

# DELIVERING HOPE!

Newsletter of Stroke Support India

Editor : Hardeep Sodhi

Stroke Support India

Delivering **HOPE**

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

Raising Stroke Awareness and  
Supporting Stroke Survivors  
and their Families

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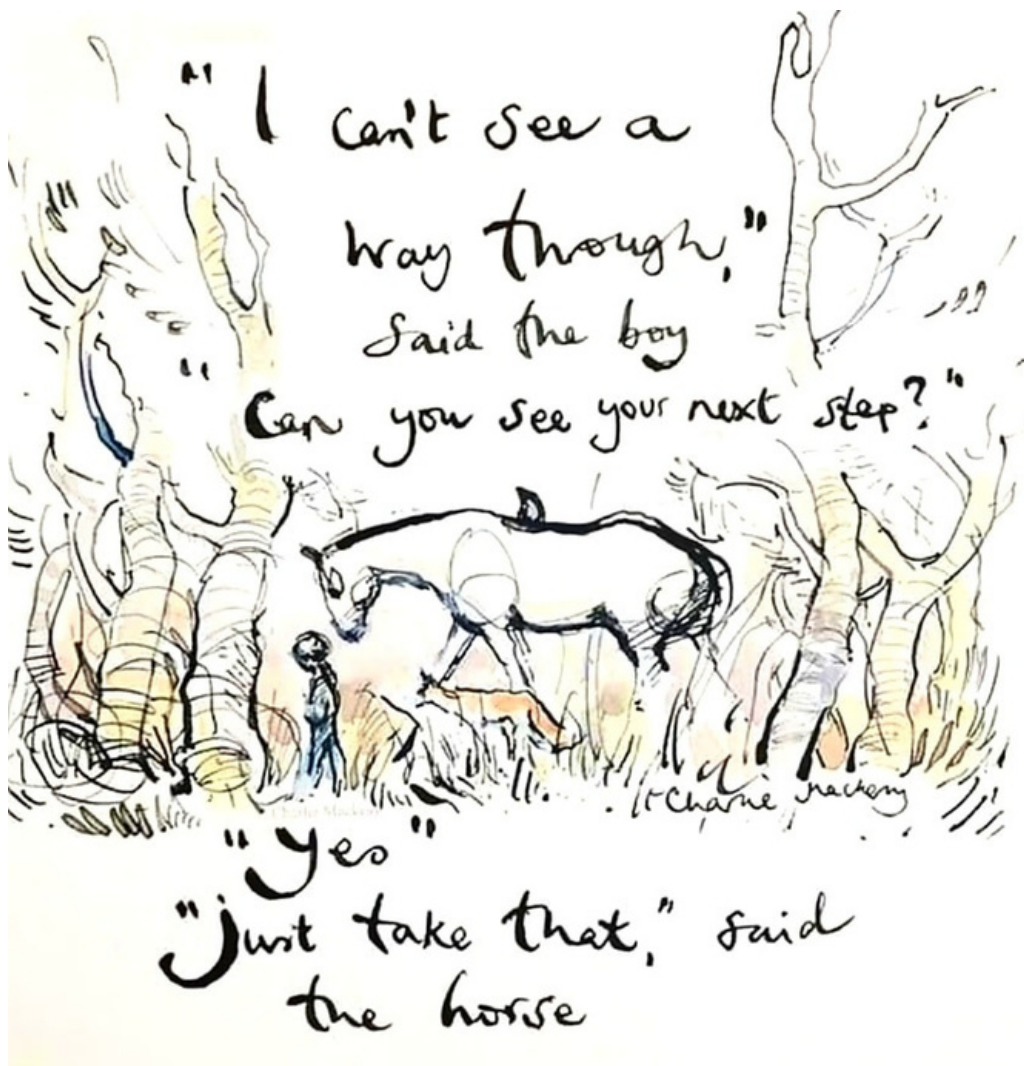
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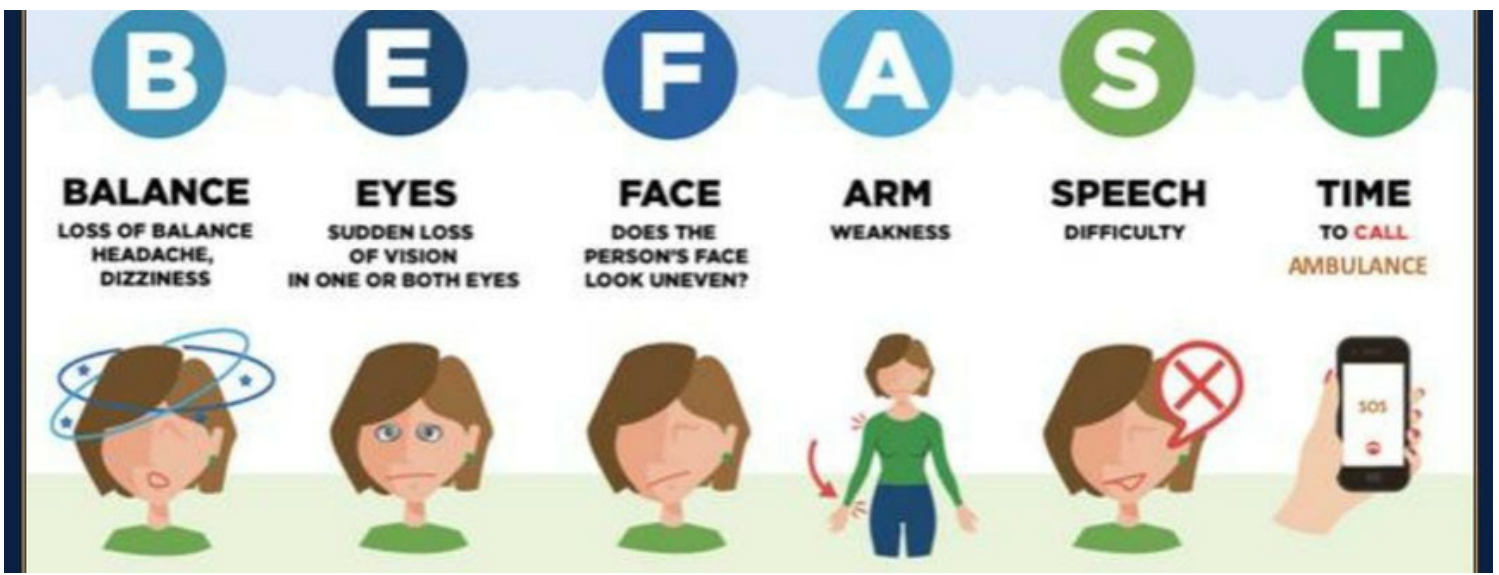
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**ALWAYS REMEMBER AND TELL OTHERS THE MOST COMMON SYMPTOMS OF STROKE AS SHOWN ABOVE ! For more elaboration please see <https://strokesupport.in/be-fast>**



## **PULSE Meet ..**

Stroke Support India was invited to and attended a " Patient Union for Learning and Support Engagement-PULSE" program organized by Boehringer Ingelheim (BI) in Dubai on 19th and 20th September 2023

It had about 20 Patient Support Organizations (PSOs) from India , Middle East, Turkey and Africa in different stages of growth. We shared inputs as well as got perspectives from trainers Medistrava arranged by BI on how to grow our PSOs further in a more structured manner.

It was quite an interesting and educative meet with many learnings. Very heartening to note that the patients' voice is finally being noticed.

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## **Job after Stroke-My Experience**

Vijendra Kumavat



I am Vijendra kumavat, living in Mumbai. I had a stroke that left me paralyzed followed by brain surgery and have limited movement consequently.

This is a short note on my efforts to get a job thereafter. Hopefully it will help those in similar situations. Getting a job after such an event is not easy, even if one is highly qualified and experienced. But I was determined to get it and my family situation also could not let me remain jobless.

I started by asking all my friends and nearby people for any work they may have for me. Some were nervous and well meaning, advising me that I should rest, and that they will let me know if they have any suitable work for me. I went to some job fairs as well but that was not very systematic and also jobs offered were far from my location.

I visited nearby offices also . Some of they were willing to try me out but with conditions such as less pay, no offer letter , no salary slip and no experience letter. This was not acceptable to me.

I searched a lot on Google platforms and came to know about an NGO who said they provide jobs for the disabled after training them. I joined them and also learn updated requirements of market. But jobs provided by them did not suit me. Some of them were in rotation shifts, others far from where I stay.

Fed up with sitting idle, I even tried for jobs not as per my past experience but did not get any success since my left hand is not functional.

I also searched a lot on Facebook where there are groups for jobs for the disabled. I joined some and through them came in contact with many recruiting companies. However jobs offered by them were in Marketing and target based and also locations did not suit me.

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## **Job after Stroke-My Experience**

Vijendra Kumavat

But one day I chanced upon a job with a big CA company. It was located in Jaipur. Though the location did not suit me, I still applied as my cousin stays there.

The Company HR called me , asked for my salary expectations. I said as per my profile you may decide. They shortlisted my profile for position of a Senior Tax Analyst. Although I prepared hard for the interview I wasn't successful since my knowledge wasn't updated and the selection criteria was tough.

However, the interviewer was impressed with my determination, communication skills and confidence. They decided to give me another chance for the position of Junior Tax Analyst. This time I prepared harder ( also out of self respect, maybe !) and also knew a bit about the Company's tough selection criteria.

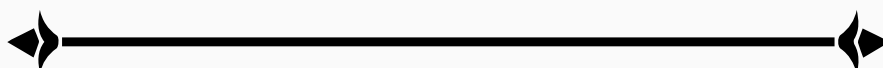
A virtual interview was conducted again and this time I cracked it, though with conditions like I have to get myself updated with latest taxation aspects and may have to sit for long hours. Further, the HR also told me I need not relocate to Jaipur, rather I can work in a remote manner. Later, if needed, I can relocate to Jaipur. This is quite acceptable to me.

The Company has also provided my Computer etc. for remote work. I am very happy to get this job and can see my growth therein.

Here is link to a Whatsapp Chat group where many jobs for the disabled are regularly posted.

<https://chat.whatsapp.com/EuXt3TDKPW1Ey1xZoi3eBI>

In short, my advise to any stroke affected looking for a job will be not to give up, to keep on trying and you will get one suited to your skills and abilities sooner or later !





## **Thoughts on my fifth strokeversary...**

Sreekanth Kesava

When someone goes through a life transforming event like a stroke, they are a completely different person afterwards. In that sense the previous person dies that instance and a new person is also born that instance. Others rarely notice or appreciate this death & birth transformation as its not a physical thing but a mental death and rebirth.

In that sense, I am 5 today!

Born on 6th Feb 2019!

When I had the stroke, after I could think properly (maybe 6-7 after weeks), also fuelled by the assurances by everyone around that it's only a matter of 6 months or so, I came up with a 5 year plan in my mind. I bitterly realised soon that planning and such things are out of the window for good.

About 6 months later, till about a year and  $\frac{1}{2}$ , it took a lot to accept the reality and get adjusted to the reality that the previous me was indeed dead. Also, the frame of mind was that I was only dead still and there was no recognition of the rebirth (as I couldn't do anything, couldn't communicate with anyone, etc). Probably around 2 years mark - when I could use the phone sitting on my lap and with 1 finger operate WhatsApp and communicate with others that I really had got a new lease on life after my stroke. It probably took me another 6 months after that to get adjusted to the new birth and life.

Physically, stroke survivors have a wide, very spectrum of changes. Physically/ visibly it could be a very small change to very drastic impacts. In my thinking, the change in mindset to readjust to the new life is the maximum. It is also very unpredictable since the thinking fuels and propels the direction and extent of impact on the mind.

This previous year was very hard - from a mindset point of view. It was very evident by the end of last year that change (if anything) is going to be very very minimal and very very slow - yet there would be a small change every year.

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## Thoughts on my fifth strokeversary...

Sreekanth Kesava

What the change would be was unknown and whether it would be a change for the better or worse either was not predictable. So I can't have a target or a goal of getting somewhere. Yet, I have to do everything, everyday for the whole year if I have to hope for any changes. In a way, the goal was just to get past the day and manage to do everything I was to do.

For example, we are doing a routine in physiotherapy, starting from the right shoulder, then right arm, then right fingers, then a bunch of things for the right hand with a plastic pipe to help, then the right knee, right thigh, right hip, finally a routine walk with the physiotherapist for few minutes either with the Walker or walking stick. That routine has not changed for the last year. Its monotonous and very very draining for the mind. However, I know I have to do the same everyday if I maybe hope to see a change. It takes a lot out of me to do it. I sometimes wonder how my physiotherapist has that much patience and dedication - for I don't have a choice/ any other life but he does! Hats off to him.

It would have been easy to give up and stop if there were no changes either. But there are changes. Can't perceive it everyday or every week or every month even . In a year maybe. And in the hope of it, not knowing what it might be, have to get past the day.

Other than that routine of getting past the day, things are ok.

It's very funny, I keep getting messages from everyone every now and then as to "how am I doing?". It is very evident that I am a broken toy which cannot play anymore. My response is usually "I am doing ok ". In my world, (and probably what everyone has in mind as well) - the interpretation is "ok" doesn't mean I am "ok" it j means that nothing else has broken from last time and there has not been further decline.

In that sense, I am perfectly ok 😊

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## **Thoughts on my fifth strokeversary...**

Sreekanth Kesava

**So, where am I physically?**

**Better. In what sense I am not able to articulate it clearly but I am slightly better.**

**People who see me after a long time usually say I am looking better. I don't know what that means but I take it on face value (literally).**

**No change in swallowing. Little change in being able to generate sound/voice but because i am not able to swallow and clear my throat, can't generate voice consistently. It's usually only a gurgling sound that nobody can understand.**

**Right hand - some days feel like I can feel some part. But It goes away after a few days to build on the feeling that had developed. So, not much has changed there.**

**My left arm is the same I guess but the left shoulder has gotten stronger. No change in chest area, abdomen, back etc (hence breathing as well as other core related activities (including my incontinence I guess)).**

**Not much change in left leg (I am guessing there might be some improvement but I can't make out).**

**Right leg - some improvement in the thigh I think but nothing below the knee. I don't know what muscles have to wake up but till I can bend the knee and fold my leg, I don't anticipate more changes.**

**There are 2 changes I am glad about,**

**1. I have had a very bad subluxation at my right shoulder for ~4½+ years . My physiotherapist has been battling with it for all that time. Last month he said finally it is getting better. For my naked eye, it seems like there is still a gap between my shoulder joint and arm. But I'll take his assessment at face value.**

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## **Thoughts on my fifth strokeversary...**

Sreekanth Kesava

2. I guess the most significant change physically in the last year (and it happened only in the past 2 months I guess) is that my right hip/ bum woke up very partially. I realised only afterwards the importance on the hip/ bum to support standing and not becoming "leaning tower of Pisa" and falling eventually. Which gave me the guts (metaphorically speaking) to stand up recently with family and friends for some snaps during a function.

It won't get better in a hurry. I need to stand and walk a lot more everyday for it to get better faster. But I only get 10 min to do this everyday with my physiotherapist.

Encouraged by the newfound improvement on the hip and the successful bold venture recently of standing against a wall during a function, I went ahead and tried some stunt recently without my physiotherapist. In short, I realized I have to continue to be the "tortoise" in this very long marathon with myself and there is no "hare" to win against. otherwise, in my zeal, I will become "Humpty Dumpty" where "all the king's men can't put me together again".

Mentally, I have not yet lost my mind. As I mentioned, the toughest part was getting past everyday and somehow staying sane. It's walking on the border of sanity and madness every so often. It's very very tempting to stop and give up/ give in to giving up. Very constantly it keeps coming back to the mind "why are you doing this still?". "What is the point of it?". "Why not stop this struggle and end it?". I mean I know all the usual worldly reasons why I should be around for my family, friends etc. etc. but it is a very surface reason. Life, when you think about long and hard is very inconsequential. How long we live, what we do, how much we do etc. etc. when that realization sets in, the questions become stronger - "why are you still fighting?" sort of questions.

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## Thoughts on my fifth strokeversary...

Sreekanth Kesava

The truth is I am very scared. Not of it ending or dying but of stopping. If there was a quick/ instantaneous way to stop and end it. I'd very gladly do it. However it will not be (I am very sure of it). Stopping going on the way I am doing currently everyday will definitely mean unbearable trouble, sorrow and burden to my immediate family, close friends etc. and increased suffering for me as well. At least if there is a definite timeline for that path, I would still weigh the "cost - benefit" and give it due consideration. However, it is un-forcastable . So, out of that fear, I am going on.

This year was also a year of acceptance. In my case acceptance has come in roughly 4 phases. In a sense, i knew these things, but for things to sink in and to realise with full understanding and to accept it takes a lot and a long time. It did for me atleast. That is what I am calling acceptance here .

1. Acceptance that this happened to me. I mean, if I was profiled, whether medically, lifestyle, diet and exercise, age, etc, etc, I would probably not fit as a likely stroke candidate in any of those parameters. I know what happened clinically speaking. But it is not easy to understand because all the medical answers tell you "how" it happened and not "why"! Getting to make peace with the fact that I couldn't answer the "why" and accept it took a very long time for me.

2. Was to accept this was not a simple disease and was permanent needing many many years to rehabilitation. In my case, only potentially marginal improvement even after many years of rehabilitation probably. For someone looking at timelines and goals/end state for almost everything, it was unimaginable that I did not know what the end state would potentially be.

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## **Thoughts on my fifth strokeversary...**

Sreekanth Kesava

3. Was to accept that I am disabled now. All my life I used to see disabled parking, disabled toilets, disabled stickers on windshields, etc. it was always viewed without thinking. It was always assumed it was for someone else. I was independent and in control of myself. I mean, I now need a "disabled" sticker + "fragile/ handle with care" sticker + "this side up" sticker, etc, etc. getting to accept that took a lot. Essentially to accept that I can't do anything which I was used to doing independently/ by myself.

4. Was to accept that this is permanent and I have to figure out living like this from now on. It might sound defeatist. I am not denying that I do hope of getting any better. I know I will. However, I have always been realistic and pragmatic. Everyone, when they see me, the usual parting reassurance is "don't worry, everything will be alright and I will become alright" (variants of those words but essentially meaning the same). I silently chuckle each time. I know now that nothing will become alright in that sense. Everything that needs to be, is already alright. The only thing not alright was my mind's alignment with the new reality.

This was most of this past year. To accept that this was my life going forward and to somehow find things to do which are somewhat worthwhile, to somehow do things to keep myself occupied, to do my best to try not to burden others (if I can help it) and do something to stay informed and hopefully stay relevant in this fast changing world as time passes.

Other than those aspects, I am "ok" in my mind as well.

In all honesty, I am generally happy in my mind. My wife is strong and independent, our kids are doing fine, my mother, sister and family, parents in law and close friends and family are doing ok (at least on the surface as much as I can perceive). Life is going on in a straight line. Nothing to complain (touch wood 😊)

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## Thoughts on my fifth strokeversary...

Sreekanth Kesava

Putting together this mind and body, where am I functionally:

- \* I watch a lot more of TV, try my best to not spend a lot of time on entertainment content but succumb every now and then.
- \* Try my best to stay connected to others and relevant as I have email and WhatsApp all the time at my fingertips
- \* Spend about 3-4 hrs everyday on my laptop. Helps me work on spreadsheets and other stuff I am unable to do on the phone.
- \* Try to help at home with what I can online (ordering things, paying bills, managing documents online, such things). Living this way, I must say, I am very very glad to be in India to experience the digital revolution first hand. Most of what I do would have been impossible to pull off anywhere else in the world currently.
- \* Spend good time almost every weekend playing cards with my friends and family 😊 (rummy mostly. Even tried poker 1-2 times 😂)

Every so often, my friends and family complain that I don't go out with them - like a round in the car , to some relaxing place, etc. they probably speculate that I am conscious of my state & looks and don't wish to see people. I actually don't mind going out. It's not a physical challenge. I am able to sit for 5-6 hrs on the wheelchair, have done a few rides in the car and have survived. I can spend that many hours without feed...

However, my biggest challenge (which is very hard for others to understand or appreciate) is my incontinence - which has not gotten better in the past 5 years. Every 1½ hrs or so is guaranteed passing urine and motions once a day guaranteed - when I am in the sitting/ vertical position definitely . So, when I have to go out somewhere , I have to prepare at least 24h earlier by gradually reducing feeds and water intake to almost nil on the day when I am going outside till I come back home.

Contd. Pg.12

## *Interrupt anxiety with gratitude...*





## Thoughts on my fifth strokeversary...

Sreekanth Kesava

Basically wring out as much water and content from the body as I can. It is still not a guarantee, but a hope to avert the mess for everyone outside or in the car, etc. I am not worried about embarrassing myself (I have gotten beyond that surely by now) but I surely will embarrass my teenage girls in front of others and their friends and I will become the source of nightmares for them afterwards.

When I starve myself of food and water like this for roughly 1½ days, it takes me almost 3-4 days, sometimes upto a week afterwards to come back to the physical condition as before. I know this as I can very evidently feel it in my physiotherapy and other things. Besides, once I get into the car and get on to the traffic, chaos and traffic jams, I realise how blessed I am not to have to subject myself to this everyday. Going out, very contrary to what others assume, is not something I look forward to or relaxes my mind, it's a genuine nightmare I am praying it will get over soon and I am back home where I can let my mind relax.

However, I recently I went to a coffee shop with my family and close friends. It was a pleasure because it was only 10 minutes from home and I knew we were going only for a brief time and will come back in <2hrs. It was great. However I still had to prepare myself for it and do the gradual starving routine for 24h.

So, functionally, There are many things to get alright from head to toe. However, improvement with Incontinence is the primary thing I am really really hoping will get better this year. Anyway, whatever number of years remain, can be used by the brain to figure out the rest of the things....

So long till I turn six (hopefully) ...

*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 some movements on left side, and slight on right hip. He can't speak and feeding is via PEG tube. But he now 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 ! You can read more of his thoughts at : <https://mindofmystrokedbrain.blogspot.com>*





## Communication Practice Group-Progressing Well !

Our Communication Practice Group is developing very well, with strong efforts from Ms Shruthi and active participation by the caregivers as well as People With Aphasia (PWA). A WhatsApp group is there with daily exercises, and frequent Zoom sessions also happen. Some aspects that are regularly practiced include:

- **Greetings**
- **Reading small passages, asking and answering questions**
- **Working with numbers, puzzles and maths**
- **Naming objects**
- **Pictures Comprehension**
- **Current affairs**
- **Sentence making- verbs, adjectives...**
- **Activities for cognitive abilities...**

Read the text below:

Anna is a She lives on a with her family. She is a mother to a cute . Anna's husband is a big and strong . Anna eats and gives . When she is not too busy, she spends time with other animals that live on the . Her best friends are and .

grass    calf    cow  
horses    goats    sheep  
milk    farm    bull

www.englishkids.com

**WORKING WITH NUMBERS**

12  
86  
115  
3+5=8

Thirty four  
Ninety  
One hundred and seventy one

**Object naming**

Can you solve this brain test?

• 1 + 4 + 7 = 21  
• 3 + 4 + 9 = 16  
• 8 + 0 + 5 = 31  
• 9 + 2 + 2 = 13  
• 7 + 0 + 8 = ?

**CORRECT THE SENTENCES**

1. The cat is barking
2. We see moon in the day
3. I am drinking biscuits

**SENTENCE COMPLETION – VISIT TO THE ZOO**

I went to the zoo with my \_\_\_\_\_ for an \_\_\_\_\_ day.

Some animals were in \_\_\_\_\_ I saw \_\_\_\_\_.

**To Join the Communication Practice Group fill form via <https://strokesupport.in/add>**

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# Marking World Stroke Day !

World Stroke Day is marked on 29th Oct. of each year. This year we met up at different places as well as made efforts towards raising awareness. Willson ji in Mumbai made great efforts towards raising awareness too, with even the Police learning :-) Some snaps ...



*It does not matter how slow you go as long as you do not stop.*

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

- [Functional Rehabilitation Post Stroke-Chat with Dr. Melitta](#)
- [Some precautions after stroke, and ways to improve speech, cognition and memory - chat with Dr. Saurabh](#)
- [Stroke of the Elderly and care thereafter - chat with Dr. Kausik Das](#)

## 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 help us in any manner in our efforts, please contact via :**

<https://strokesupport.in/volunteer>

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