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DELIVERING HOPE !

Newsletter of Stroke Support India

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Stroke Support India

Delivering **HOPE**

Web : strokesupport.in

Raising Stroke Awareness and
Supporting Stroke Survivors
and their Families

**"The most certain way to
succeed is always to try
just one more time."**

-Thomas Edison

**Holds in life as well as
Stroke Recovery
....Persist !**

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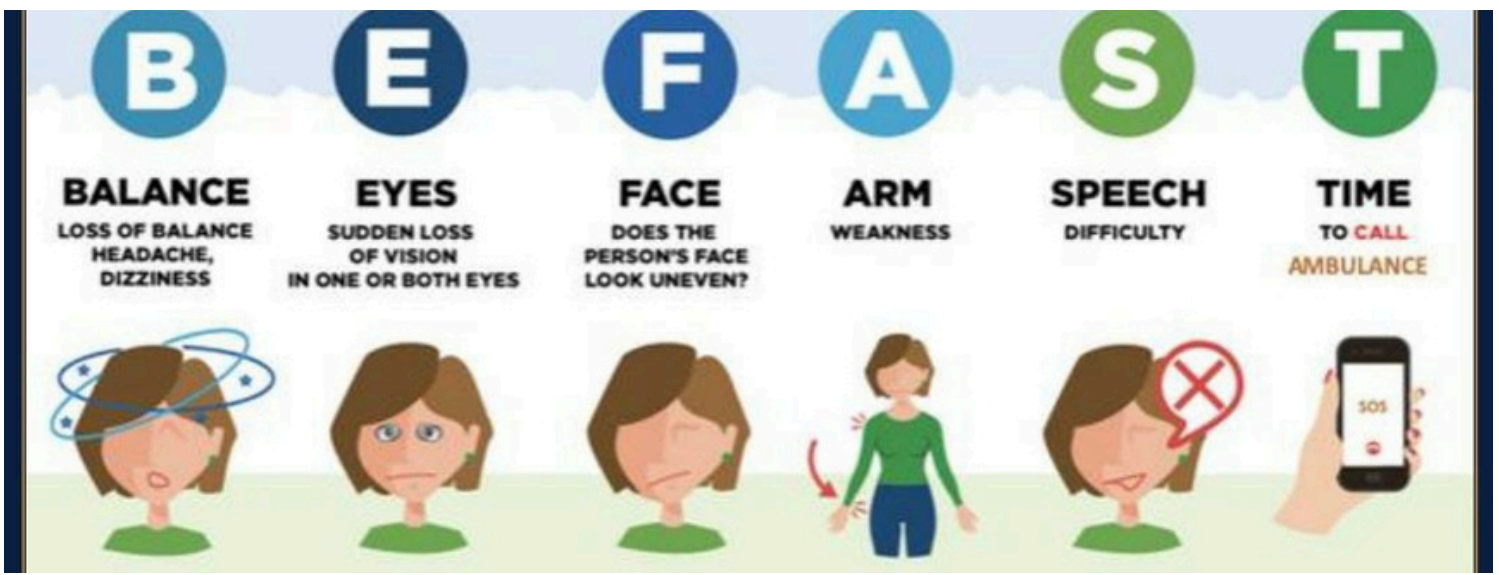
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ALWAYS REMEMBER AND TELL OTHERS THE MOST COMMON SYMPTOMS OF STROKE AS SHOWN ABOVE ! For more elaboration please see <https://strokesupport.in/be-fast>



Meetup of Patient Support Organizations in Dubai - Patient Union for Learning and Support Engagement (PULSE)

In September 2024, Stroke Support India participated in the second PULSE Workshop. This was a meeting of Patient Support Organizations in Dubai organized by Boehringer Ingelheim. About 20 PSOs from the Middle East, India, Turkey, and Africa participated. The focus was on learning about Health Policy and Health Technology Assessment (HTA) related aspects. There were excellent interactions and learnings from one another.

Here is a group photograph.



Let me tell you the secret that has led me to my goals: my strength lies solely in my tenacity. —Louis Pasteur





Hyponatremia after stroke

Hyponatremia is caused due to imbalance between total body water and sodium. Depending on the severity, the signs and symptoms can vary. They may range from being asymptomatic to headache, nausea, confusion, muscle weakness, delirium, and seizures. In stroke patients, hyponatremia is most often caused by a condition known as SIADH (Syndrome of Inappropriate Antidiuretic Hormone secretion). Other contributing factors include a restricted salt diet and certain antihypertensive medications. Hyponatremia can sometimes hinder recovery from a stroke.

Please do be aware of this as it can worsen an already affected , and comes with confusing symptoms . As an extract of a conversation of our Support Group shows...

Priya Prasad: “My mom has had a situation today owing to low Na and K levels. She has had slurring of speech and lost consciousness for almost 2 hrs. Any oral medicines that any of you have used? Pls advise.”

Anu: “Fluid (water intake)restriction helps- take less than 1.5 L per day to manage hyponatremia.”

Hardeep Sodhi: “Ohh..low levels of sodium may sometimes mimic stroke. Hope you are in touch with a doctor/ hospital and taking their advise. My mother suffered a couple of times with these when initial treatment was at hospital under controlled conditions.”

Dr. Apoorva Pauranik: “रक्त में सोडियम की कमी के अनेक कारण हो सकते है:

१. ब्लड प्रेशर कम करने वाली दवाइयों में यदि diuretic हों तो
२. भोजन में नमक एक दम कम कर देना
३. किन्हीं कारणों से कुछ दिनों के लिए खान पान एक दम से कम हो जाना
४. दस्त उल्टियाँ, पसीना आदि अधिक होना.....”

For the complete article (including in Hindi) see:

<https://strokesupport.in/hyponatremia>



If you get tired, learn to rest, not quit.





Like the Wind...

Richard Crookes

Suffering a STROKE was like having the carpet ripped from under one's feet. The floor went as well. In a few seconds, I was transformed from a 57-year-old healthy, Active, self-employed male who could do anything anytime to a lump of flesh on a hospital trolley.

The skills I had learned as a child—standing up, writing, even holding a cup—had gone, and my speech was heavily slurred. Half my body would not work due to a Short Circuit Somewhere in my Blackbox.

The first harsh realization was that something terrible had happened when I stood looking in the mirror, shaving. That day was March 7th, 2021, and it was 7 a.m. Life as I knew it was gone, as the razor crashed to the floor, and at my right side, any function ceased to exist. Amazingly, I finished my shave with my left hand!

Lost for words, I attempted to clean my teeth. Confused and seeking answers to what was going on, I fell into a chair and looked out the window. The birds that visited the bush outside the window were doing their usual thing. I watched the clouds darken as they moved in. Life was average outside. I was alive, and yet.

Confused, thinking about what's next, my Nurse arrived. When she spoke, I couldn't answer. My voice was a mumble, and drool was running down my mouth. I did not know if I could have stood up and walked or if I would have slipped on my drool and fallen. My Nurse was on to my problem within minutes, comforting me and explaining my situation. Her words entered my black box. I stared at her as she whispered, holding my hand and ensuring it'd be okay.

The word Stroke was tumbling through my black box like those tattlotto balls. My number has come up. I was confused, calm, and broken. All simultaneously, not knowing where to go next. My Black box scrambled! My Chart plotter is gone! I have been Hacked! Can we swipe left? Can I be Rebooted?

My wife arrived arrived. Her life as she knew it, that of my sons and many around, was gone too. I was drowning in confusion, or was I dreaming? ...

Contd. Pg.05





Like the Wind...

Richard Crookes

I lay there thinking this was a bad dream ...But it couldn't be. I'm Surrounded by many faces prodding, poling, poking, telling me I'll be okay. You've had a STROKE.

As time moved on, my hard drive was damaged beyond repair. There was nobody in the hospital to tell me how to get better. Only vague noises about the need for "rehabilitation" and "exercises" and "medication" – so many words I had never heard before...

Several days later, some old mates arrived to push me every day. I was in a wheelchair for some time. Stability was like a runny egg- my right side wasn't getting any messages from the hard drive in my brain. It was challenging and frustrating, and I was lost at sea, clinging to whatever hope I had.

The days were long, followed by sleepless nights thinking what, when, why, how is this my new life now? Then daylight would appear, and a new routine controlled by others would unravel before me as I lay there thinking about what would happen next. My life, as I knew, was gone forever. I hear and see one word every day, and it ain't bingo or want a beer. It is rehabilitation! Walking from wheelchair to walking frames – these are my new friends!

Dressed in green, with my life savers dressed in blue, it ain't no dream. There's no fishing rods or spanners to swing or clients to assist with catching fish. It's me, a physio, and a paper cup. I have to push it along a table. Yes, a paper cup, and I need all my might and strength.

After many weeks, thanks to Heinz, I graduated with a 250-gram tin of baked beans. This tin became my new friend. Every day, every spare moment was spent trying to lift it. The mates and the Physio pushed me on daily until my tremors took over, and the tin would end up somewhere, at times, on my Physio or assistant's lap.

Contd. Pg.06

It always seems impossible until it's done





Like the Wind...

Richard Crookes

After five long months in the Hospital, I was booted out. The next chapter is about to start. And there are no books to guide me for what I and many others endure once I leave hospital care. You are alone. Yes, alone. Even if you have a wife or Partner, you're ALONE. Your black box that's been programmed from prior learning and life skills is gone ...Yes, Gone. All there is now is a Program that's like a blank tape. Yes, you are, or should I say you have been recycled? Hard but true!

It was a Survival experience when I dropped in the middle of nowhere with no tools. Good luck; let us see how you go. There are no do's or do n'ts, as they have been blanked out since the stroke. All prior learning and leadership skills one might have had are gone as your computer crashed.

Yes, I have an assistant most of the time these days. From the simple learning to wipe one's ass with one hand that never endured this task before, which was more entertaining than Fred Astaire!

Yes, you start again, my friends. The new life is Challenging and frustrating. Failures everywhere. Battling with depression. Something else they need to put in the book life after STROKE.

I am lucky I can still get around until fatigue kicks in, knocking me for a sixer; yes, just like that energized Bunny, I am down for the count. One side is fit, and the other is to annoy me. Then those tremors kick in—try to hide them and be as Brave as Gunga Din.

So, after three years, everything has stayed the same. I have a great team that's taken me on to help in Adelaide; I'm on a botox program. No, I'm not Flavio. It's all injected into my hand and arm to help minimize the tremors. It is working to some extent.

Contd. Pg.07

The only thing that overcomes hard luck is hard work.

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Like the Wind...

Richard Crookes

Nearly like Fark Telstra, as the lines are down again, we all know what that's like, but for us stroke patients, lines are down every day. There is no book or manual for stroke patients, no index to look up, and few who can advise what, where, or how.

Apart from all the above (and despite these !) , I am also helping stroke patients in the NT along with the Stroke Foundation. I have met quite a few over the last 3 Years in the NT and Southern States. I have lost a couple of old mates, too—one under 65 and another in his 70s. At present, I know 32 people personally who have been affected by stroke between 2021 and now. Every story is usually the same, but every stroke is different. Some are lucky to walk away and carry on with life as usual. Many others are not so.

Hospitals are struggling all over with the increase in stroke patients. In the territory alone last year, 744 People suffered from stroke. In 2021, when I had mine, there were 699 people in the NT who suffered from stroke...Our numbers are climbing. Some of us are lucky to survive.

Yes, you are lucky to survive, but with minimal education on survival after stroke or prevention of stroke limited in the NT, our numbers are climbing, and the aftercare is the same. However, if you are lucky enough to be under 65, you're sometimes eligible to get assistance from the NDIS; otherwise, your rehabilitation and assistance will be minimal unless you are rich.

Stroke can affect anyone at any age. I've met young children 4 years old who have suffered from stroke and right up to 75. We are all at risk, no matter how fit we are. When it happens, it happens. But you can minimize the chances with a simple checkup with your GP. Several things can cause a stroke- high blood pressure, infection, and trauma to name a few. So it's up to you what you do.

STROKE AFFECTS NOT ONLY YOU BUT EVERYONE AROUND YOU..



Richard is a stroke affected based in Australia. He was leading an active life when he suffered a stroke in 2019. Since then with very rigorous efforts he has recovered and now is a very active stroke advocate in Australia. More about him via : <https://www.facebook.com/profile.php?id=100008372943586>





World Stroke Day 2024 efforts

World Stroke Day is marked on 29th October each year. It is a day for all stroke affected to renew their resolve and to raise stroke awareness so that others are saved from this terrible malaise.

Stroke Support India organized and participated in several events around World Stroke Day. Here are some photos of the same.



Stroke Symptoms Awareness Standby displayed at Churchgate Station Mumbai, Kailash Hospital and Promhex Hospital Greater Noida.....

Contd. Pg.09

When things feel overwhelming, remember...one thought at a time, one task at a time, one day at a time.

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World Stroke Day 2024 efforts



Stroke Warrior Willson Gaekwad distributed Stroke Symptoms leaflets at Mumbai - Kudos to his efforts !



Some Stroke Warriors met up for a lunch in Bangalore- thanks a lot to Shruthi for her great efforts in organizing it !

Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no hope at all.

—Dale Carnegie





Momentous Memories!

This page carries photos of some momentous happenings in the lives of Stroke Warriors on our groups over the last few months. Great examples of how to live a fulfilling life despite adversities !



Aparna Bhattacharjee- visiting places and celebrating with family !



Gururaj- on the beach with family, and traveling in a metro with an Aphasia card- excellent effort at spreading awareness too!



**Rajesh Arora- who went on his motorcycle to the World's highest and toughest road!
Read more about this at :
<https://strokesupport.in/unstoppable-rajesh/>**

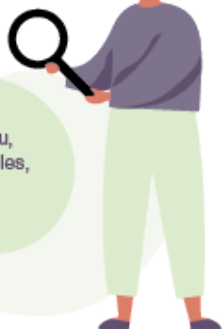




Some tips for the affected - managing memory and thinking problems !

Manage your memory and thinking problems

1 Keep your brain active



Crosswords, Sudoku, reading, jigsaw puzzles, brain training.

2 Rest and relaxation



Rest and relaxation help your brain to process things. Try walking, listening to music or mindfulness.

3 Exercise



Being active can help cognitive problems and physical activity releases chemicals that make you feel happier.

4 Be kind to yourself



Try not to put too much pressure on yourself or expect too much.

5 Speak to your GP



Sometimes cognitive problems are caused by medication or low mood.

6 Talk about it



Share your feelings with family/friends

Image Source- University of Birmingham .For more information please visit-
<https://www.birmingham.ac.uk/research/applied-health/research/support-tia/memory-concentration-and-thinking>.

(Compiled by Harini Gali)





Stages of Stroke Recovery - a Stroke Warrior's Perspective

Hello, everyone; let's start with an introduction!

My name is Suraj. I'm a 22(now) 21(then) years old stroke warrior. I've been fighting it for over 15 months now. Let us break my journey into 3 phases. The first was the first six months. During this time, I was least active and could not do anything. Yet I was not stressing about my disease probably because of 2 reasons: I didn't know how deadly disease stroke is and how lethal it can be in the future. Secondly, the first 6 months is the time when you get the best and fastest recovery, and that makes you happy and gives you confidence that soon you gonna overcome it.

Then came the second phase, which was for 6 to 10 months post stroke. I started to realize what stroke is; it is just not like another disease. The fast recovery of the first 6 months disappeared. It still happened, but much more slowly. However, I also accepted that recovery is a lifelong process and the brain is always capable of learning. This was the phase where I started to feel depressed, tensed, anxious, and low, and I began to doubt if I would ever recover or not. But I kept grinding and exercising.

Then came the third, ongoing stage, where acceptance came, and slowly, things also became better. I became a lot better and more independent than in the first few weeks or months of the stroke. By becoming much more knowledgeable about stroke, I could become my own advocate. The realization dawned that one will sooner or later get what one works for, not necessarily what one desires. Also, hard work always pays off.

Here some suggestions for all stroke warriors per my experience:

1. Exercise as much as possible; exercise daily.
2. Get tons of sleep
3. Eat healthy
4. Stay positive
5. Strive for recovery, even if it does not happen quickly enough!

Suraj
Stroke Warrior

**If you can't fly, then run. If you can't run, then walk. If you can't walk, then crawl.
But by all means keep moving**





Some More Happenings (recordings of some prior Zoom Sessions on YouTube) -

- [A shoutout about efforts of Stroke Support India by Dr. Nirmal Surya \(Present President, Indian Stroke Association\) Very grateful !](#)
- [Chat with Stroke Warrior and Neuroscientist Dr. Bruce Hetzler](#)
- [Stroke Warriors Speak -Akshay, Vibha, Ankita and Aparna](#)
- [Stroke Warrior Willson on his first strokeversary !](#)

and some Plans!

Similar and other activities are planned in future as well, including more offline ones. Most hearteningly, all are done by voluntary help and participation of the members of Stroke Support India. *All your ideas and help is welcome !*

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

PS : Volunteers needed ! If you want to be involved with and help us in any manner in our efforts, please contact via :

<https://strokesupport.in/volunteer>

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