He is by my side and all my victories are due his Grace. And surely more will happen.

Today by the grace of God I am focusing on myself to make me better than what I was and yes I am achieving my goals too with the help of God. Daily I practice some writing, reading and do exercises. I do 200 pushups every day and jog for 2 hours a day - approximately 15-20 Kilometers daily.

Recently I participated in a marathon event for 10 km which was my first marathon after stroke (I used to run earlier - about 20 years prior to my stroke !). I was so happy that I finished the course. Day by day, by the grace of God there are improvements in me.

In closing, I'd just like to say God is good and merciful. He has given me a second chance in life, just like for all stroke warriors. To all stroke warriors - just believe in God, find goals and purpose in life and you will be thankful for each and every day; and be well on way to your recovery. I thank God for my stroke and the purpose He bestowed upon me through it.

Be blessed.



See <https://youtu.be/E5vP2kHYthk> for an inspirational video of Willson !





Etarnacept Injection - A Breakthrough in Stroke Treatment ?

BY- DR. SHRUTI
PARIMOO

Whenever a stroke occurs, a process called inflammation occurs. It is a reaction to any kind of disturbance like an injury. This process involves a lot of chemicals. One chemical involved is called TNF (Tumor Necrosis Factor). TNF is the target for a class of drugs called TNF inhibitors which have been used for a variety of conditions like Rheumatoid Arthritis, Psoriasis etc.

Recently a member of this drugs class called Etarnacept has been used with promising results for chronic post-stroke deficits like problems with walking, fine movements, speech, memory etc. A pilot study conducted with Etarnacept showed immediate improvement in post -stroke chronic deficits when the drug was given peri-spinal (around the spine).

To further assess the efficacy of this treatment, a large-scale trial called PESTO (Peri-spinal Etarnacept To improve Stroke Outcome) is being conducted in Australia. However, this being a new treatment and still under investigation, the long-term effects and safety profile is still unknown. In fact, The American Academy of Neurologists has issued a warning for this to be considered experimental since a lot of patients are considering it to be "The Cure" in spite of a lot of unknowns and the treatment being experimental. Therefore, for now the recommendation is to stick to the tried and tested method of physical, occupational and speech therapy and hope for the best.

For further details you can check the following links

<https://www.flintrehab.com/etanercept-stroke/>

<https://www.pestotrial.org/>



About Dr. Parimoo

Dr. Parimoo is a graduate doctor who is also a stroke survivor. She had a stroke in 2016 and is still undergoing rehabilitation. She is also doing a work from home job.



Some Rehabilitation Thoughts

BY- MS PURNIMA KARIA

We all live in this fake bubble “ I am fine, nothing is going to happen to me” . But Stroke can happen to any of us. It can be a devastating, life changing event that causes not just the physical,cognitive and visual challenges but an emotional turmoil to the patients as well as their loved ones.

There is no clear cut formula for therapy interventions or treatment approaches for stroke.Each patient comes with a unique set of problems and reacts in a very different fashion even if they present with the same location of the stroke in the brain. Each patient has his or her demands, personality, expectations and priorities. Family situation of each is different too.

Many patients are experiencing severe loss of their self-identity leading to challenges in their coping skills and integrating back in their communities.Their previous roles have been snatched away from them causing tremendous deficits in their ability to lead a meaningful quality of life

For many of our patients recovery of their arm and leg may not be enough, it's about getting their life back and have a sense of belonging to self, family and their communities at large

Role of a therapist is to identify each patient's/family's priorities- which could be physical, visual, cognitive or emotional or combination of all.

The therapist has to evaluate also : Is the therapy intervention approach effectively decreasing the burden of care for the patients, families /caregivers?

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Remember - a little progress each day adds up to big results !



Some Rehabilitation Thoughts

BY- MS PURNIMA KARIA

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A therapist may have a very different perspective or goal which may be different from what the patient or family expectations might be. Understanding patient/ family expectations as well as communicating clearly the goals the therapist is working towards will avoid any miscommunication / mismatches. It is also important for the therapist to work towards preventing learned dependency behaviors and providing functionally-based treatments which can be applied to real life challenges.

We as therapist should not only focus on the patient's deficits, important as they may be, but also tap into healthy brain areas that may be DORMANT , and aim for enhancing for existing capacities that may aid recovery and to maximize the quality of life, functional independence, health, and well-being of our patients.

Further, we have to identify the Barriers that are interfering with their recovery process or their participation in therapy, and work towards minimizing their impact.

We as therapists have the huge responsibility to reestablish the patients' shaken sense of self by building in success experiences through functional challenges that are within the reach of the patient.

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About Ms Purnima Karia

Purnima Karia is a senior occupational therapist (OTR/L,) and a certified driving rehabilitation specialist (CDRS) and has a graduate certification in Low Vision Rehabilitation. She graduated from University of Bombay and has been working in the United States since 1991. She has a great passion for the rehabilitation of Acquired Brain Injury clients, including strokes, traumatic brain.injury, Parkinson's, Mild Cognitive Impairment etc





Some Rehabilitation Thoughts

BY- MS PURNIMA KARIA

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This includes the following :

- Establish a structure and a routine with patient and the family for continuity and expectations, provide answers to their concerns and challenges.
- Provide confidence in their ability to safely achieve desired tasks in variety of settings
- Promote healthy behaviors with self-management of their risk factors

Needless to say, therapists have a great deal of influence on the degree of independence a patient achieves . This means working towards , and balancing :

- Developing a patient's insight or awareness of limitations and the ability to accept the fact that new life goals must be established. and,
- Creating an experience that gives the patients a vision of themselves as actors in the world. That is, as individuals more than just patients .



A stone is broken by the last strike of a hammer. But it were the earlier strikes that lead to the result of the last one ! Success is always the result of continuous efforts.



Some Happenings...

- [Speech Practice Session \(Third \) with Shruthi](#)
- [Physiotherapy session \(Sixth \) with Dr. Forum](#)
- [Chat with stroke warrior Syed Asif Hussain](#)
- [Understanding Post Stroke Dysphagia - chat with Mr. Prasanna Hegde \(SLP \)](#)
- [Varmam Therapy for Stroke - Chat with Ms Vardhini](#)

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 !

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