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DELIVERING HOPE !

Newsletter of Stroke Support India

Editor : Hardeep Sodhi

Stroke Support India

Delivering HOPE

Web : strokesupport.in

Raising Stroke Awareness and Supporting Stroke Survivors and their Families

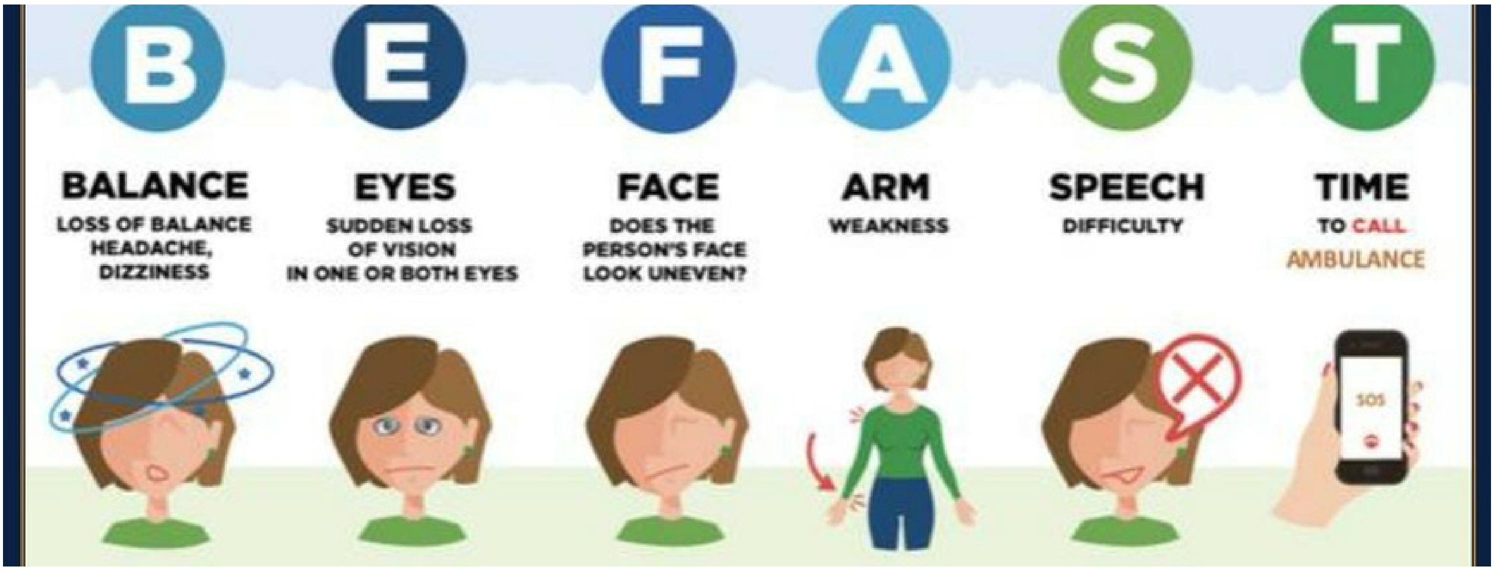
HOPE....

is the power that gives a person the confidence to step out and try.

-Zig Ziglar

Remember, Stroke Warriors-hope, determination and perseverance are the keys to recovery !

This issue:



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

Our Standys Campaign Continues- Help Others avoid Stroke ! Spread Awareness of Stroke Symptoms via Standys available from us- some examples here :

AIIMS Delhi-Stroke Clinic

Esplanade Court Complex, Mumbai

RML Delhi-Stroke Clinic

Delhi High Court Complex

For more details and to get one for your Hospital, Chemist Shop etc., see:

https://strokesupport.in/standy

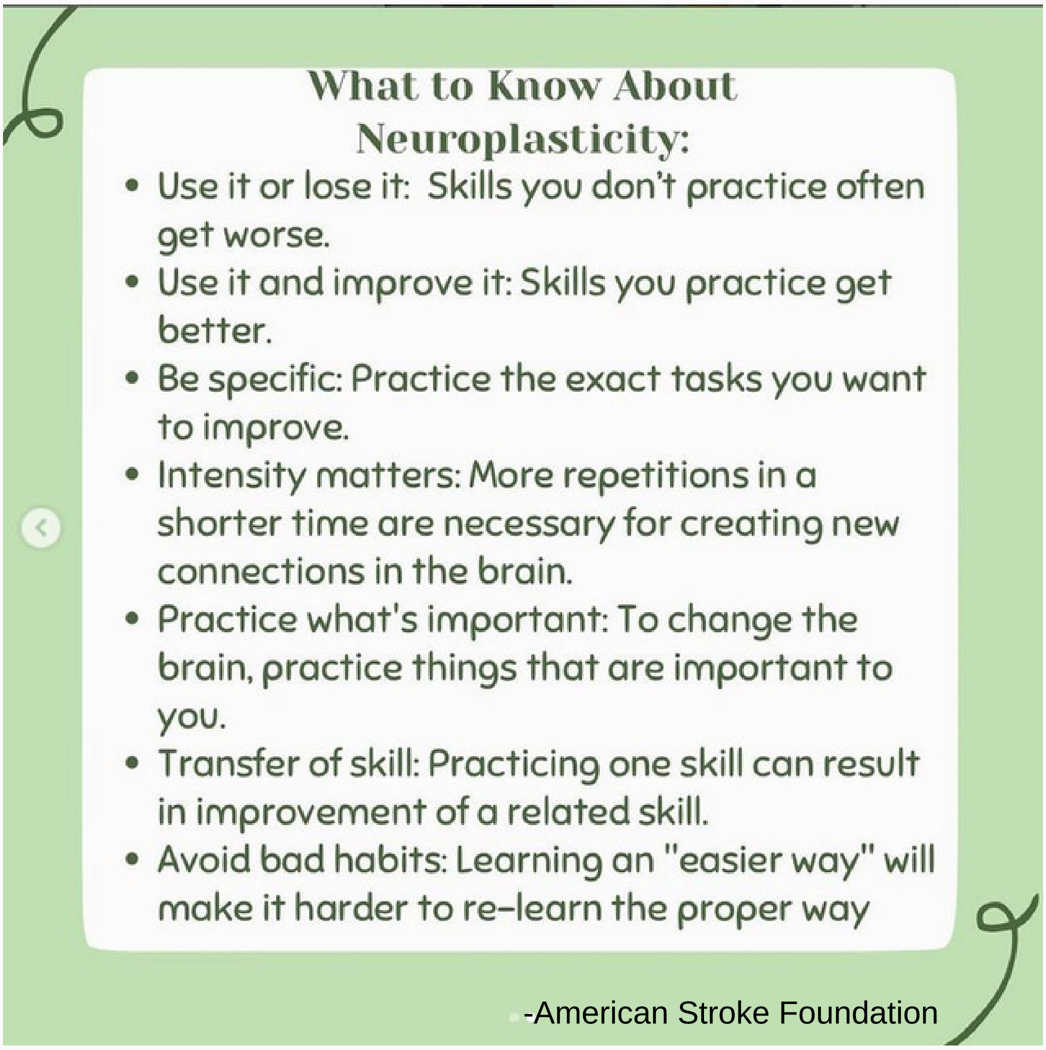
Thank you for your help !

Neuroplasticity - the Science behind Stroke Recovery

BY- HARDEEP SODHI

Neuroplasticity is the ability of the brain and the rest of the central nervous system to generate new neurons and neural pathways, and change the structure of the cells in response to its changing environment.

This is how the brain compensates for and recovers damaged cells after a stroke.



What to Know About Neuroplasticity:

- Use it or lose it: Skills you don't practice often get worse.
- Use it and improve it: Skills you practice get better.
- Be specific: Practice the exact tasks you want to improve.
- Intensity matters: More repetitions in a shorter time are necessary for creating new connections in the brain.
- Practice what's important: To change the brain, practice things that are important to you.
- Transfer of skill: Practicing one skill can result in improvement of a related skill.
- Avoid bad habits: Learning an "easier way" will make it harder to re-learn the proper way

-American Stroke Foundation

Neuroplasticity is a constantly occurring process, and it happens throughout the entirety of peoples' lives.

This offers strong hope for all stroke effected.

For more on neuroplasticity, including some videos see:

https://strokesupport.in/neuroplasaticity

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

The Road To Recovery

BY- MAHALAKSHMI

As a caregiver to my 75-year-old father who suffered an acute ischemic stroke about a year ago, I feel privileged to be a part of a platform where I can share our experience on the road to his recovery.

My father has always been a jovial person; he loves to make people laugh with his anecdotes and jokes and he enjoys traveling. A bibliophile, a great storyteller and an ardent music lover too. After my mom, who passed away 3 years ago, my dad filled the space that was void due of her absence. He has been my pillar of support, guide and friend.

My brother lives in Singapore and owing to the pandemic induced lockdown, my father couldn’t make a visit. When finally, the restrictions were relaxed, he was very eager and excited to meet my brother’s family after almost two years.

But little did we know that the person we had seen off at the airport would transform into a stroke patient in a span of just 1 month.

I still remember that fateful day as if it were yesterday. It was 24th March 2022. I was returning to Bangalore after attending a family function. I had called dad in the morning to inform him that I had boarded the train. He seemed perfectly normal at the time. That was the last time I spoke to him. Just as I had reached home, to my disbelief, my brother contacted us and said that my dad had a medical emergency. The symptoms appeared to be that of a stroke. We were extremely anxious as we could not even travel to Singapore on such short notice due to the restrictions on international travel.

Luckily, the TPA drug was administered within the 3-hour window. A surgery to remove the blood clot in the artery of the left brain was conducted. Unfortunately, even after the best of the efforts by the medical team, we were informed that he had suffered right hemiparesis ,expressive aphasia and swallowing difficulties(dysphagia) as a result of the stroke .I never imagined that my dad whose strength was language and speech would lose the ability to speak. Another tough aspect was that as per the Singapore regulations nobody was allowed to be with my father for the two weeks that he was in the hospital, except for some very limited period. Thankfully, they had scheduled video sessions to connect with him once or twice a week. It was so hard to see him eat just mashed food.

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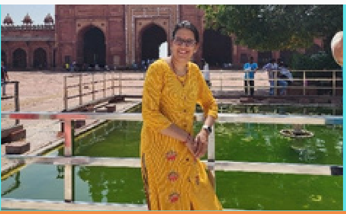

Mahalakshmi lives in Bangalore and, besides being a caregiver to her father, is an HR professional and mother of two adorable daughters. She enjoys reading, traveling and meeting with people. Of late,post her father's stroke, she has started researching on various topics related to health and fitness, and advising friends and family on same.

The Road to Recovery

BY- MAHALAKSHMI

We were waiting with the hope that this was temporary and he would regain his lost functions in a week or so. However, we were informed that it would take time- at least 6 months or even more for them to get restored. It was shocking because a person who used to cheer everyone up with his words and used to be so active was now practically disabled. His medical reports were saddening to read and gave me sleepless nights as this was the last thing I expected.

How will we go forward? How will we handle this situation? How do we take care of him now that he is dependent on us for day to day living? How do we now communicate with him? These were the apprehensions that ran in our minds.

Today, there is greater awareness as well as accessibility to various support systems for the recovery process, from the different types of wheelchairs to well- trained physiotherapists, speech therapists and support groups too. With a wide pool of resources, we felt much more empowered and less distressed about the caregiving process. Yes- initially there were some hassles but over time we have learnt to adapt our mechanisms to suit the needs of my father.

It has been a year and my father, through rigorous physio is now able to walk with support and is able to communicate through mono-syllables and gestures. He is also independent in eating food and brushing teeth. He is now able to read and spends every morning reading the newspaper. TV and movies are other ways he passes time. Still there are days he is in pain and feels low. With comforting words and sharing similar stroke survivor stories, we make sure he stays inspired. Though dad now does not entertain us with his lively chats like before , he certainly makes our day pleasant with his innocent gestures and frequent laughter and smiles during our conversations with him. We have learnt to accept what has come our way and have found ways to keep ourselves going.

For all those on a similar journey, please do not lose hope, our positivity and confidence is their strength. We need to appreciate all improvements, be it big or small and also respect the process of recovery without placing burden on the affected person. Recovery is a marathon, not a short sprint and we must be willing to be with them till the finish line.

Thoughts on my Fourth Strokeversary !

BY- SREEKANTH KESAVA

6th February back again!

4 years today. 1,460 days (1,461 actually - leap year inbetween)

Why does it seem to me like 4y is a long time but 1,461 days feels less? Seemed like it last year too. I don't know if others feel the same thing.

It's my 4th Strokeversary as referred to in our Stroke Support Group that I am part of ...

It's actually the 4th death anniversary of mine.

It is also the 4th birthday of mine...

"The king is dead, long live the king" types... Worried about the 2nd part of that slogan becoming real though....

I am a strange being with the mind of a 47y+ old and the body of a 4y old...

So how was last year for me?

Physically speaking, going in the right direction. Extremely extremely slow, painfully slow, frustratingly slow - but the needle is moving and moving in the right direction.

The only gauge where the needle has not moved (moved in the wrong direction actually) is with swallowing. Big one that! Unfortunately there has been no encouraging movement.

I can't exactly say I am disappointed - as I have reduced my expectations very very low with everything. However, I am guessing there is still some residual hope and that makes me feel sad! The thought that I might never again eat in my life saddens me no end! I used to love food a lot!

I wonder what I would have eaten if I knew the dinner on 5th feb 2019 would be my last meal. (I probably would have died by overeating anyway if I knew 😂)

Contd. Pg. 7

> “Do what you have to do until you can do what you want to do.”
>
> *-Oprah Winfrey*

Thoughts on my Fourth Strokeversary !

BY- SREEKANTH KESAVA

It was not so bad for maybe 3½ years or so. I had become quite immune to the feelings triggered by seeing foods. However, over the last 6-8 months, my sense of smell has slowly improved. Earlier I could smell almost nothing, but this year it has been improving. I am pretty sure my mind was not prepared for such a sensory assault after 3½ long years. The smells drive me mad everyday. Whether it is garnishing different things, fresh coffee brewing, different masalas, spices, subzis, mixed rice, etc., the smells drive me crazy.. I almost always know what is cooking everyday and what I will not be eating that day. I guess the thought that the writing is on the wall is very hard to digest!

Mentally speaking it has been probably the hardest of the 4 years.

The first 2-2½ years was relatively easy for the mind. After the initial couple of months coming to terms with what had happened, it was easy. I couldn't do anything - so it was easy to not get affected by situations. Every situation had a straightforward response from my mind - "what can I do? Nothing!" So it was easy to - sort of - be detached from everything.

3rd year I guess was spent in the novelty of being able to communicate (even if it was just WhatsApp and email). I guess I was just enjoying that ride and getting used to it and more comfortable with it.

However, the last year has been a year of exploring boundaries of what to get done with my ability to communicate with others. I am still bedridden and don't do anything myself, but with the help of many friends, family and well-wishers, being able to get things done.

And that is haunting!

When I was ok - I would do what I could. It was reasonably clear in the mind what I can do and what I cannot. However, with this approach, it is never clear what can be done.

And that weighs heavily on the mind! On each thing, I am unable to let go and lay back. There is a constant nagging thought of "am I trying enough?", "Am I thinking this through correctly?", "Am I approaching it the right way? .

If I can't get something done, I can't let go. "Have I tried enough?", "have I tried everything?", "am I giving up easily?", etc.

People whom I drive mad regularly will certainly know what I mean..

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Thoughts on my Fourth Strokeversary !

BY- SREEKANTH KESAVA

That is very draining...

It is also pressurising - In a very different way. I know most folks I am close to - will do stuff for me if I ask. They definitely will. Before the stroke, they probably would have said no or thought twice. In any case, there would be very little reason to ask. Now I know for sure they will. So I have the added pressure to be judicious and consider the need and not take undue advantage of the kindness and goodness of folks. That plays on the mind constantly as well...

Anyway, an evaluation of the body every year is customary - so here goes... (I guess I will go toe to head!)

* Left Foot - Ankle seems ok, but less mobility and strength in the toes.
* Left leg - I am guessing getting stronger slowly. No change flexibility or range of mobility though
* Right foot - nothing. I have to be in a splint most of the time . The ankle just buckles without it. Nothing with the toes either.
* Left leg - little more movement in the thigh. Nothing below the knee. Thigh very slowly picking up. Can drag the leg better than earlier. Can't lift it though - different set of muscles needs to wake up for that.
* Hip - I am unable to make out changes on the left side. I am guessing there is some improvement.
* Right hip - I know it is a bit stronger than earlier as it gives better support when I stand. It would completely buckle earlier.
* Back - I can't make out any changes - I am guessing nothing has changed.
* Abdomen/ chest - nothing as well.
* Left hand (fingers, wrist, arm, shoulder) - definitely getting stronger. Gross movements only though. Struggle with fine motor skills.
* Right hand - no change in the wrist/ arm. Shoulder slight movements
* Neck - still weak and head is always tilted font and left side
* Face muscles a little better but most of it still feels like a cardboard.
* A little more movement in the tongue and lips/ jaw - very far from good.

Above sounds like getting the technical specifications of a machine without understanding its functional use

Contd. Pg. 9

Thoughts on my Fourth Strokeversary !

BY- SREEKANTH KESAVA

So, a general overview goes like this:
*** Can't get up. Still bedridden and have 2 attenders 24x7**
*** Can't swallow and still fed by PEG tube.**
*** Can't talk**
*** Still severe incontinence - both 1 & 2**

But;

*** Can type a lot faster and easier on the phone - can communicate better.**
*** Can't speak, but can bring out voice a little more than earlier.**
*** Can't use my right hand but left hand is stronger and can do more.**
*** Can't move my right leg much but can stand for sometime without support (need folks to make me stand though)**
*** Can walk few times up and down the hallway in our house (maybe 15ft each way) , using a walking contraption with nurses supporting.**
*** With the physiotherapist support (him and only him!), I manage to walk that distance with a walking stick or a regular walker - with the right hand strapped to it (as the wrist and fingers don't move).**
*** Can't sit up on my own but once put in the wheelchair, can sit for a much longer time.**
*** Can use the laptop for sometime and that's a huge huge relief - can open, understand and work on spreadsheets .(I was going mad on the phone with spreadsheets)**
*** With the help of a marvelous contraption gifted to me, can play cards with folks - great distraction once in a while.**
*** An achievement for me - I can stand for 30 seconds - with the eyes closed!**
*** And the cherry on top - I think the mind survived the year and still works. I think I Can still think straight**

While the " *Can't* "s haven't changed much, there are many more " *Can* "s that are very slowly getting added.

So overall, nothing has changed but almost everything has changed... (Except swallowing of course!).

So what am I expecting in the 5th year? Nothing - just take every day as it comes with no expectations and we'll see next 6th February...

Contd. Pg. 10

Thoughts on my Fourth Strokeversary !

BY- SREEKANTH KESAVA

I am very thankful and grateful for many people for doing so much for me and getting me across so far.

It is not an award acceptance speech - so I am not calling out names, but you know if you are one of them. Please also know I am extremely extremely grateful for your presence by my side always.

If you have given me remote support by interactions on mail/ chat etc. Thank you very much for your support. I started my messages/ posts in the first place to have those interactions and I crave for it still.

If you have silently read my messages/ posts, thank you very much as well for listening to the written voice of my mind (with a stroked brain...)

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 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

T-Shirts !

We have a limited quantity of T-Shirts as shown available. If you want to wear them and help towards our mission, contact us !

My Bike My Time Machine !

BY RAJESH ARORA

(Rajesh Arora- ACUTE ISCHAEMI CVA - LEFT MCA, INFARCT, RIGHT HEMIPARESIS, ACUTE APHASIA, THROMBOLYSED WITH IV ALTEPLASE)

THE LIFE THAT MANY WILL NOT UNDERSTAND: IT'S BEEN A YEAR TODAY AND I CELEBRATE MY ANNIVERSARY WITH MY BIKE

I own a motorcycle because of a personal life choice.

One day when I am very old and when I cannot ride anymore, it will be in my garage as a trophy of my memories.

I have met people who taught me something and have the same spirit.

I meet people now who get wisdom from me.
I get wet,
I get cold,
And I have been hot & sunstroke,
I was afraid,
I fell,
And I stood up,
I even hurt myself.

But also, I laughed out loud with the wind.

I spoke a thousand times with myself and Still do.

I sang and shouted with joy like a madman,
now the road ahead of me...

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> **"You don't have to see the whole staircase, just take the first step."**

My Bike My Time Machine !

BY RAJESH ARORA

And yes ... sometimes I cried.

I have seen wonderful places because of motorcycles. I have made curves that even my dad would be proud of; other times I made curves full of terror.

I stopped many times to see a landscape.

I spoke with perfect strangers.

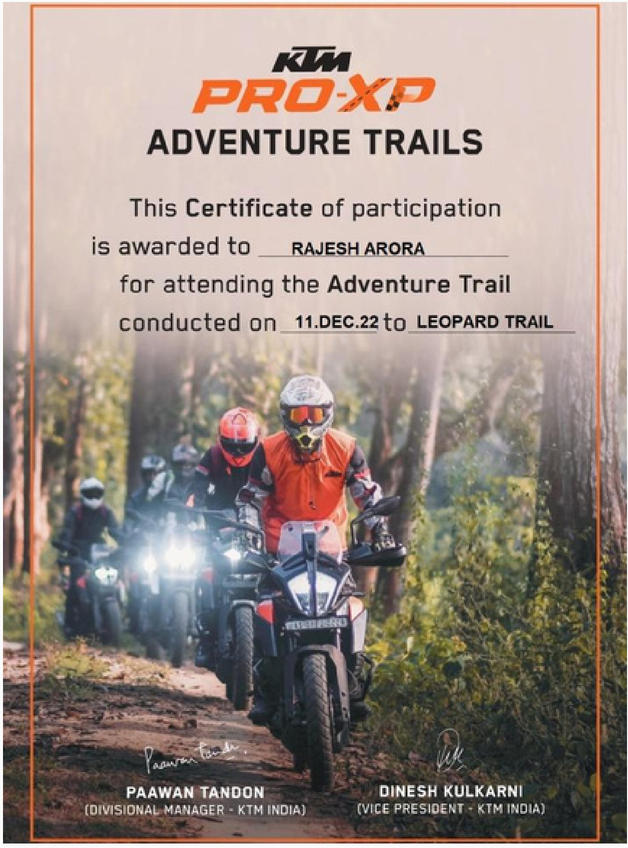
I go out with frustrations inside and return home with a feeling of absolute peace in my heart.

I always think how dangerous it is, knowing that I have ACUTE BRAIN STROKE, and meaning of courage is to advance even feeling fear.

Every time I go out to my ride I think about how wonderful it is. I learned through gestures to communicate with other riders.

I spend money that I do not have, I gave up many things, but it's all worth it...

My bike is not a means of transportation but is a piece of steel, aluminum and plastic with wheels that I am blessed with, it's part of who I am.



KTM PRO-XP
ADVENTURE TRAILS

This Certificate of participation
is awarded to RAJESH ARORA
for attending the Adventure Trail
conducted on 11.DEC.22 to LEOPARD TRAIL

PAAWAN TANDON
(DIVISIONAL MANAGER - KTM INDIA)

DINESH KULKARNI
(VICE PRESIDENT - KTM INDIA)

KTM PRO-XP PRESENTS
ADVENTURE ACADEMY

CERTIFICATE
OF COMPLETION

Presented to
Rajesh Arora
for the completion of Bronze Level training
at KTM Adventure Academy conducted
at Off-Road Adventure Zone
on 18th September 2022.

Philippe Geelhand
DINESH KULKARNI

I love my family & friends and the joy of great people & motorcycles!

May the angels guard my travels, for they know the road ahead of me...

Some Happenings..podcasts !

- What is Aphasia - Bangla Podcast
- Stroke Symptoms - explained in Konkani
- Explaining Neuroplasticity - Punjabi

If you are good in speaking any local Indian language and want to help with podcasts, please contact !

and some Plans!

Similar and other activities are planned in future as well, including offline ones. 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 !
PS : Stroke Support India is looking for Stroke Ambassadors (part time paid role, about 10 hours/week). For details and to apply see:
https://strokesupport.in/ambassador

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