



Raising Stroke Awareness and Supporting Stroke Survivors and their Families

Know and Help!

What is Aphasia?

Aphasia is a condition, frequently a result of Stroke, that robs you of the ability to communicate

Aphasia Awareness: 84.5 % of people even in much advanced USA do not know about Aphasia!

https://www.aphasia.org/aphasia-resources/aphasia-statistics/

There are three types of Aphasia:

- 1) Broca's aphasia: People with Broca's Aphasia may understand others but have difficulty speaking and forming words and sentences.
- 2) Wernicke's aphasia: People can speak but can't form meaningful sentences or understand what is being spoken. Also termed as 'fluent' or 'receptive' Aphasia.
- 3) Global Aphasia: Patients can produce only a few recognizable words and understand little or no spoken language.

OUR MISSION:
RAISING STROKE AWARENESS AND
SUPPORTING STROKE SURVIVORS AND THEIR FAMILIES

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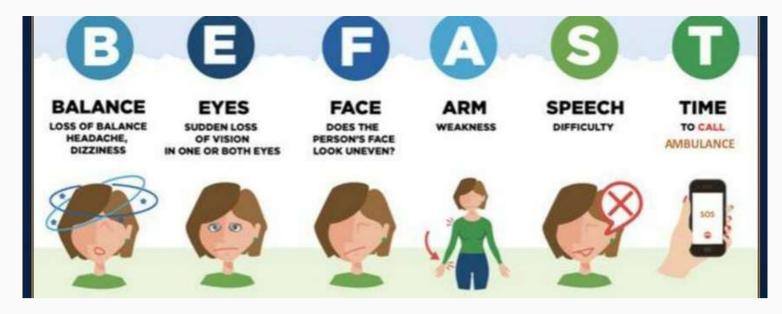
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ALWAYS REMEMBER AND TELL OTHERS THE MOST COMMON SYMPTOMS OF STROKE AS SHOWN ABOVE! For more elaboration please see https://strokesupport.in/be-fast

Life without communication is difficult to explain!

Here are few tips to communicate with the Aphasia Affected:

- · A: Ask simple, direct questions.
- P : Provide multiple communication options
- H: Help communicate if asked
- A : Acknowledge frustration
- S : Speak slowly and clearly
- I: If you don't understand, say so
- · A: Allow extra time

Some more tips :

- Grab Attention before you begin conversation.
- Minimize any background noise.
- Use simple phrases and sentences.
- Don't raise voice unless indicated.
- Emphasize on keywords.
- · Don't talk down or in a childish voice.
- Have patience. Don't complete the aphasia sufferer's sentence.
- Use gestures, writing or drawing.
- Don't ignore the person in group conversation.
- Encourage independence. But also help communicate if asked
- Confirm with yes/no questions.
- Use apps to communicate better.



My Stroke Journey

BY- ARVIND CHITTOR

The year was 2019. I was working in Qatar as an operations manager, I got a stroke days after I was asked to relocate to a new location, leaving all my friends and team behind. I realize now in retrospect that I had taken unwanted stress of hearing this news, I would do anything to undo my past actions if possible. I had plenty of friends to spend time with. I remember it like yesterday, I often stayed up late at night, watching movies or chatting with friends after a long day at work. I had a really bad lifestyle with bad sleep cycles and bad food habits that damaged my health even further. Plus, I was a chain smoker and used to go rally on alcohol once a week.

Let me talk about when my stroke happened. I was out for a latenight run the night before my stroke after my work- which I had been doing regularly over the last few months. Running is healthy but not as healthy without proper rest and recovery. I had also ignored the warning signs I had over last week. I had terrible headaches which I assumed was just like another.

In the morning, I saw my roommates in the kitchen and called out for help, because I couldn't get up from bed. Luckily they helped me to the restroom to freshen up. After much effort, they made me sit on a bed when I couldn't balance myself. I just laid down as I couldn't sit. Luckily one friend noticed my lips drooping and called the apartment manager. He saw that something was really wrong with me and dialled the emergency number for help.

The
Secret of
Success is
to be
found in
your
Daily
Routine!

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A little progress each day adds up to big results.. make your "Pinky Moves" each day!



Arvind Chittor's Journey, Continued....

An ambulance took me to the nearest stroke ready hospital where I was admitted in emergency and was advised emergency surgery. They called my family to inform them of the situation and everyone flew in immediately. I had no clue what went wrong when I opened my eyes. A kind nurse patiently explained to me the condition I was brought in and the current condition of my disability.

I was admitted in a COMA as per my surgeon, initially, I had facial drooping and loss of balance at my residence. My total stay at the hospital and the rehabilitation facility was around 3 months. I was discharged only after they replaced my skull back which was removed during decompression surgery in November. And my cranioplasty was done successfully on Jan 1st. I was very strong throughout my stay at the hospital with great motivation I got from the staff who attended me and my family members who flew in as soon as they were informed.

Believe me when I say, I literally had no hope until my rehab team took over my recovery process. The initial attention and care was a real gift and blessing for me as I wouldn't have been discharged by being able to walk if it wasn't for my therapist, Dr Faraj, and my family who was always with me, cheering and constantly monitoring my progress.

I was confident that I can recover from this, and it's just temporary paralysis.

Life
without
struggle
is a deadlog, our
struggles
keep us
alive!

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Being negative only makes a difficult journey more difficult - you may be given a cactus, but you don't have to sit on it!

- Joyce Meyer



Arvind Chittor's Journey, Continued....

I was strong willed with all my family looking after me, although I was aware I won't be able to use my left arm for a while. I still insisted and was naïve to keep asking to be discharged to resume my work. I had a great set of doctors and therapist to get me through the first phase of recovery. Everyone was very attentive and used to take me for my routine therapy as soon as my breakfast was completed. And I was in the therapies till post noon.

The most effective support I had was my family as they kept pushing me for my exercises and sat with me to keep me motivated, especially my elder brother who gave me, "the never give up" attitude. I continued my exercises in the room after my rehab therapy was completed.

I was actively looking for a good rehab institution in my city, which was similar to QRI, Qatar. Unfortunately I couldn't find any immediately. But with prolonged search, I found the best therapist after a year passed by. I can really vouch for him as none of my previous therapist gave me manual stretching like my current one did. He helped me break the abnormal pattern with his hard work and skills

Although I'm completely independent now, I need support to cut vegetables as my finger movement is still to recover. I am happy I progressed from fully dependent to an independent man over the months of recovery. Its almost 2 years now since I had the stroke and there was not one day without exercising. I'm positive that, "THIS TOO SHALL PASS". I have crossed so much hurdles and just a few more left now.

Destiny created not by the shoes we wear but by the steps we take!

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Do what you have to do.... until you can do what you want to do!

- Oprah Winfrey



Arvind Chittor's Journey, Continued....

I'm noticing improvements in my fingers after I followed the advice from a fellow patient, "Mr Sunish" and my therapist "Dr Senthil", to keep trying things with the affected side, saying, even if it doesn't come today it will eventually happen with multiple tries. So I would advise the same. Even small things like opening the door, turning on the lights, etc can help. Recently after manual stretching, I've started to use a pegboard to do pick and drop activities, which is helping to keep my fingers open.

The next thing is getting a job since I worked in the frontline retail sector. I couldn't continue my job in India, but I kept attending interviews and I was lucky to get selected for a few. While I'm waiting for the offer letters.

I planned on starting my own firm of business consulting where I could work from home. I gathered design experts and social media marketing team to give additional services to my clients. In less than one month, I was able to get 2 clients. I'm happy that I was able to make use of my unlimited time to make my cash flow permanent for now and for my future.

Presently I am running a business consulting firm with digital marketing services. I have figured out that the key is never to lose hope- losing hope is never an option.

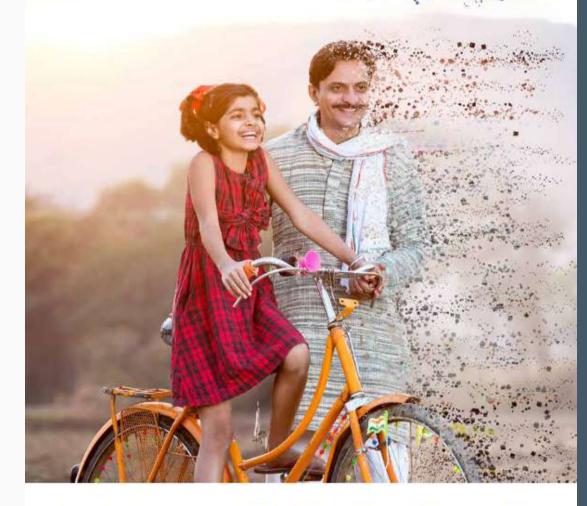
If you get tired, learn to rest, not quit.



Yes, we can!

Marking World Stroke Day on October 29th!

Minutes can save memories



Learn the signs,
Say it's a Stroke
Save #Precioustime

For more information: www.worldstrokecampaign.org











Vorld Stroke

Our Petition on change.org to Raise Stroke **Awareness** has gathered more than 1300 signatures! Please help it cross the next milestone. Please go to:

<u>https://change.org/b</u> <u>e-stroke-aware</u>

Remember- The difference in winning and losing is most often not quitting.

- Walt Disney

Aphasia- When your Brain holds your Words Hostage!

Communication Aspects of Stroke

-Moumita (Speech-Language Pathologist)

A stroke can sometimes cause temporary or permanent disabilities and requires intense rehabilitation. Depending on which area of the brain is affected by the stroke, patients may any or a combination of difficulty swallowing, communicating their thoughts through words or writing, and difficulty understanding spoken or written language among other problems.



As Speech-Language Pathologists, we mainly deal with individuals who have swallowing difficulties and/or difficulty understanding language, difficulty with communication, or cognitive impairment.

COMMUNICATION:

Communication is the act of giving, receiving, and sharing information – in other words, talking or listening or reading. If you had a stroke that controls any of these areas, your ability to communicate might get affected. Not being able to communicate can get frustrating not only for the person affected with stroke but also for the family members and caregivers.

REHABILITATION:

Sometimes despite intense and regular therapy, achieving functional communication is difficult or takes more time than we expected. Such situations can be very frustrating especially when you know what to say but are unable to convey it accurately. During such frustrating moments using Augmentative and Alternative Communication (AAC) mode is helpful.

WHAT IS AAC?

Augmentative means to add to someone's speech. Alternative means to be used instead of speech. Some use AAC for the most part of their life, while others use it for a short time till they can talk. There are different types of AAC. These include: No-tech and Low-tech options such as:

- · gestures such as pointing, actions
- writing
- drawing
- · spelling words by pointing to letters, and
- · pointing to photos, pictures, or written words

Strive hard and you will get there... where you wanted to be.

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Aphasia- When your Brain holds your Words Hostage!

Communication Aspects of Stroke

-Moumita (Speech-Language Pathologist)

High-tech options include:

- · using an app on a tablet or phone to communicate
- · using a computer with a voice called a speech-generating device

A Speech-Language Pathologist can help you find and learn the right AAC system for you and your loved ones. A lot of people wonder if using AAC will stop someone from talking or will slow down language relearning. This is not true, in fact, research shows that AAC can help with these concerns. People who use AAC can also improve in reading and writing.

Some of the benefits of using AAC are:

- · increased independence for everyday activities
- · ability to better participate in day-to-day life
- fewer communication disruptions
- better connectivity with family and friends
- improved mental state with fewer episodes of frustration

Speech and language therapy varies for every individual depending on the area of stroke and the problems they exhibit. So, there is no one size that fits all.

Recovering language skills can be a slow process. But with patience and persistence, most can make significant progress.

Also remember, assessment and Speech-Language Therapy starts in ICU itself, so don't delay the therapy process for better and faster improvements.

Moumita Hati is an active member of our Stroke Support Group, and a Speech-Language Pathologist and Swallow Specialist practicing at Mumbai (Maharashtra). She has done her Master's from Ohio University (USA) with special interest in Neurological disorders and adult and pediatric feeding and swallowing skills.

Don't complain that rose bushes have thorns rejoice that thorn bushes have roses!

See
Positive
to Be
Positive!



Some Happenings...

Several activities are regularly undertaken by members of Stroke Support India. A small list includes :

Zoom meetups on:

- Journey to recovery- a chat with Ms Tsgoyna
- Chat with Stroke Warriors Kati and Henning
- Second Physiotherapy Session with Dr. Forum (PT)

Podcasts on:

- Stroke and Depression a Podcast in English
- Neuroplasticity and Stroke a Podcast in Bangla

Other efforts

- A series of Zoom chats are underway with a major medical services company.
- Free Communication Improvement Sessions for the stroke affected conducted.

and some Plans!

Similar and other activities are planned on the way forward. Some are already underway. 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, suggestions and help welcome.

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