The First Memorial Oration in honor of the founders of Madhuram Narayanan Centre for Exceptional Children - Air Vice Marshal V Krishnaswamy and Mrs. Jaya Krishnaswamy on Saturday June 28th 2025.

Neurodevelopmental Challenges in Children with Intellectual Disability Empowering families through early intervention

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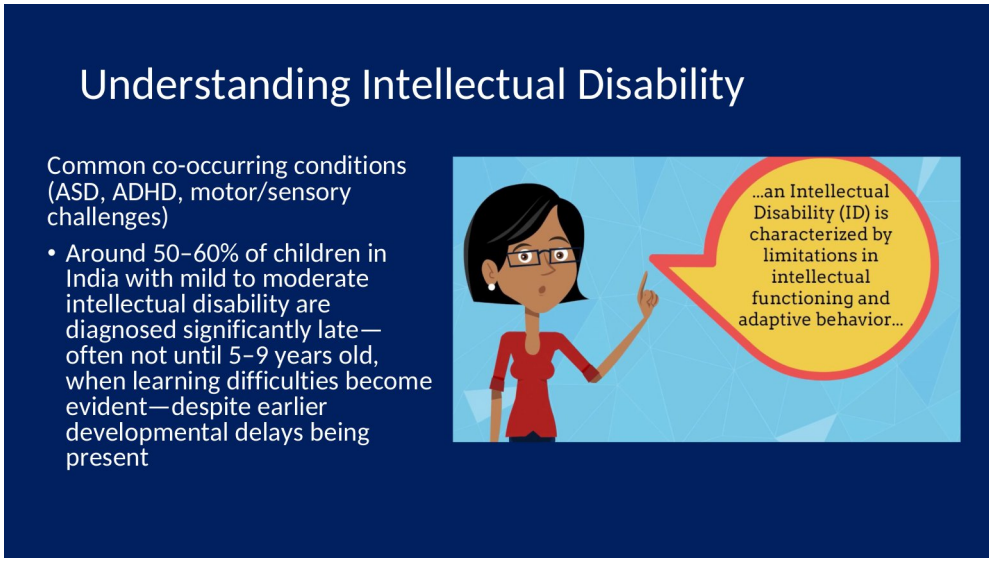
FIRST MEMORIAL ORATION IN HONOUR OF FOUNDERS
MR. & MRS KRISHNASWAMY
SATURDAY 28TH JUNE 2025

Good morning to everybody Thank you for that introduction. At the outset I believe that everything in life is something to be thankful for. And so, I would like to start with gratitude and I am deeply honored that Madhuram Narayanan Centre and Bala Mandir Kamaraj Trust for considering me worthy of delivering the first memorial oration. When they approached me and invited me, they said you knew Jaya well, you knew her work and so it would be very appropriate if you come and do it. They did not realize that it was I who is being honored being given the privilege. Thank you very much. They said do you want to give a topic and I said you give me the topic on which you would want me to talk on.

Jaya was a gentle firebrand if you want to call her that. She was like a little oil lamp constantly, always burning available to light other lamps but never losing its own flame. I like to use that analogy a lot because some of us think that if we have to do service we have to be like a candle. We have to serve and serve and we give everybody and we disappear. Like Dr. Vijayraghavan already mentioned unless your cup is full you cannot help others. If your cup is empty there is nothing you can do, so make sure self-care is a priority, take care of yourself. I am a doctor and that is something I will harp on. Make sure you are physically, mentally, emotionally balanced and take care of yourself. Otherwise, you may have the grandest dreams and biggest things you want to do but you will never end up doing and the proof of that is the life of Jaya and AVM Krishnaswamy. They served for a long time. If you want keep on serving a long time first look after yourself. Now the topic: ***Neurodevelopmental challenges in Children with Intellectual disability empowering families through Early Intervention***. The topic is actually of

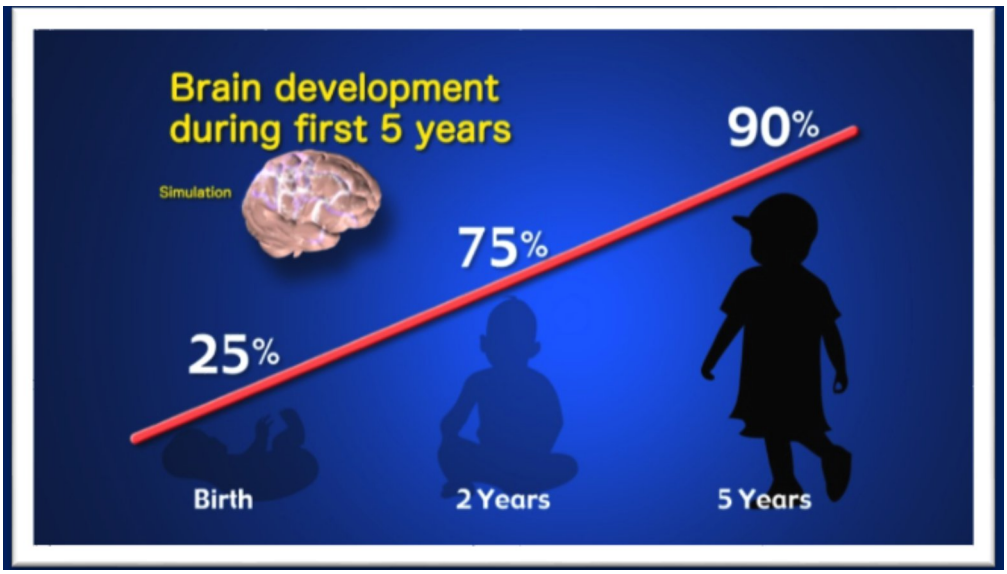
enduring urgency and personal passion. Let us understand that every child is a different kind of flower whether they have a disability, normal or whatever. The fact that they are born into this world makes them very special. So, I speak not as a clinician or a researcher but as an advocate for every child whose potential is yet to be understood and for every family striving to build a better future amidst overwhelming uncertainty. As a neurologist I see a lot of disability. Unfortunately, neurological illness –a majority of them are associated with disability, in young people and older people it is especially associated with disability and in my own little way I have tried over the years to not let the family get totally overwhelmed when they have to care for such people. The second thing I always emphasize is I encourage the patients that you can always bounce back, not just bounce back to where you were, but bounce forward, rise and become something bigger and better than you were and let me tell you when they have that motivation they start achieving things they dreamt that they could never achieve and that is the kind of hope we need to give people who have been knocked down with disability. The other thing which is very important is that when you recover and when you bounce forward don't let the whole thing be okay. I have survived this difficulty. It has to go beyond that and I tell people that they have to start thriving. You have to thrive and go one step further and inspire, be an inspiration to yourself and to others. Jaya and Krishnaswamy really lived that through their lives.

So, we are talking about Intellectual disability.

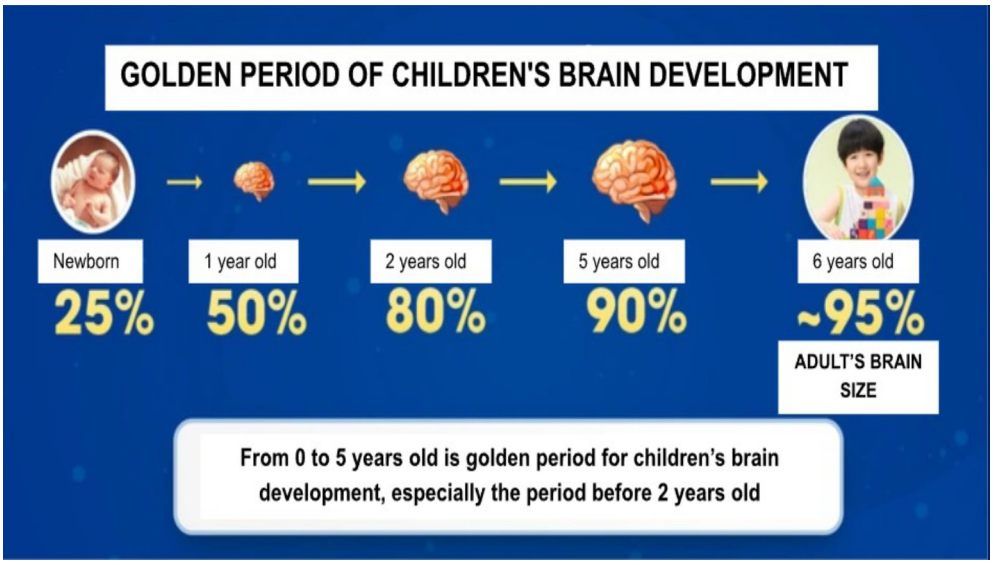


What is the definition of Intellectual disability, nothing complicated. It is limitation in intellectual functioning and adaptive behavior. So, what we need to understand is why we are talking about Early Intervention, why does it matter. It matters because 50% to 60% of children are diagnosed only when they are 5 or 6 years old, and by that time the

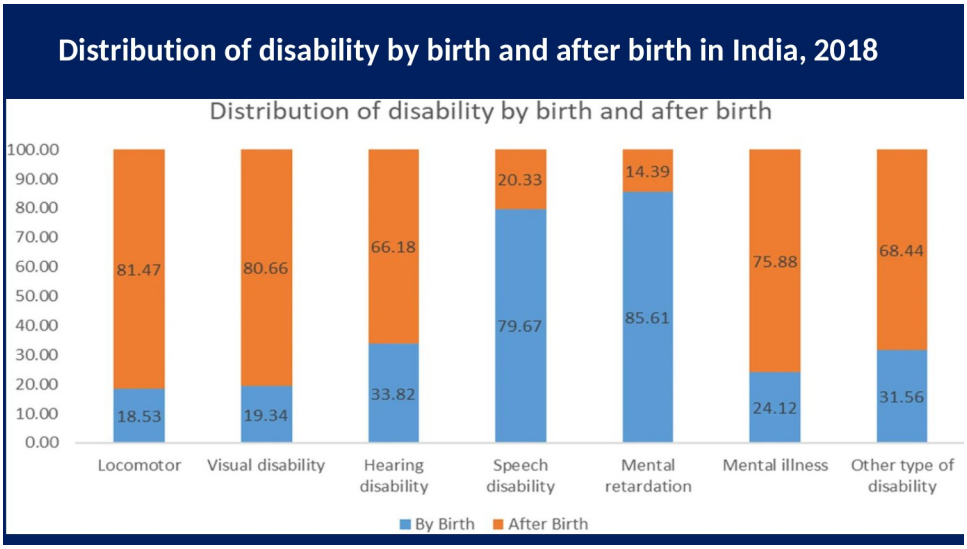
child's brain is 90% developed. So, you have very little space to work in. So, if you start identifying and diagnosing problems much earlier, especially before 2, it is a very critical period for us to start intervention.



Then you can actually start to shape the rest of the brain because neuroplasticity is best at that period. Now, neuroplasticity is the ability of the brain to change in structure and functioning when you put in external stimuli and stimulate the brain from outside. This is something we cannot afford to lose and that alone, as a neurologist I can tell you, is enough reason to keep on advocating Early Intervention. So, you will find that the new born is already born with 25% of skills and as quickly as one year old the brain has developed 50% of its skills. I would push it further and say that 0 to 1 year is more critical as speed is much higher. Then by about 2 years it is 80% developed and at 5 it is 90% and by 6 years it is almost an adult as far as brain development is goes. So, I don't need to advocate anymore for Early Intervention.



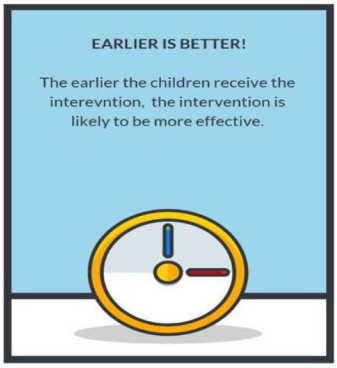
It has been found that it is possible to identify various disabilities pretty early. The table

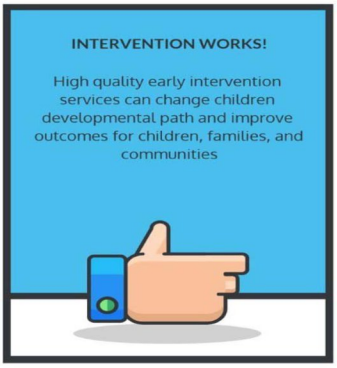


here shows you locomotor, visual disability, hearing disability, Speech disability and mental retardation and all of this can be easily diagnosed if they happen during birth or soon after birth. The window of 0 to 1 year is a very valuable window. Why is Early Intervention so important? Early Intervention is a system of services that helps young children with disabilities or delays to learn basic skills and catch up with their development.

WHY IS EARLY INTERVENTION IMPORTANT?

Early intervention is a system of services that helps young children with disabilities or delays to learn basic skills and catch up with their development.

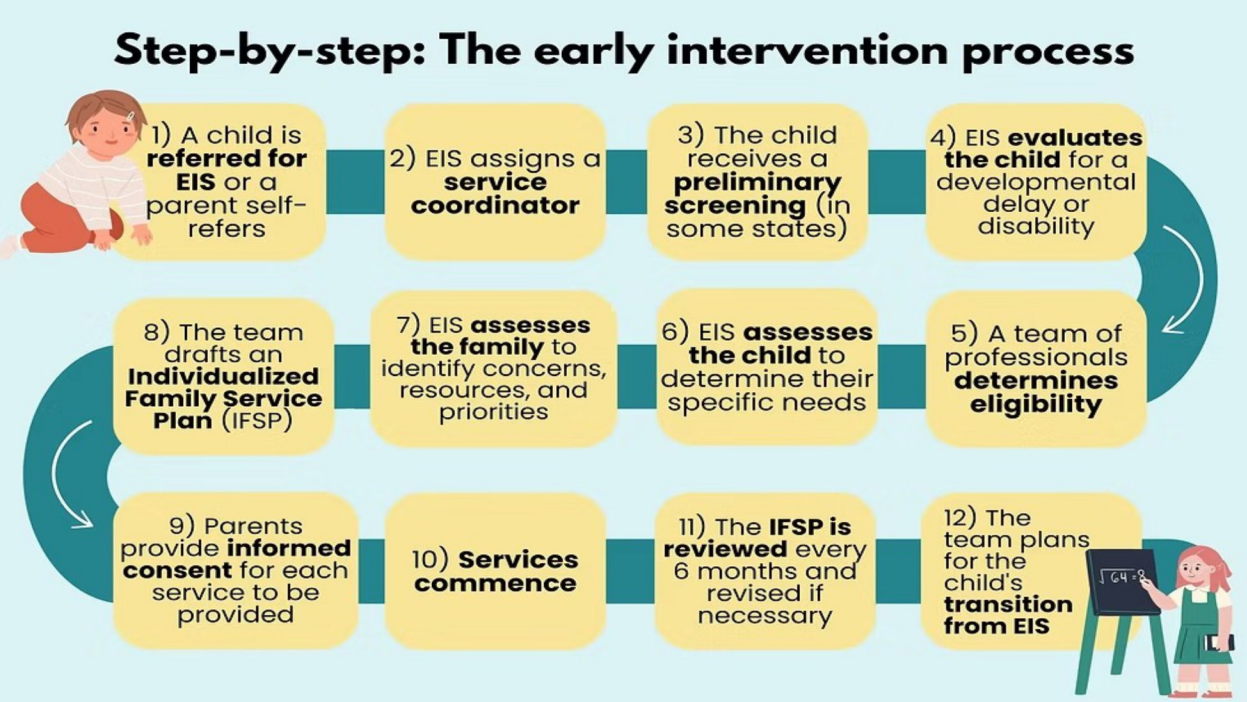






The crucial word here is CATCH UP. The brain is growing but not at the pace it ought to grow. So, when you do Early Intervention, you are helping to catch up and that is a tremendous thing because the result is fantastic and earlier the children receive intervention it is effective and if the intervention is of high quality, it can completely change the future of the child and family. When you help the child, you are helping the families. So, lot was said earlier that family support is important.

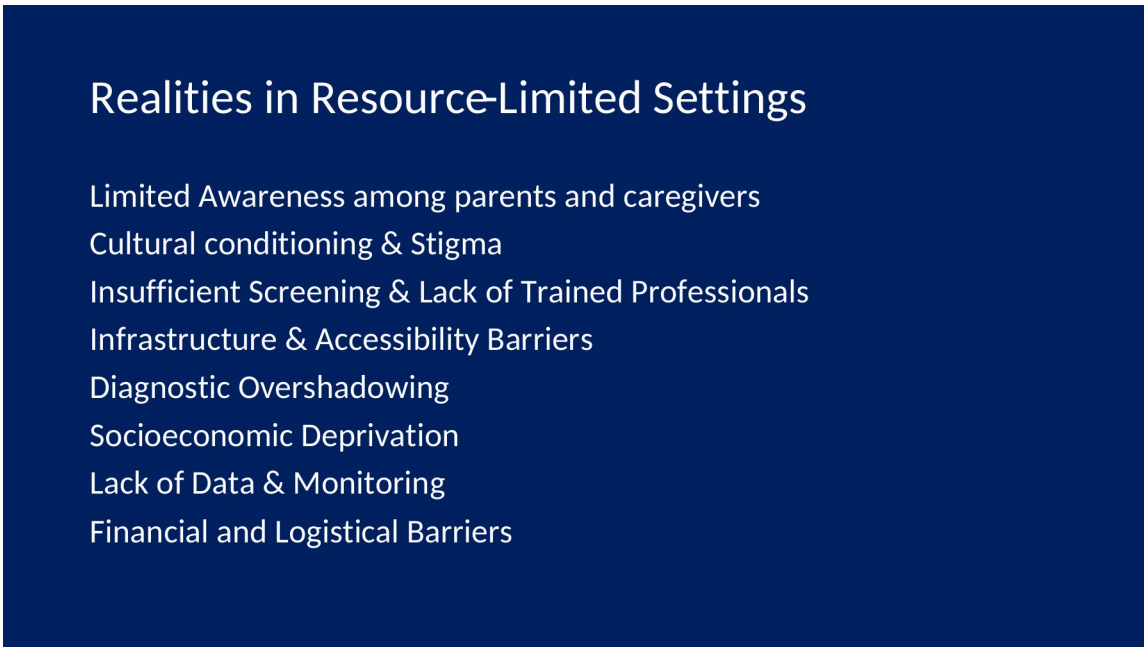
If you look at the step-by-step Early Intervention, I am carrying coal to Newcastle to tell this audience, but the reason why I put this slide is because some people think it is very tough to do Early Intervention. So, as you see there are stages which you can follow, you can get help as you go along. Be aware when a child is referred to EI services who does it. The EI services assign the child to a service coordinator. You will do preliminary screening, evaluating the child and you create a plan which is individualized for the family. What works for one family may not work for another family. Identify their concerns and priorities and we keep on assessing and reassessing the child. Keep working on realigning the child to the services. Thenof course professional helpis called in with informed consent.



I want to spend a minute on this informed consent. Sometimes in today's' world if you want to do good other people think you are doing it for a reason. As a doctor let me tell you that there is lot of difficulties we face. If we charge for the service, you are considered to be evil. So be very careful that when you are doing some intervention which is a little bit invasive make sure you get informed consent. Then you are protected. It is a very important thing which many service organizations neglect. Of course, you start the services and review regularly and if you actually plan it can be done by just a small person who is dedicated and who has got the skills and want to do something for the children.

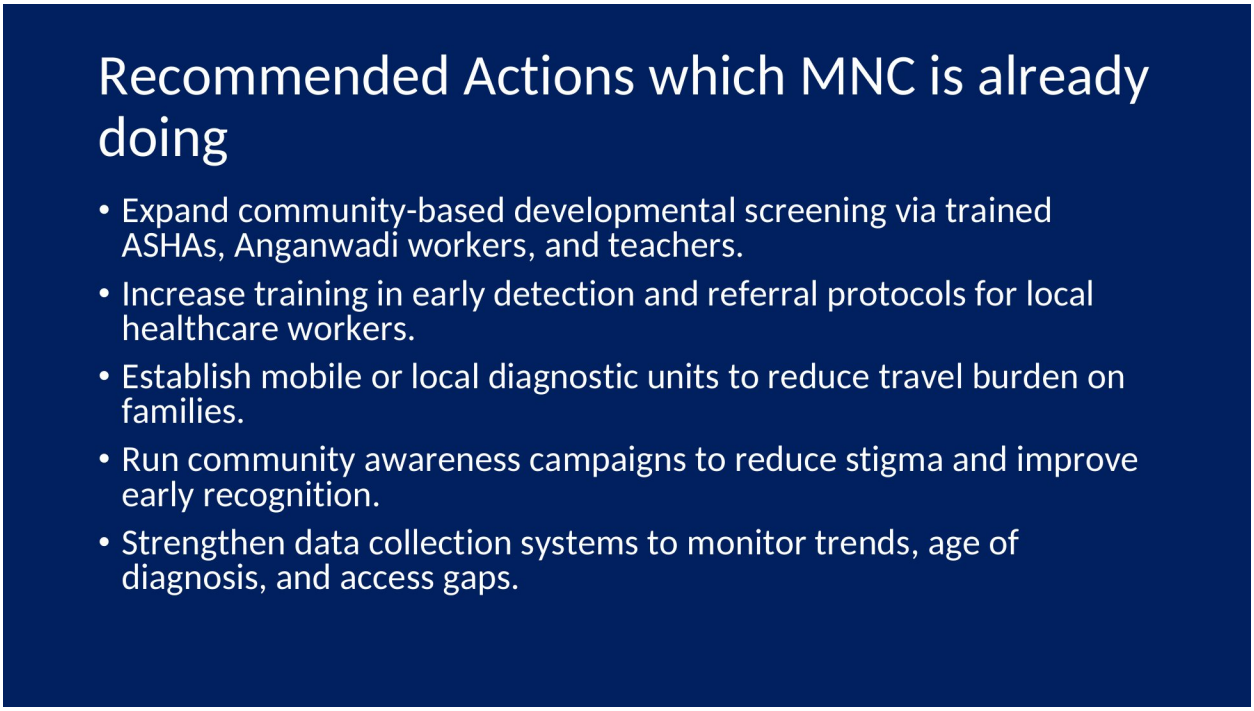
But there are rural areas which are resource limited areas. Why are we having problems in establishing proper Early Intervention there. One of the things is limited awareness among parents and caregivers.

I advocate and I am a specialist in epilepsy, I take every opportunity to educate every level of person on what is epilepsy, because everybody has in their imagination some concept of the condition and they color it with other experiences. I always say that my biggest competition is *"pakkathuveetu mami*, because I have studied for 17 or 18 years and I give a prescription she will come and say things "*Aiyoo did they give you this, enbrotherkukoduthangaottheyvarale"*, don't take it. So, we have to be very alert to that and so awareness and current information transmissionis important. You are probably doing it anyway keep on doing it.



The second thing is cultural conditioning and stigma. In India this is a major thing as each caste and community have their own version of how to look at things. In fact, I think the villages are better that the cities as disabled people are accepted as part of the community in villages, more than the city. Insufficient screening and lack of trained professionals is another reason. Centers like you MNC are there to correct that. Then again, we have to give more and more training for the staff and make them more and more competitive. Then comes Infrastructure and accessibility barriers. I cannot go to the center every day as I have to travel for 3 hours from my home. So that is where your peripheral centers play a huge role. So, congrats on expanding your services to peripheral centers. Then comes diagnostic overshadowing. Sometime when you make a diagnosis of Autism or ADHD the child may have epilepsy or something else which is actually interfering with your Early Intervention process. So, you need to understand that sometimes unless that is dealt with this will not get better. Next is socioeconomic deprivation. It is getting better day by day but it is still a big problem. Then there is lack of data and monitoring – this is another area. We have Dr. Vijayraghavan with us here and since he is associated with us, we request him to set up a system for monitoring. We do not monitor our work and that is why we have so few publications and so few information is available. I request Dr. Vijayraghavan to pull our old data available and organize it which will contribute a lot of information for us. Last are financial and logistic barriers. When we ask something from the Government, ask for a project under their schemes what will take 2 weeks will take 2 years. These are things we have to learn to live with.

Some of the recommendations I am humbly submitting to you is as per the slide below.



You are probably doing some of it. The public private association is useful sometimes and we underuse it. The Government, especially in TN, our PHCs are the best in the country by the way. You have already a lot of systems incorporated there. So, if you can link it with your data, you can collaborate with them and you will find it very much easier to expand your community. Increase training in early detection and have protocols. Go to PHCs and tell them if you recognize this then it is to be referred to the healthcare workers. We have the least mortality rates. It does not mean we have the least disability rates. Establish mobile or local diagnostic units to reduce travel burden on families. This is something anybody doing any service has to note. I am a Rotarian and we try to do this but challenges are there. A mobile unit which can bring services at the doorstep would be wonderful thing to take away the accessibility barriers. Run community awareness campaigns to reduce stigma and improve early recognition. Go to a senior citizens home or anywhere an apartment building and do awareness there. Ask them – listen I want to talk about disability how much do you know. The Indian Women's Association is a body with some of the top women in the city and when I told them I want to talk about epilepsy first they were hesitant but later they found that they knew nothing about it. They were like Oh we dint know anything. They are still giving keys if you have convulsions. Whether you know anything or not, know what to do when someone has convulsions and it will save somebody's life. Strengthen your data collection systems to monitor trend, age and access gaps.

Technology is playing a very big part in our world now. I have started playing with AI now. Though I am 78 years old I cannot miss that boat. It is fun I tell you.



What you need to know is that AI actually has world over created a lot of useful systems for this kind of work. So, you need to go and explore it, may be if I get somebody to teach you the basics of it – Chat GPT I shall send. Chat GPT feels like a friend now. So, this Ismail and Alharbi (see slide above) study suggests that they can do a lot of our apps which can be put through mobile phones. This country is the highest user of mobile phones. Also, we are the highest user of WhatsApp. This is a statistic a proven statistic. So, leverage that. We have also got in our country the multi-language communication. So, it is tool you cannot afford to ignore. Make use of that for communicating, for nurturing, everyday send a tip in WhatsApp I am doing it for my communication. I am a brain health ad resilience coach now I use it in my consultations and coaching practice. Train your front-line workers to use AI basic tools and culturally diverse data can be collected because of that. If MNC were to run in Mumbai or Calcutta what would be the data you would get. Safeguard privacy, Next is conduct pilot and long-term impact studies in varied settings. So, I decided in this oration that how and why the future can be rather than yes good work has been done, but you have to get to yes great work has been done and that is possible. Technology has changed my life. As a neurologist when I trained there was no MRI or CT scan and we used to go dangerous tests to diagnose. Let me tell you that every time I see a MRI today I say thank you God for this is because I

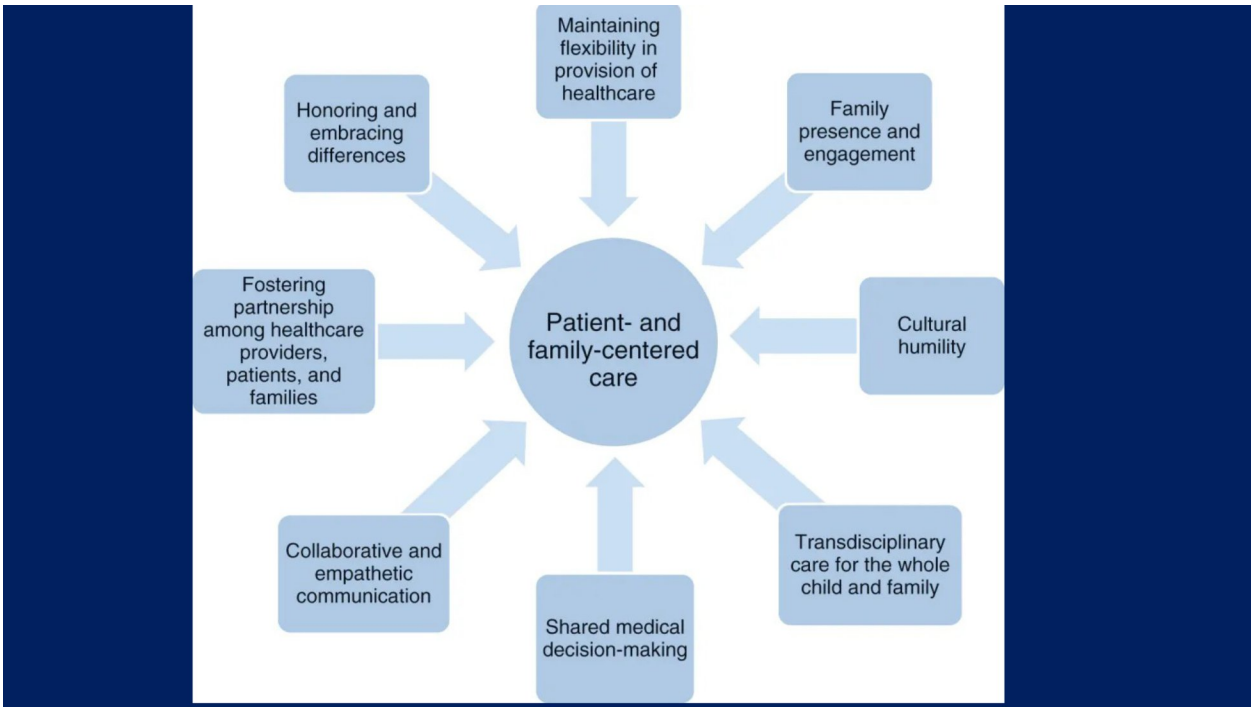
can see the brain in 3 dimensions without having to do any harm to the patient. So, understand the future is fantastic. So don't get left behind.

So, when we have a child, we have various levels of support-the family, schools, communities and society.



Now more and more, a lot of work is being centered on family-based support in India. In medicine we have been using the family as our care givers in hospitals. We don't have enough nurses, we don't have enough staff to do small things for the patient. So, we use the family. One family member is allowed to stay in the hospital unlike USA where they say the patient has been admitted and you can go home. Give us a call in the evening. Your visiting hours are 6 to 8 or whatever, that is it. So, the family and the patient are far away, and let me tell you if you are a patient, I am a cancer survivor you definitely want family. So, family care will actually increase the impact of the work you are doing.

What does the family centered care to the child do to help the caregiver? It maintains flexibility in provision of health services, family presence and engagement and cultural humility. It helps in transdisciplinary care for the whole child and family. I may have an elderly mother-in-law to look after and also a child to take care. If I go to the center I cannot do both, I am handling two or three people to share the services.



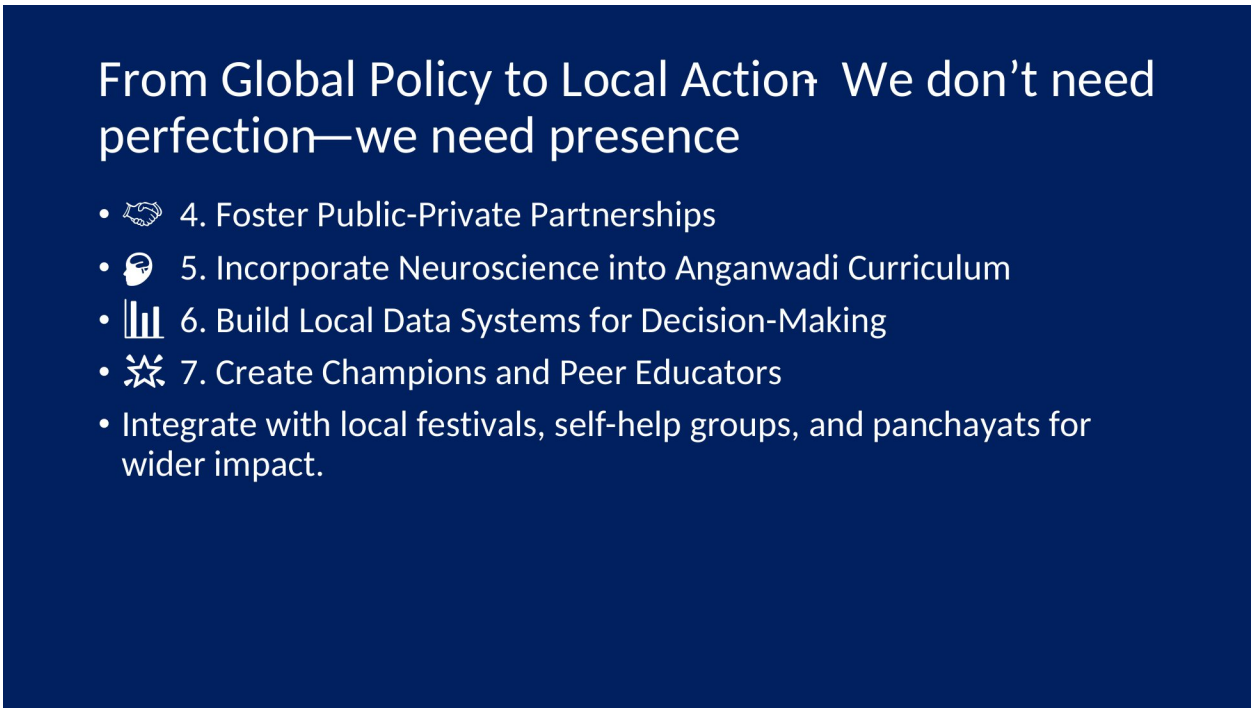
Patient and family centered care helps in fostering partnership among healthcare providers, patients and families. It also helps in honoring and embracing differences.

The last area, which I want to address, is how to go from global policy to local action. See we have to localize and simplify the screening tools. We have done that in medicine. We have a lot of standard tools. We have to run a study. For instance, my Ph.D. was in creating an evaluation tool, bedside evaluation tool for speech disability, which has all the concepts

From Global Policy to Local Action: We don't need perfection—we need presence

- 1. Localize and Simplify Screening Tools
- 2. Train and Empower Grassroots Health Workers
- 3. Leverage Indian AI & EdTech Startups
- Promote indigenous AI solutions like:
- CogniAble (AI-based autism screening)
- Thinkerbell Labs (education for children with visual/cognitive impairments)
- TARSHI or eSanjeevani for tele-counseling and follow-up
- Encourage state governments to fund these under Atmanirbhar Bharat and Digital India missions.

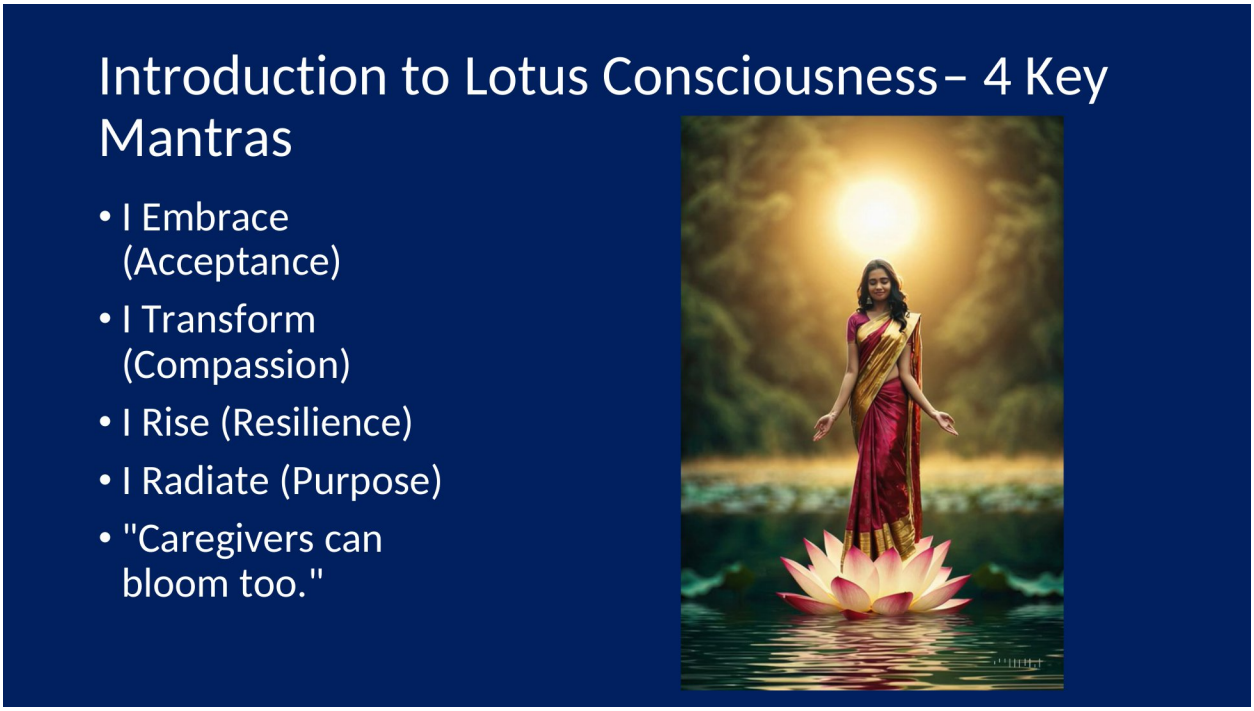
We were not following the Washington scale or whatever as it has no relevance to our population.To take the tool to use that is where your research comes in and if you can validate certain tools and that gets recognized that is going to help somewhere else. So, train and empower the grass root health worker. Now some of the grass root worker do good work, and some of them don't but let me tell you it is thankless job. Nobody really values them. So, if you can start showing that value especially when you start collaborating with the Government, they will do a fantastic job. Because they care for the community they come from. Then comes Indian AI and Edtech startups. We are serving the entire world in computers. America will close down if Indian computer workers come back. So, understand that there is a lot of knowledge base here. Talk to Hyderabad, talk to Bangalore, talk to Infosys, talk to IIT Madras – they get very involved in Bio medical research and there is something called CongniAble which is an AI based autism tool. I dint know that, when I researched for this talk, I understand there is a simple tool already available. So, I have got a PDF of all the tools available in India on AI. I will send it over to you, which you can start checking. Encourage the State Government to fund you under their schemes, you can squeeze your projects there. Of course, tele counseling and tele consultations. It has been happening since Covid. But we can activate it some more. Foster Public private partnerships.



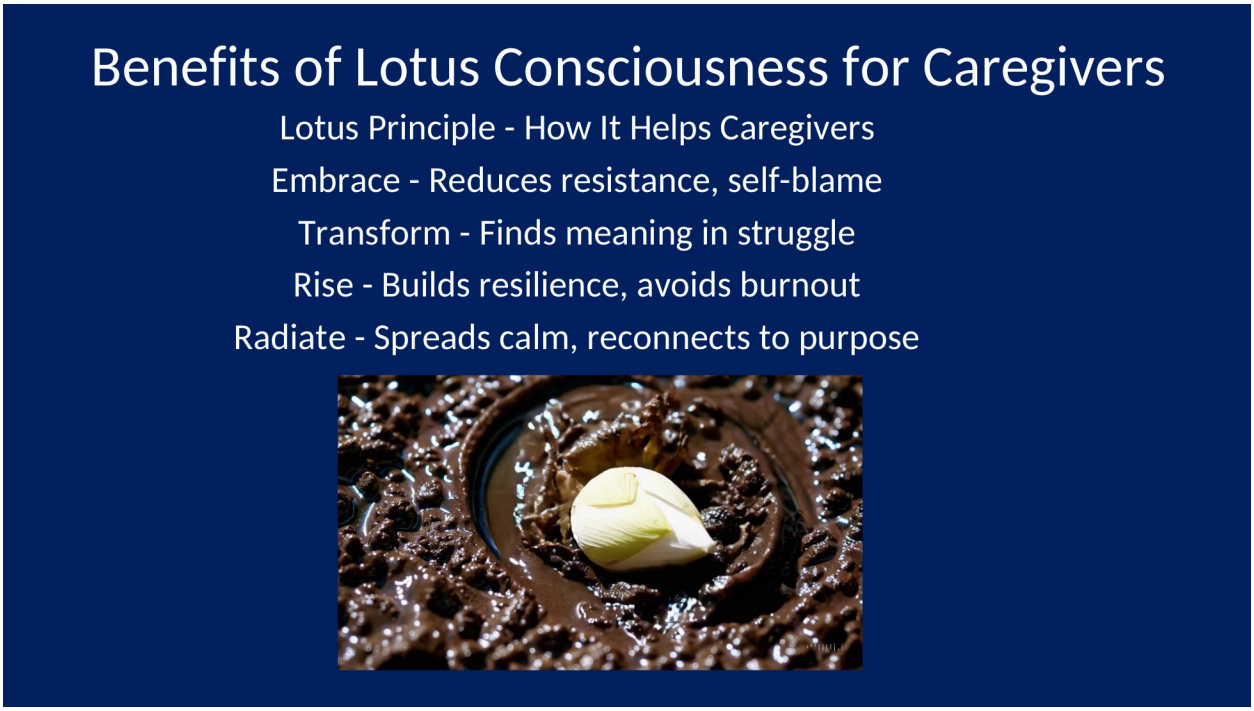
Incorporate neuroscience into Anganwadi curriculum. Teach them basic neuroscience; tell them what is brain, how it functions, what it does and what it does not do, what goes haywire when the child has a seizure what goes haywire when they have an ADHD.

When they understand this, they are better workers. Build local data systems for decision making and make everybody a champion and peer educators. One of things I do and you can also do it is to integrate teaching and awareness with community festivals. Celebrating Pongal in Bala Mandir with some dance or something and I will give a little talk on Early Intervention. Because, if you call for health programs nobody will come.

I have actually written a book and introduced the concept of Lotus consciousness in which I say you can leverage your challenges. So, I say don't just overcome adversity, convert it into an advantage and this adversity is the mud in which the lotus blooms. So, I say embrace the mud.

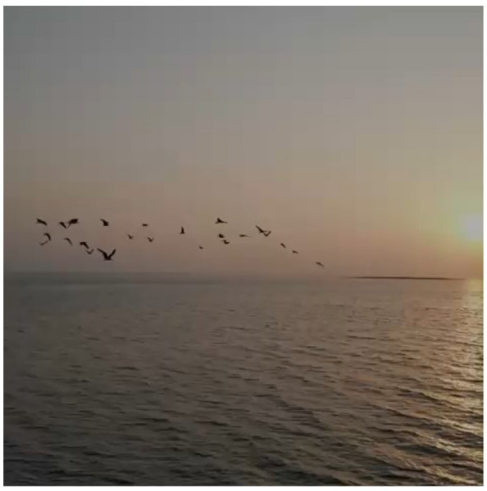


When the lotus is growing it tries to put its root through slushy mud. It is not easy and it works very hard and then it anchors itself. When it has some hold then only it pushes forth the stem. So, it embraces the mud and after embracing it starts transforming to become a plant, and even when it transforms to become a plant it is not easy because of the water and so many things you have to push through in order to break surface. That is the Rise part of it and when you break the surface you are a radiant lotus that is an inspiration to yourself and to the world and you are contributing your service to the world. Now this has become the theme of all my coaching programs. In my case I had a diagnosis of rectum cancer stage 3 in 2016 as a part of my routine checkup. Let me tell you it was a blow. I had 2 years of very tough treatment and I said I am not going to allow that stop me from what I am doing.



I am helping so many people and I will continue to help them. First, I will help myself that is why I said self-love and self-care is a must.

So how does the lotus principle help the caregiver. The lotus consciousness is about becoming who you are meant to be, because you think when a challenge happens everything is over. It is finished. I cannot be what I wanted to be. I never dreamt that I am going to be in coaching.





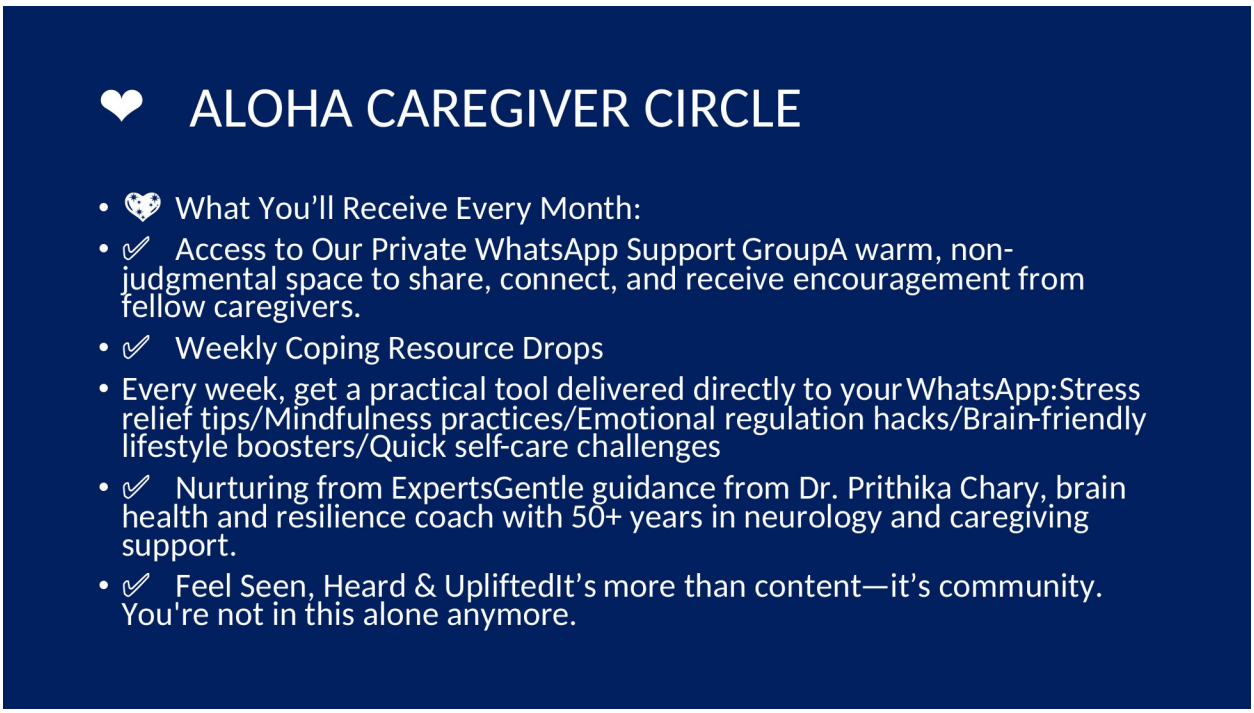
so, I was sitting during covid and I was sitting during my treatment. I learnt some technology and I played around and then I discovered the on-line coaching classes. That is it. So, you can be somebody whom you never thought you are meant to be. So please don't give up. Reset, reevaluate, rest and don't give up. What does every care giver need. There are 15 things that every care giver needs: Boundaries, Self-care, financial planning, time management, rest breaks, diet and nutrition, stress management, acceptance, mindfulness, celebrating small wins, communication skills, support system, resilience skills, emotional release and adaptability.

So, I created a special program for caregivers. We call it Aloha. Aloha in Hawaiian means 'Breathe". Every care giver often ignores or overlooks all these aspects. Care givers should set boundaries many care givers do not set boundaries. Don't be the candle. You have to be the oil lamp. So, I have created what is called the Aloha Care Giver Circle which is a WhatsApp Community

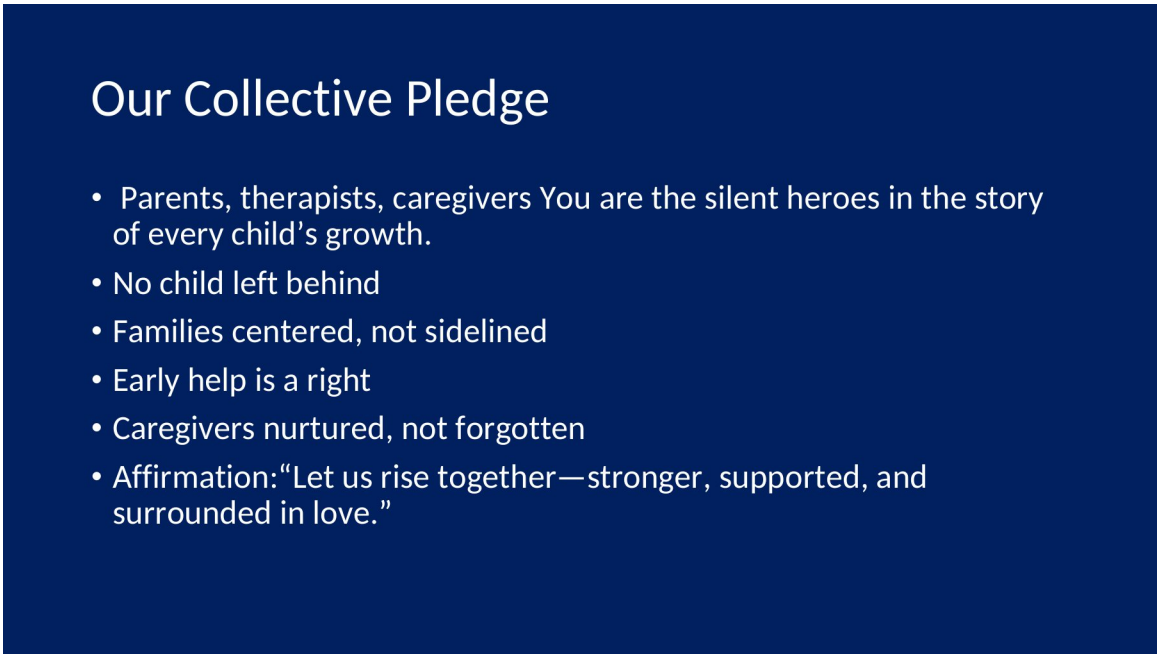


You may wonder why is she talking about money. Without money you cannot pay for your services. We give some emotional supports and it is platform to share everything with each other. Share their experiences or the problems and your time as a caregiver has to be held. We are about to hold you, you are not alone; you hold everyone and so allow us to hold you. So, what exactly does the space hold for you. You learn to care for yourself as you deeply care for others. If you are an unpaid family which is what most of the people are facing tiredness, overwhelmed emotionally drained, you are not alone.

What will you receive if you join the Care giver circle every month? It is more than a contact; it is a community.

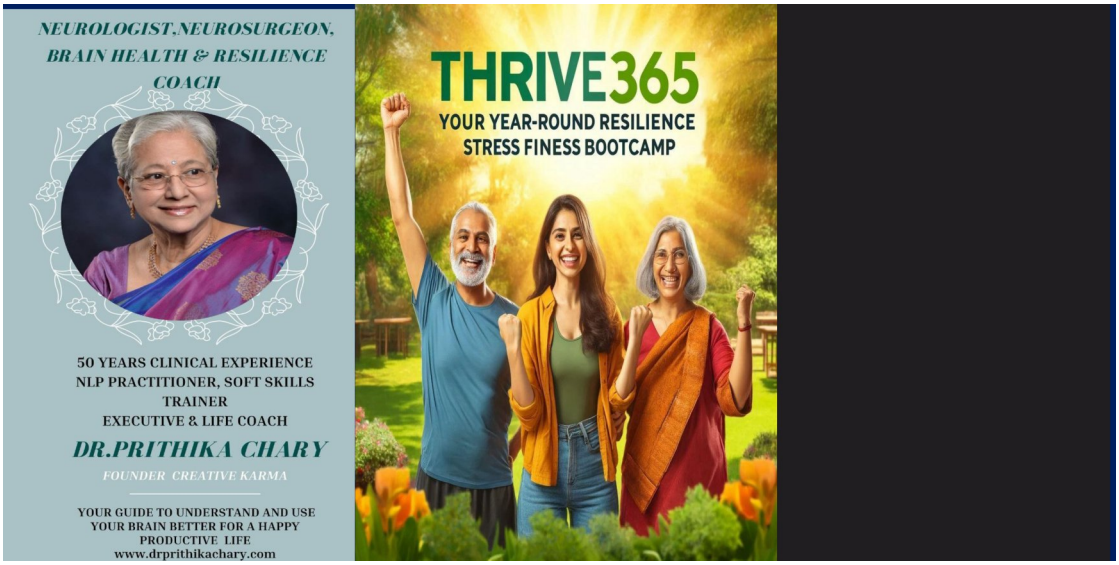


I offer the Aloha membership for all MNC registered care givers free. So, you have to set up a system so that we get them into the WhatsApp group. So that I can keep nurturing them and sending them messages and they are also understanding. Once we set it up, we can do an orientation program or something like that, tell them how it works, how to



Connect with it even if you are not a part of Aloha. Take a pledge. You are the silent heroes of every child's growth. Caregivers must be nurtured not forgotten. No child should be left behind. We have to rise together stronger, supported and surrounded in love.

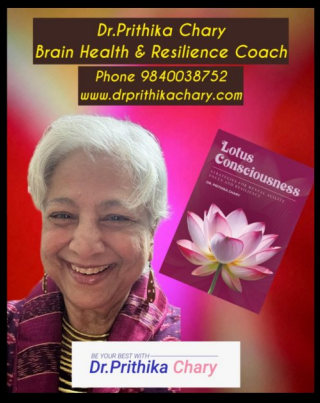
How to connect with the community even if you are not a part of Aloha Join our 10x – 100x WhatsApp community. Anybody can join, and we have here the whole goal is to thrive 365 days and not for only one day.



I now give you the sources. My face book, linked in., Instagram etc. See how smart I am in technology.

Contact

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I want to end with a poem by Kahlil Gibran “Fear”

It is said that before entering the sea
a river trembles with fear.

She looks back at the path she has traveled,
from the peaks of the mountains,
the long winding road crossing forests and villages.

And in front of her,
she sees an ocean so vast,
that to enter
there seems nothing more than to disappear forever.

But there is no other way.
The river cannot go back.

Nobody can go back.
To go back is impossible in existence.

The river needs to take the risk
of entering the ocean
because only then will fear disappear,
because that's where the river will know
it's not about disappearing into the ocean,
but of becoming the ocean

I have also written a book “Lotus Consciousness” about my cancer experiences. Please read the book. The obstacle is the way. So in Lotus consciousness you believe that you embody. In Bharatnatyam there is something called Satvika Bhava where you transcend and become the role, that is what I am telling everybody to be. The river in each of us has journeyed through pain, programming and patterns. We have diagnosed our self-sabotage, we have excised the emotional tumors and we stand at the edge of becoming. And yes,it’s scary, to leave behind the old identity, to no longer be defined by the familiar stories, to stop saying “ this is just how I am”. But it is not the end. It is the beginning. Today we rewire our brains and say anything and everything is possible. I am unstoppable. I am here for a purpose and I will do what God put me here for. So, I become the ocean.

Becoming the Ocean

Slide 2

"That river is each one of us. We've journeyed through pain, programming, and patterns. We've diagnosed our self-sabotage... we've excised the emotional tumors... But today–**we stand at the edge of becoming.**

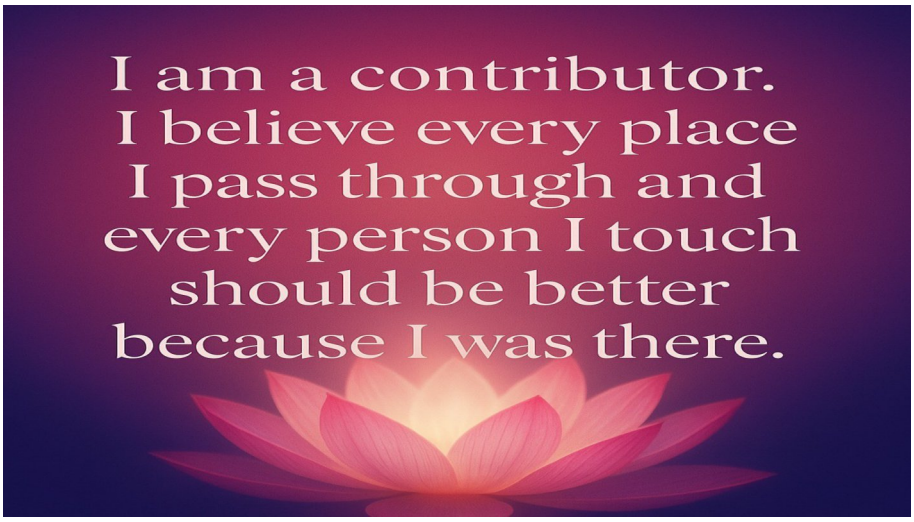
And yes, it's scary. To leave behind the old identity. To no longer be defined by the familiar stories. To stop saying, *'This is just how I am.'*

But this is not the end. It is the beginning of a greater truth.

Today, we rewire. Today, we don't disappear. Today—we become the ocean. We rise in Lotus Consciousness."



Because my driving force throughout my life has been that I am a contributor. I want a person or a place to be better because I have touched it or passed through it.



I hope I have touched your life in some small way, inspired you in some small way to become one who does good, because the world has a lot of bad in it and if you want to negate that more of us have to do good. More of us have to help others; more of us have to think about others.

Thank you very much for the opportunity.