

**We are all now connected by
the internet, like neurons in a giant brain**

-Stephen Hawking



WE FOUGHT COVID BY GOING DIGITAL

Oxidative stress plays a major role
in the pathogenesis of
Multiple Sclerosis



➤ Difficulty in Moving

➤ Problem with Speech

➤ Loss of Sensation

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➤ Weakness

➤ Feeling Tired

➤ Dizziness

➤ Depression

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Disclaimer: The content of this publication is based on clinical expertise of healthcare professionals and the life experiences of PwMS and their caregivers. It is intended to serve as a guide to patients, family members & caregivers. It is **not** a substitute for or does not supercede individualized physician treatment and advice. MSSI does not endorse any particular treatment for MS.

MS is an extremely variable condition and people can respond differently to treatments. Treatment decisions need to be taken in conjunction with a neurologist and should take into consideration the unique health and life circumstances of each individual. MSSI does not approve, recommend or endorse any specific products, therapies or services, but provides information to assist people in making their own choices.



Hello everyone!

Greetings from MSSI Delhi!

As the first wave of virus receded at the beginning of the year and the vaccine was publicized in full steam, we were under the impression that we conquered Covid 19. So we let our guard down and

joyously thought we will be out into the world now with full freedom to meet all our members. But without warning the second wave hit us violently with a tragic outcomes. To combat this, MSSI organized many webinars with leading neuro-physicians who reassured us with their opinion and MSIF Advisories.

MSSI volunteers were busy with telephonic counseling, face to face video counseling etc. to reassure our members. We formed virtual localized Support/Connect groups to connect and support each other and worked closely with the Government disability sector. We managed to keep up with the much needed home physiotherapy service to the maximum possible. All our other projects continued online. Our social media sites were busy creating MS awareness like never before, increasing our reach manifold.

The good news is MS people were not greatly affected and the pandemic scenario was not that dire in the MS world.

Our motto now is "Get Vaccinated"!

We hope and pray that this storm will blow over soon & our cheerful, live day care programs, home visits, medical camps, outstation visits etc. will start once more.

We sincerely hope you will enjoy going through our much researched 17th Handbook!

Cheers to all of you!

Bipasha Gupta

Hon. Chairperson,
MSSI Delhi

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MSSI DELHI TEAM

From Foot Soldier to Chairperson-all of us have played all the roles.

The **MSSI DELHI** Team is a small but highly motivated & enthusiastic group of people consisting of seven ladies and one very brave gentleman (after all he is one against many!) along with four staff members.

All of us in the **Managing Committee** have played various roles during our term in the team and are happy to change hats depending on the need of the hour.



BIPASHA GUPTA- Our HON. CHAIRPERSON Bipasha has played many roles in MSSI. Her patience with MSP's, her organising abilities, and her dedication to all the projects that she takes up is amazing. The physiotherapy project thrives under her guidance. She can persuade even the most reluctant friends to join her and volunteer for MSSI's events. Her attention to detail both in the office and even when she is dealing with people on the phone is astonishing. She certainly leads from the front and is a major driving force in the organisation.

MRIDULA (MILLY) MURGAI- Our HON. VICE-CHAIRPERSON joined the Managing Committee in 2017 but had been an active volunteer for many years before that. Her contribution to the MSSI Team has been sincere and remarkable. She works in four NGOs simultaneously and in MSSI she presently looks after its Social Media aspects, both in Delhi and at the National level. With 4 PwMS in her extended family her association with MSSI is deep and committed.



MEENAKSHI BHUJWALA- Our HON. SECRETARY there are very few words which can truly describe what she brings to the MSSI team. She has worn all hats in the Committee and in all of them she has excelled. She joined MSSI in 1996 soon after her husband was diagnosed with MS. When Bipasha joined MSSI in 2001 they forged a strong bond and together built up the Delhi Chapter with fresh ideas and fresh energy, alongside building lasting deep relationships with all its members & their families. A sense of humour with quick repartee-along with a deep empathy for our PwMS are her main characteristics.

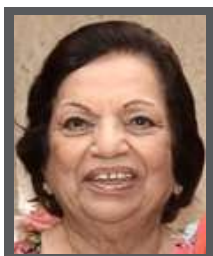
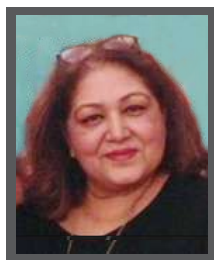
RAGINI MATHUR- What can you say about our Hon. Jt. Secretary that can describe her energy levels, her involvement with other causes, and her ability to take on any job and finish it! Ever ready to make Home Visits, to patiently listen to and counsel our MSP's and to remain passionate and committed to all our members. Deeply religious, she does not let it come in the way of her commitment, despite her prayer schedule or fasts, Ragini is ever ready to venture out with an apple and a handful of almonds for a whole day of Home Visits. She also looks after MSSI Delhi's Scholarship project very systematically and efficiently, and now knows the academic records of all the children, often counselling them as well!





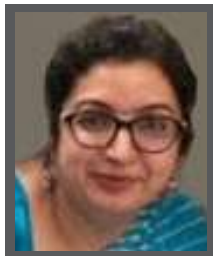
PRABAL MALAKER- Our HON. TREASURER is the solitary male member in the Committee. Despite having to deal with a group of very independent minded ladies, Prabal more than manages to hold his own- with his humour intact! A PwMS himself, he does not permit his limitations to limit him. His background in the Armed Forces gives him his never say die spirit, always immaculately turned out, Prabal is disciplined, meticulous and systematic. He has contributed immensely to the working style of the committee & staff by constantly reminding us to focus on the job at hand; he has created efficient management information systems (MIS) so that the Delhi Chapter is always up to date in all its project data & information. Fighting for disability rights is his forte. He is a well-known face in the Social Justice Ministry as a spokesperson for MS. His one weakness? He is a foodie- and despite his great self control & discipline cannot resist a good meal!

PRAVEEN KHETARPAL- Our ever-smiling, indomitable Hon. Executive Committee Member never ceases to surprise us by her courage and her belief in her ability to surmount all odds. Our immensely successful IMSD 2019 was possible due to her tremendous efforts. Nothing can stop her from approaching Govt officials or other people to help MSSSI. She often does not wait to take the lift to higher floors. Her commitment & determination carries her up the stairs despite all odds. Her contacts in media circles and her fund-raising abilities have been extremely valuable for MSSSI. She is a great spokesperson and ideal representative for MSSSI, and we love having her as a part of our team.



MEERA HORA- Our senior most Hon. Executive Committee Member has been with us since 2003. Meera (popularly known as Pinky) really enjoys Home Visits and is never short on energy or enthusiasm to participate in all our programmes. She has never missed MSSSI Delhi's Day Care programmes and is our trusted purse holder at fundraisers. She personally writes out literally hundreds of birthday cards with individual personalised messages to our ever growing list of members. With over 725 members that is more than 60 cards a month!

NINA KOCHHAR- Charming and always elegant, Nina is admired by everyone for her fairness & generosity. Scrupulously objective, she has us turning to her often while making difficult decisions. Nothing daunts her- whether it is collecting funds for MSSSI, doing PR for the team, resuming her golf as soon as the first lockdown lifted. She connects with everyone, young or old, and her friends, ex colleagues and associates have been added to MSSSI Delhi's support team! Home Visits are her passion and her enthusiasm towards all activities is infectious. She is a very valuable and highly respected member of our Executive Committee.

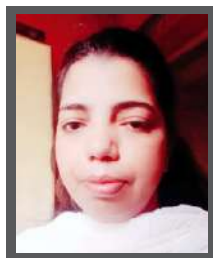


PUJA CHAUDHRY- Admin Officer: Not long ago, Puja was not even willing to take her name off the Confidential list! Today she is a very active and hardworking member of our Office Staff. She is extremely diligent and takes care to note all the details of the assignment she is handling. We can see the visible difference in the levels of efficiency in the office and the constant updates that she sends to all the Executive Committee members. This new kid on the block brings the knowledge & exuberance of youth along with the maturity and experience that a not so easy life has brought her. She is hard working and completely focussed. Her gentle reminders about approaching and missed deadlines keep all of us on our toes. She is a welcome addition to our team.



RAJKUMAR NATH– One of the main pillars of our office, Rajkumar comes from a pujari family of Kalkaji Mandir, Delhi. He was discovered while he was trying to put up phone wires for a new connection on Bipasha's terrace one hot afternoon. He was more than happy to be offered a job with MSSSI and joined as a field resource as well as office boy. Soon he moved on to working on the computer and running errands for MSSSI. He is an eager and quick learner and today is an indispensable part of our staff. He lives close to the office, has his own motorbike, and is everyone's go-to guy! He enjoys his work – at least that is what he tells us – and we enjoy having him around as our general Jack of all trades. Rajkumar is married to Neetu and has two sons – Tanishk and Nishant.

SHASHI VERMA-When Bipasha met Shashi Verma at a charitable dispensary, she was a simple graduate home maker with brief work experience. Realising that she was a sincere, hardworking young woman, she was offered the job as an office assistant at MSSSI Delhi. Her home is just a few minutes' walk from our office & that is a huge advantage for all of us. Her timings were adjusted so that she worked from 8 am till 1.30 am and could go back in time for her son's return from school. We trained her to be the office assistant and project coordinator. After 12 years in the job, she now knows all the PwMS by name and face. Many call her often to just unburden themselves-Shashi chats lending a compassionate ear to their troubles and counsels all of them positively. Her smiling face is always there to welcome them at all our functions. She is our point of contact in the office and like Raj Kumar is very much part of the extended MSSSI family. Her son Garv is now in Class 10, and her husband Prashant Verma works for LG.



SHAGUFTA FATIMA: Shagufta is our home care attendant and has been tending to our home & bed bound women PwMS since 2017. She makes daily home visits across Delhi & NCR relieving caregivers with daily chores of bathing the PwMS , tidying and settling their rooms, changing the bed linen, keeping them company, and often cheering them up with little gestures like a face massage, shampoos, haircuts, simple manicure & polish change . All this even as she sings & hums some songs which the patients sing along! She was sorely missed by them during the lockdown period but is back again now buzzing around the city & suburbs. Married even before she turned 18, Shagufta is now completing her school graduation through NIOS alongside her work. As a brave single parent to 3 young children Naaz (16) Muskaan (14) and Aryan (12) she is working hard to educate her children for a better future.

GOPAL CHAKRABORTY is our efficient, part time, NGO specialist accountant. He has brought immense relief to MSSSI Delhi by solving the many problems of our regular accounting. He was introduced by Anil Gupta, our life member, as a trustworthy and good-natured accountant and has lived up to his reputation. Mr. Gopal visits us twice a month and does the rest of the work online very systematically. He coordinates with the centralised MSSSI HO auditor efficiently, allowing the rest of the MSSSI members to concentrate on the day to day running of the organisation. He is very particular about every penny spent and makes all of us watch the expenditures carefully. His wife's name is Sampa and his son Aniket is studying B.Tech in NIT. He lives with his family in NOIDA.



WHAT IS MS?

Multiple sclerosis (MS) is one of the most prevalent diseases of the central nervous system. It occurs as a result of immune damage to the myelin sheath, which insulates the central nervous system's nerve fibers. This damage blocks the passage of nerve impulses from the brain to other parts of the body.

It is not yet known quite how this damage occurs. Environmental factors and genetic predisposition are almost certainly involved. Symptoms vary widely and include blurred vision, weak limbs, tingling sensations, unsteadiness, incontinence and fatigue. Some people may feel and seem healthy for many years after diagnosis, while others may be severely debilitated very quickly.

MS is typically diagnosed between the ages of 20 and 40 and is more common in women than men (3:2). Across the world 2.5 million people have MS. India is estimated to have at least 50,000 MS persons or may be much more since awareness of this disease is still poor in the rural area and small towns, although access to internet is changing that.

Symptoms in early phases of MS occur abruptly, in intermittent episodes and without any recognizable cause. MS is not a fatal disease - one can live with it for decades- although the disability may increase and livelihood problems may arise, such as loss of employment, restriction of social activities and increasing expenditure on drugs, therapy rehabilitation and nursing care.

MS attacks on the nervous system in four different ways:

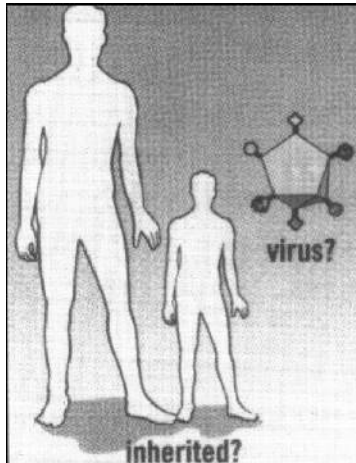
1. Benign MS affects approx. 20% of patients Only a few episodes occur at intervals of several years and there is hardly any disability.
2. MS proceeding in episodes (RR) (initially in approximate 70% of patients) The symptoms occur suddenly, last for few days or weeks and then disappear again.
3. Secondary progressive MS After a prolonged period the MS usually changes into a progressive phase and the symptoms disappear only incompletely.
4. Primary progressive MS (approximate 10% of patients) In primary progressive MS, the disability gradually increases without distinct episodes.

This form is more likely to affect patients whose disease starts later, who are at more than 40 years of age.

Human brain imaging with functional magnetic resonance (MRI) is among the most common and trusted diagnostic tool that came into existence 20 years ago. Today, doctors use MRI to follow changes in brain activity and diagnose MS.

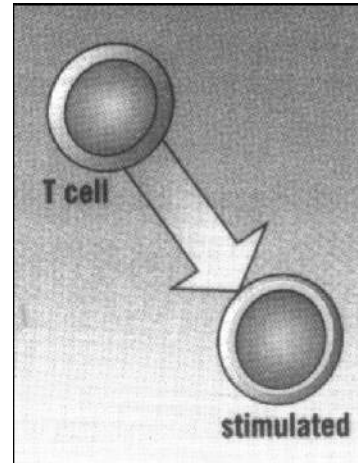
There is still no drug to cure MS, but many modern treatments are now available to modify and slow down the effects of the disease, and give a better quality of life.

WHAT HAPPENS?



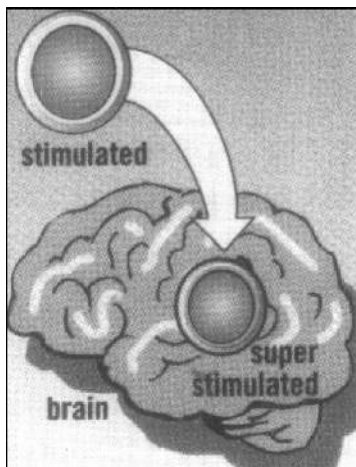
1. MS inside the body

No-one knows exactly what triggers Multiple Sclerosis (MS). It might be triggered by genetic factors or by chance infection, with a virus, for example. Whatever the trigger, the body is somehow confused into attacking its own nerves. The symptoms of MS result from damage to the outer coating of nerve cells.



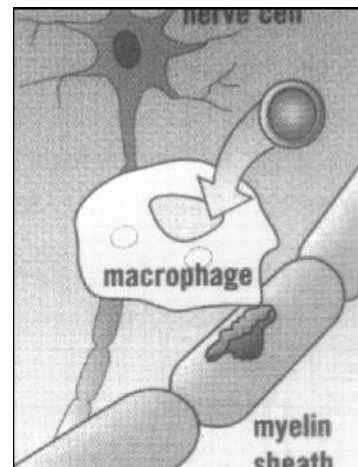
2. MS inside the body

It is the immune system that becomes confused into attacking the body's own nerves. Some of the body's immune cells, known as T cells, are stimulated to coordinate this attack. Normally these T cells would only be involved in attacking infectious agents such as viruses and bacteria.



3. MS inside the body

Once stimulated, the T cells are able to enter the brain, which contains lots of nerve cells. Inside the brain, T cells become further stimulated or super stimulated to coordinate an attack on the nerve cells. The attack causes damage to the insulating outer coating of the nerve cells. This coating is called the myelin sheath.



4. MS inside the body

Inside the brain, super stimulated T cells bring about damage to the myelin sheath by activating other immune cells called macrophages. It is the macrophages that 'eat' the myelin sheath around nerve cells. Holes develop in the myelin sheath causing messages to travel more slowly along nerves. This decrease in the speed of messages produce the symptoms of MS.

DON'T ISOLATE YOURSELF

MS is Socially Acceptable

The first sign that anything was wrong was the tingling on the lips and fingers, numbness left side of the chest and abdomen, and continuous vomiting. The numbness descended from the left side of the face to the left side of the body, arms and legs within a matter of few days. She was limping and couldn't concentrate for the most serious exam of her life- her Class 12th boards. More frightening still, She couldn't feel the tooth brush in the left side of her mouth and the gargling of water. This led to various tests and finally the MRI scan confirmed Multiple Sclerosis.



Meghna was affected by MS probably much earlier but no one could recognize the symptoms when it was diagnosed at the age of 8, she and her family were devastated and had no one to turn to for answers and support. When they met a representative of the MS Society they realized they were not alone and there were hundreds of others coping with MS and finding strength in each other.

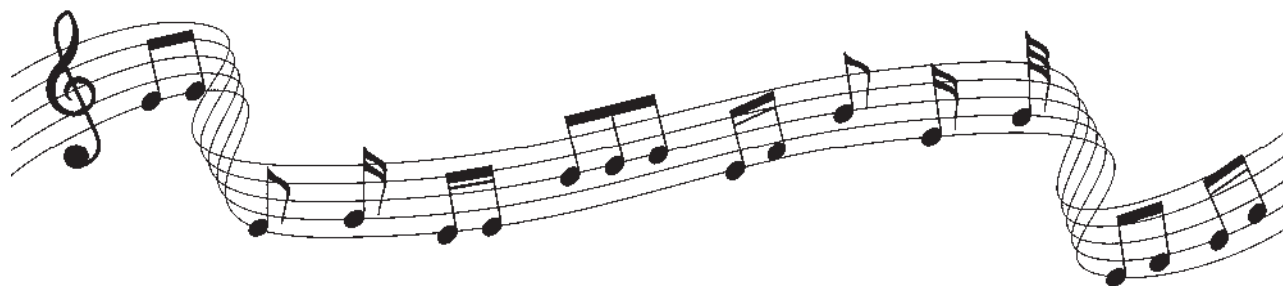
MS is an unknown illness-not just as far as its origins are concerned, but also because society can scarcely imagine what MS means: poor powers of concentration, memory lapses, rapid fatigue etc. make it difficult to keep pace in working life. Physical disabilities reduce social contacts and ultimately, in a society that focuses on performance and lifestyle, there is a great danger of being marginalized by disabilities and financial burdens.

That is why the MS Societies welcome people with MS. Through its eight countrywide offices, MSSSI supports several thousand individuals which includes MS persons and their families.

MSSI....

- Creates public awareness, thus avoiding isolation and ensuring enlightenment and acceptability
- Provides help for patients through offers of therapy, nursing projects, transport services, advice centers and support groups.
- Communicates new points of view and takes action to make further improvements in the quality of life of MS persons
- By organizing and participating in international symposia with specialists from all over the world, and developing efficient concepts and initiating research projects.

"When I was first diagnosed I did not dare tell anyone about my illness." Very often, MS sufferers ask the Society to send mail in plain envelopes because they are afraid neighbours might find out about their illness. Do not isolate yourself, understand what MS is and get in touch with the Society. We will help you manage your life with care.



HOW SINGING INFLUENCES OUR HEALTH

SING LOUDLY.. SING JOYFULLY..



- * Singing communicates to the body the "right" vibes that increase our vitality;
- * During singing in the human brain, special chemicals are made that help us feel peace and joy;
- * Singing improves blood circulation in the throat area, which has a beneficial effect on vocal cords, tonsils and numerous lymph nodes in the throat and therefore significantly increases local immunity (in other words, we rarely catch colds);
- * Improving blood supply during singing leads to brain activity intensification: it starts working more intensely, memory improves, any information is easier to perceive;
- * Singing is very useful for lung diseases, as it works as a respiratory gymnastics that promotes the development of chest, proper breathing, and significantly reduces the number of acute lung conditions;
- * With regular singing, the level of immunoglobulin and hydrocortisone, which are signs of good immunity, increase in the body;
- * Methods have been developed that treat stuttering through singing and help improve diction;
- * Singing is used even in the fight against overweight: sometimes excessively full people are available when they feel a feeling of hunger instead of eating to sing two or three songs.

Attention, Folks! Singing improves blood supply in the head area and generally rejuvenates the body, skin condition improves.

This is why experts recommend singing at least 5 minutes a day, equating singing to physical exercises.





LIVING WITH MS

When you get an illness like bronchitis or the flu, you know you'll be feeling better and functioning normally within a week or so. A chronic illness, like multiple sclerosis, is different. It may never go away and can disrupt your lifestyle in many ways. But attitude, you should be better able to cope with the changes.

How can i maintain a positive attitude?

MS should not define who you are. You are the same person you were before you were diagnosed-you just have a heavier

load to bear. The best thing you can do is to learn how to make your life better.

Here are some tips:-

Find a support group. Support groups can be a very useful sharing experience. They provide an environment where you can learn new ways of dealing with your illness. You may want to share approaches you have discovered with others. You will also gain strength in knowing that you are not facing hardships alone.

Get help if you need it. The most important step you can take is to seek help as soon as you feel less able to cope. Taking action early will enable you to understand and deal with the effects of MS. Learning to manage stress will help you maintain a positive physical, emotional, and spiritual outlook on life. A mental health care provider can design a treatment plan to meet your specific needs. Strategies can be designed to help you regain a sense of control over your life and improve your quality of life. At times, it depression is present, medications may be ordered to help lift your mood.

Consider counseling. Sometimes people have problems that are better addressed in a one-on-one atmosphere. By participating in individual counseling, you may be able to more effectively express sensitive or private feelings you have about your illness and its impact on your life and relationships. Call us to help you get and appointment.

Take care of yourself. Follow nutrition guidelines, exercise, develop stress management techniques, and get enough rest.

Be proactive in your health, get educated, and ask questions. But don't let MS takeover your every conversation.

Keep a diary. Write down your experiences, symptoms, and feelings. Not only will this be a valuable tool for your doctor, but it will also help you learn to express yourself.

Take control. There is often such a sense of uncertainty with MS, that it may help to take control of the things in your life that you are able to control. You should also consider some of your life planning Issues, such as finances, work, adapting your home, and other practical issues.

WHAT IS MS, MOM ?

Often children of an MS parent are worried about them and worry about the future, Frustration may arise when you are unable to keep up with them or to make commitments the way other parents can. Some the children may also feel ashamed and embarrassed to go out public with a parent who requires assistance with a cane or uses a wheelchair. The best way to handle these concerns is to talk about them. Ask your children questions about what they are thinking Try to alleviate some of their concerns.

What else can i do to help my Child/Children?

Find someone else your child can talk to about your illness. Remember that you are not alone. You do not have to be the only person your child talks to about MS. Developing a trusting relationship with a friend or family member can be both helpful and healthy for children. Share how you are feeling, both physically and emotionally. Talk to your child, Do not be afraid to start the conversation. Children appreciate it when you open the door. Conduct open and honest discussions. Keep the door open.

Children are not always ready to talk, Let your child know that you will be available if he or she has something to discuss. Allow your child to feel whatever emotion he or she is experiencing. Help your child to manage his or her emotions. Do not try to change what he or she is feeling. Include your child in family decisions. Whether you're dividing up the household chores or going to the hospital for treatment, it is important to involve your child in all of your decisions. It will give your child a sense of control and belonging.

Seek professional help if you need it. There are many counselors and support groups that can help your family adjust to the changes that are occurring.

Common Questions Children Have About Ms

Q If you have MS, does that mean I'll get it?

Unlikely. MS is not passed directly from parents to children.

Q Will your symptoms get worse?

Everyone's experience with MS is different. A person's MS can get better, worse, or stay the same.

Q Why is there no cure?

The cause of MS is still not known. Scientists need to discover the cause first and then they can work on developing a cure. Intensive research is on world wide we are confident of an early breakthrough.



TALKING TO YOUR CHILDREN ABOUT MS

Talking openly with your children about multiple sclerosis helps relieve their anxiety about your condition. Children of all ages are very intuitive and know when something is different or has changed. Talking with your child opens the lines of communication and helps to reduce fear and stress.

When parents are reluctant to talk to their children about the disease, kids misinterpret silence as an indication that the situation is so bad that it cannot be discussed. Parents who can talk with their children about MS convey a message of trust, confidence, and strength.

When responding to questions or concerns, take into consideration your child's age and maturity level, and don't overwhelm them with information they cannot understand. If you have more than one child, it may be helpful to talk to them individually so that you can tailor your discussion to their level of understanding.

You may want to ask them how they would like to learn about MS- reading a book alone or with you, watching a Video, or going with you to a doctor's visit.

What Emotions Do Children Experience?

All of the following emotions are normal reactions to a parent's diagnosis:

- Anger ● Fear ● Embarrassment ● Guilt
- Sadness ● Resentment ● Depression ● Helplessness

These emotions may lead to changes in behavior for your child. Here are some signs to watch for:

- Increased concern with their own body and wellness
- Difficulty maintaining close friendships
- Higher anxiety and stress
- False maturity ("growing up too quickly")
- Behaving badly in public
- Lying to friends about the parent's illness
- Regressive behavior (acting younger)
- Temper tantrums
- Waiting until parents are tired at the end of day to ask for things (such as help with homework)
- Poor performance in school
- Nightmares, bed-wetting, and trouble falling asleep.



Beyond these behaviors, which in moderation are considered normal, your child may have additional difficulty coping with your illness. In some cases, you may want to seek professional help.

MS is a serious illness, but you can live with it. All it needs is the understanding and commitment of your loved ones and society at large.



#myMSstory: Nidhi

I am Nidhi Gaur and I am here to share my world with you...

If anyone would ask us to relive a phase of our life once again, I am sure most of us would choose our childhood. And I am no different. Despite having lost my father at an early age of nine, the overall picture that I remember from those good old days were of a little girl who was content and happy with what she had. Yes, I was raised by a single mother, but love was in abundance. She gave us the best that she could, and my brother and I grew up to become confident individuals. I was the good child in our family and was loved by one and all. I felt the same in school with all the teachers praising me for my good conduct and sincerity and I was quite the chatterbox which earned me a lot of friends throughout. I finally felt settled after being appointed as a librarian at the age of 21. Three years later, I married the man of my choice and life seemed just about perfect.

When MS started affecting me

Two years into the marriage and we felt ready to bring a child into our lives. With dreams and hope, I began my journey towards motherhood, but little did I know that I was in for a surprise. My life was changing through the second trimester of my pregnancy. One day while returning from the school, I suddenly felt it became difficult to walk. Although I was always very independent, it often became increasingly tough to balance my body while walking. Doctors suggested its pregnancy-related and so I took it lightly. Finally, on 15th July of 2007, I gave birth to a beautiful boy. Just when I was beginning to celebrate, Doctors told me he did not cry at birth and what was to be a few hours of observation in the ICU ended up being a week-long stay at the hospital. I finally held him after a week. I was still unable to walk. Ten days later, I fell and just could not get up. I was unaware of it, but MS was slowly entering my life. I got admitted again for assessment and finally came face to face with Multiple Sclerosis – an incurable illness of the Central Nervous System. I started with my treatment and with the help of suggested steroids, I was back on my feet in just 5 days as if nothing had happened. My lovely child Vaasu was already one month old by then.

With no knowledge on the medical condition or its treatment, much to my relief back then, I was put on oral steroids which gave me enough strength to get back in action and forget all about MS. I got back to being a busy and hands-on mother to my new-born and he became my priority. From taking care of his small needs, giving him medication to changing my sleep patterns, I completely indulged myself with all things motherly. While I was making room for much love and so much to look forward to, life shook me again. Vaasu just turned four and we got to know that he could not see and that he has severe form of epilepsy. His treatment started and my days were starting and ending while taking him to different therapy centres. Steroids were keeping me seemingly healthy and I did not feel any difficulty with MS. After a few months, I started developing different skin problems from scabies to herpes and many more. I could not touch my own child due of the fear of infection. I was advised that this is because of the high doses of oral steroids, despite which the steroids were not stopped. I had to move to Ghaziabad in 2008 for my son's treatment and therapies and there I consulted one more doctor who immediately asked me to stop all oral steroids. I slowly tapered the doses and stopped the medicine completely. This was the most challenging phase for me with real struggle and I entered the real world of Multiple Sclerosis. I was determined to sail through this with a smile on my face and I got busy with my son's daily therapies and treatment while MS was slowly becoming a permanent resident in my life.

In 2009 I started feeling heaviness in my legs, which made it difficult for me to walk. In the same year, one more symptom occurred in the form of Trigeminal Neuralgia. Simply put, it is a sharp stabbing pain on one side of the face that occurs in the trigeminal nerve triggered by chewing, speaking, brushing the teeth or even a slight touch on the face. Speaking of personal experience, even sitting under the fan became difficult and it became a habit to sleep without fan and AC during summer. Gradually, this led to difficulty in speaking and eating. Doctors prescribed heavy anti-epileptic drugs to control the pain, but I knew this excruciating pain has become an integral part of my life and the side effects of the medicines took a toll on my body. The biggest problem was my dependency to walk.

My encounter with other MS Fighters

They say when life gives you lemons, make fresh lemonade and I wanted to live by the same motto. I wanted to live, laugh, and drop any negativity out of the window. I got connected with MSSSI and my circle of friends got bigger with time. I got to meet other MSPs too and I developed a strong bond with them. It was having friends like family and sharing our experiences all along. On the other hand, seeing the progression of MS patients made me realise my possible future. Last year, I met a person who graduated from using a stick for assistance in walking to being on a wheelchair in no time at all. Many other people were facing the progression of the disease, though each had their distinct journey around MS. There was one thing in common and that was the disease worsening with time. That is how MS progresses. I lived little bit of my future seeing them and I was mentally prepared to start using a stick, then a walker, then be on wheelchair and finally rest on a bed. Deep inside, I was sure of the progressive nature of MS.

My challenges with MS

From a person getting 5 stars for her handwriting in school, I turned into a person who was not able to write straight or follow lines. I started finding it difficult to match my signature. My legs were so numb that I could not feel the slippers on my feet. It even became difficult to control my bladder and I became hesitant to go out. I started believing that diapers will be my saviours. Slurred speech and poor recollection added to my miseries. I was forgetting things more often. I used to feel anxious and depressed for no specific reason. On top of that the facial pain became a part of my daily life. I used to sit in public quietly just so that no one notices me and the problems that came along.

The theory of Karma had always fascinated me, and I started believing it is my duty to undergo all such sufferings as the only way to expiate it.

Time flew by with no major changes in either my condition or of my child Vaasu. I was trying to lead a normal life and though I might have looked fine from the outside, I was completely shattered from inside and did not know how to deal with the uncertainty of our future.

From despair to hope

In 2011, one of my Aunts shared about Nichiren Daishonin's Buddhism. I was so sure about the retribution of Karma that I did not take her seriously. She continued to approach me with other fellow practitioners and somehow their warmth got to me. I got drawn towards the practice by reading Dr. Daisaku Ikeda's words, "Only you can write the script of your life. The scenario of your life is not written by some external power; it is not a result of coincidence nor predetermined by destiny. You write the story of your own life and you are its star player."

Now that I look back, those words were music to my ears and turned out to be life changing. They touched my heart and I decided to give it a shot. I wanted to understand the right purpose and spirit behind living a meaningful life.



When I started meeting people in the organization, I got immensely inspired by the way they conducted themselves. My perspective towards life started changing and I indulged myself more into the practice. I could finally fulfil my suppressed desire of meeting new people, making new bonds with them and in the process, I learnt so much from their own struggles.

In due course my life started changing on a fundamental level and I started to find a meaningful purpose of my existence. Although, my struggles with multiple sclerosis continued along with the growing responsibility of my son, it was a new me handling everything with a smile and gratitude. I made friends like family, got involved in their lives and sufferings, encouraged them to fight their hardest and promised myself to instil hope.

Hope is a decision and I decided to give hope to each person I meet. Struggle was not a stranger anymore, we became friends and that why I could live with it without inhibition, fear, and any pain at all. My priority shifted from worrying about the future which I thought was unpredictable to my present which I knew I could live to the fullest and create memories for myself and the people that I love.

Today, I am still sick, but I choose to look at what I have got,
I might be in pain, but I know in my heart that I fought.

To the fighter in all of us.....

Let's keep the spirit alive, done fear, let's fall but rise again
Let's believe in the power of healing as they say no pain, no gain

Love,
Nidhi

ADAPTING YOUR HOME

Because daily activities-Including leisure activities-can cause fatigue more quickly in people with multiple sclerosis, it's important to modify your activity levels. And, because MS can make moving around difficult, making certain changes to your home environment may help conserve energy and increase independence.

What Devices and Equipment Are Available?

An occupational therapist or rehabilitation specialist or your local MS society representative can recommend a variety of devices that are designed to make home care and daily activities more comfortable.

some examples include:

- Grab bars /railings
- Reacher devices
- Sliding boards /ramps
- Cordless / Mobile Phone
- Wheelchairs /walkers
- Remote call bell
- Bath chair with wheels
- High stool in kitchen
- Non slip rubber floor mats



Along with appropriate medications, exercise, and other management techniques, this equipment can help you maintain your independence.

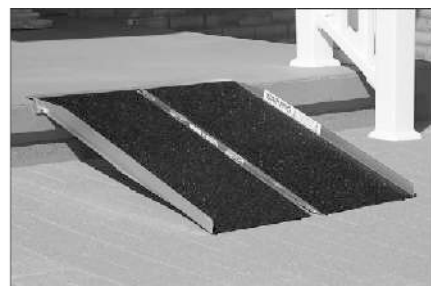
What changes can I make in my home?

Following is a list of the most common recommendations that can assist you dressing, bathing, using the toilet, general hygiene and self-care activities, eating and drinking, working in the kitchen, cleaning, and shopping. Not all of these recommendations may benefit your personal situation. Your Society or rehabilitation specialist can help determine which of these recommendations are best for you.

Dressing

- Get dressed while sitting in a chair that has arm rests. This will help you keep your balance.
- Roll from side to side to get pants over your hips. You can do this while sitting in a chair or lying down on your bed.
- Wear clothes that are loose-fitting and have elastic waistbands.
- Choose wrap-around clothing instead of the pull-over type. Also choose clothing that opens in the front, not the back.
- Wear clothing with large, flat buttons or use Velcro closures.
- Use a zipper pull or attach a short loop on the end of the zipper to zip pants or jackets.
- Use non slip socks and a long-handled shoehorn for additional assistance.

All these are easily available online



Bathing

- Install grab bars inside and outside the bathing area or shower.
- Use a shower chair with back support & wheels
- Put extended lever handle taps to make them easier to turn
- Put a nonskid mat in the bath area
- Use a handheld hose for showering and bathing
- Use a long-handled sponge Or scrubbing brush.
- Use soap on a rope, bath mitts, or Sponges with soap inside, or a soft soap applicator instead of bar soap.
- Use lukewarm water very hot water can cause fatigue and aggravate your symptoms.
- Sew straps on towels to make them easier to hold while drying.
- Place a towel on the floor outside the bath area to dry your feet so you don't slip
- Put a towel on the back of your chair and rub your back against it to dry or use a toweling cloth robe instead of a towel to dry off.



Using the toilet

- Use an elevated toilet seat and/or safety rails to assist standing from a low surface.
- Do not use towel racks or bathroom tissue holders to help you stand.
- Install a handheld shower-head near the toilet for convenience.

General hygiene and self-care

- Use hairbrushes and combs with built-up handles or handles with finger loops.
- Use toothbrushes with built-up handles or use an electric tooth brush.

Eating and drinking

- Rest your elbows on the table to provide more motion at your wrist and hand.
- Sit with your knees and hips bent at a 90-degree angle in a straight-back chair
- Use utensils with built-up, lightweight handles or use a "spork" a spoon and fork in one.
- Use a nonskid mat to stabilize objects on the table.
- Use a plate guard or thaali with a raised lip to prevent food from spilling.
- Use a long straw with a non-spill cup or use a plastic mug with a large handle.
- Use Melamine or stainless steel utensils instead of china and glass.

Working in the kitchen

- Have at least one counter workspace that has been lowered so that you can reach it from a sitting position.
- Don't close jar lids or containers too tightly once they have been opened
- Use pans with a wide base that cannot be knocked over easily.
- Use a food processor for vegetable cutting and peeling
- Use plastic containers to avoid breakage.
- Use nonskid mat to stabilize bowls and plates.
- Place utensils, pots, pans, in an accessible area or cupboard instead of in lower cupboards.
- Sit when getting things out of lower cupboards
- Use two hands to pour liquids.
- Use blunt scissors to open packages
- Use electrical appliances whenever possible.



Cleaning

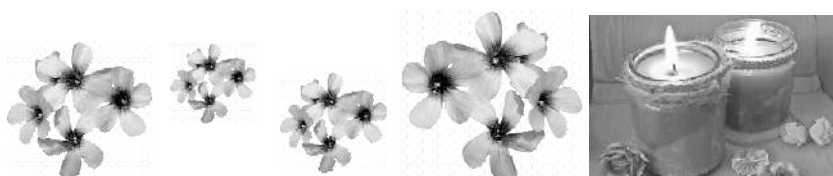
- Use long handles on sponge mops, cleaning brushes, dustpans, brooms or window washers.
- Sit to fold laundry, wash dishes, iron clothes, use the sweeper, mop the floor, or plug in appliances at low outlets.
- Adapt counters and other work surfaces so that you can reach them from your wheelchair or from a sitting position.

Shopping

- Call ahead to make sure the store has the item you need.
- Call a taxi or ask a friend or family member to drive you.
- Make a list so that you minimize your time spent and that of your escort.

Other useful tips

- Always keep emergency numbers in an accessible location; like a whiteboard or under a fridge magnet; consider having them on speed dial on your phone.
- To avoid slipping or tripping, remove small rugs and floor mats.
- Make your environment as comfortable and as pleasing as possible.
- Use soothing colors to decorate, use scented candles or potpourri in fragrances that relax you.
- Keep photos and music around that lift your spirit.
- Keep your room fresh & well aired by opening doors and windows twice a day



If you are concerned about daily care, surround yourself with plants or flowers. Make sure the temperature and climate in your home are suitable to your sensitivities. The more comfortable and uplifting your environment is, the more positive your attitude will be! By maintaining a high quality of life and a positive attitude, living with MS can be more manageable.

GLOBAL COVID-19 ADVICE FOR PEOPLE WITH MS

MS, the corona virus and vaccines-updated global advice

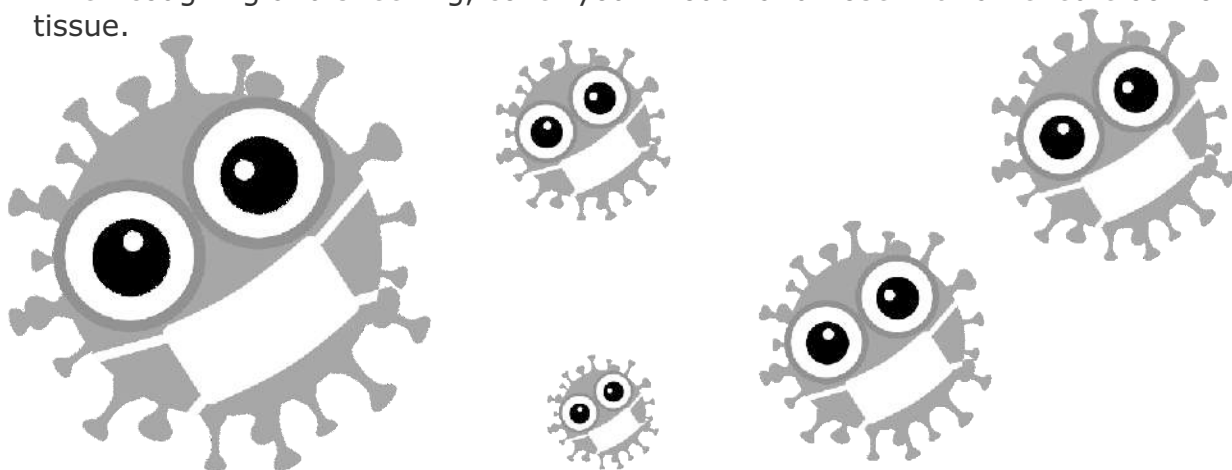
COVID-19 is a new illness that can affect your lungs, airways and other organs. It is caused by a novel corona virus (called SARS-CoV-2) that has spread around the world.

The advice below was developed by MS clinicians and research experts. It is based on the emerging evidence of how COVID-19 affects people with multiple sclerosis (MS) and expert opinion. This advice will be reviewed and updated as further evidence about COVID-19 and SARS-CoV-2 becomes available.

Advice for people with MS

Current evidence shows that simply having MS does not make you more likely to develop COVID-19 or to become severely ill or die from the infection than the general population. However, the following groups of people with MS are more susceptible to having a severe case of COVID-19:

- People with progressive MS
 - People with MS over the age of 60
 - People with higher levels of disability (for example, an EDSS score of 6 or above, which relates to needing to use a walking stick)
 - People with MS and obesity, diabetes or diseases of the heart or lungs
-
- Practice social distancing by keeping at least 1.5 metres distance between yourself and others, to reduce your risk of infection when they cough, sneeze or speak. This is particularly important when indoors but applies to being outdoors as well.
 - Make wearing a mask a normal part of being around other people and ensure that you are using it correctly by following these instructions.
 - Avoid going to crowded places, especially if indoors and the room is poorly ventilated. Where this is not possible, ensure to wear a mask and practise social distancing.
 - Wash your hands frequently with soap and water or an alcohol-based hand rub (70% alcohol content is considered most effective).
 - Avoid touching your eyes, nose and mouth unless your hands are clean.
 - When coughing and sneezing, cover your mouth and nose with a flexed elbow or tissue.



- Clean and disinfect surfaces frequently especially those which are regularly touched.
- Talk to your healthcare provider about optimal care plans, through video consultations or in-person visits where needed. Visits to health clinics/centres and hospitals should be avoided unless they are recommended based on your current health needs.
- Stay active and try to take part in activities that will enhance your mental health and well-being. Physical exercise and social activities that can take place outside and with social distancing are encouraged.
- Caregivers and family members who live with, or regularly visit, a person with MS in one of the higher risk groups should also follow these recommendations to reduce the chance of bringing COVID-19 infection into the home.

National and international guidelines on physical distancing vary between at least 1 metre and 2 metres. People should consider their national guidance and be aware that these are minimum distances, longer being better.



Advice regarding disease modifying therapies for MS

Many disease modifying therapies (DMTs) for MS work by suppressing or modifying the immune system. Some MS medications might increase the likelihood of developing complications from COVID-19 but this risk needs to be balanced with the risks of stopping or delaying treatment.

We recommend that people with MS currently taking DMTs continue with their treatment, unless advised to stop by their treating clinician.

People who develop symptoms of COVID-19 or test positive for the infection should discuss their MS therapies with their MS care provider or another healthcare professional who is familiar with their care.

Before starting on any new DMT or changing an existing DMT, people with MS should discuss with their healthcare professional which therapy is the best choice for their individual circumstances.



Advice regarding aHSCT

Autologous Haematopoietic Stem Cell Transplantation (aHSCT) includes intensive chemotherapy treatment. This severely weakens the immune system for a period of time. People who have recently undergone aHSCT should consider extending the period they remain in isolation during the COVID-19 outbreak to at least six months. People who are due to undergo treatment should consider postponing the procedure in consultation

with their healthcare professional. If aHSCT is given, chemotherapy should be administered in rooms isolated from other hospital patients.

Seeking medical advice for relapses and other health concerns

People with MS should still seek medical advice if they experience changes in their health that may suggest a relapse or another underlying issue such as an infection. This can be done using alternatives to in-person clinic visits (such as telephone or video consultations) if the option is available. In many cases, it is possible to manage relapses at home. The use of steroids for treating relapses should be carefully considered and only used for relapses that need intervention. There is some evidence that receiving high-dose steroids in the month prior to contracting COVID-19 increases the risk of a more severe infection requiring a visit to hospital. Where possible, the decision should be made with a neurologist experienced in the treatment of MS. People who receive steroid treatment for a relapse should be extra vigilant and may want to consider self-isolation for at least a month to reduce their risk from COVID-19. Note that once someone has been infected with COVID-19, steroids may be used to treat COVID-19, to dampen the excessive immune response often referred to as a 'cytokine storm'. Note that the steroids and dosages used in this context are different from the situation of a MS relapse. People with MS should continue to participate in rehabilitation activities and stay active as much as possible during the pandemic. This can be done through remote sessions where available or in clinics/centres as long as people with MS attending the clinics/centres follow safety precautions to protect themselves and limit the spread of COVID-19. People with concerns about their mental health should seek advice from their healthcare professional.

Covid vaccine

The Covid vaccine is safe and recommended for people with MS. Refer to details regarding vaccine on the following pages

Advice for children or pregnant women with MS

At this time there is no specific advice for women with MS who are pregnant. There is general information on COVID-19 and pregnancy from the World Health Organization. There is no specific advice for children with MS; they should follow the advice above for people with MS.



COVID-19 VACCINES AND MS

In this section, we will review the current vaccine types and discuss vaccination timing and disease modifying therapy administration. Given the seriousness of COVID-19-which carries a 1-3% mortality risk as well as risk for serious illness and prolonged ill-health for many-we wish to emphasise these key points:

- **All people with MS should be vaccinated against COVID-19**
- **People with MS should be vaccinated now that the vaccine is available to them**
- **Even once you have received the vaccine, it is important to continue to take precautions against COVID-19, such as wearing a face mask, social distancing and washing your hands, because new variants are emerging that may not be protected against by the current vaccines.**

There are several COVID-19 vaccines in use in different countries around the world, with new ones being approved regularly. Instead of assessing each vaccine individually, we have provided information below about the main types of COVID-19 vaccines in use and in development. This guidance is based on available information and we will update it as new data become available.

We do not know how many people in the COVID-19 vaccine clinical trials had MS, so data on the safety and effectiveness of COVID-19 vaccines specifically for people with MS are not yet available. Our guidance is therefore based on data from the general population in the vaccine clinical trials, and guided by prior experience regarding vaccination of people with MS.

Vaccines work by using a part of the virus that causes the disease (such as its genetic code or 'spike protein'), or an inactivated or weakened version of the virus, to prompt a response from the human immune system. In turn, this causes the body to produce antibodies and T-cells (a special population of white blood cells) to fight the virus, preventing it from entering and infecting other cells in the body. These vaccines do not lead to any genetic change in our bodies, will not get into the brain, and would not alter the genetic code of a foetus. There are currently five different types of COVID-19 vaccine in use or in development that work in different ways (with examples below).

1. mRNA vaccines have the genetic code for the coronavirus 'spike' protein made as an "mRNA" (a type of temporary genetic message), which is formulated into tiny fatty droplets for delivery. The mRNA directs production of the spike protein, which is seen and targeted by the immune system (that makes antibodies and T cells).

- o Pfizer-BioNTech (Comirnaty)
- o Moderna (Moderna mRNA)



- 2. Non-replicating viral vector vaccines** have the genetic code for the spike protein in a viral vector. These vectors are best understood as just the shell and delivery mechanism of a virus (commonly from an adenovirus), but they lack the parts a virus needs to replicate and so can never cause an infection. Similar to mRNA vaccines, viral vector vaccines direct the production of the spike protein so that it can be seen and targeted by the immune system.
 - o AstraZeneca/Oxford (Covishield)
 - o Gamaleya Research Institute (Gam-COVID-Vac or Sputnik V)
- 3. Inactivated virus vaccines** use an inactivated form of the whole coronavirus. The coronavirus has been 'killed' so that it is unable to get into cells and replicate, and it cannot cause a COVID-19 infection. The immune system recognises the whole virus, even though it is inactivated.
 - o Sinovac (CoronaVac)
- 4. Protein vaccines** have the coronavirus spike protein itself (not the genetic code), along with something that boosts the immune system (an 'adjuvant') to ensure the spike protein is targeted.
 - o Novavax (NVX-CoV2373)
- 5. Live attenuated vaccines** use a weakened, but still replicating virus. Such vaccines work by causing a mild infection in people with regular immune function. **They can be dangerous in a person with a compromised immune system, so would not be suitable for many people with MS, due to the way some disease modifying treatments work.**
 - o Currently (March 2021), there are no live attenuated COVID-19 vaccines in use – they are only being researched.

People with MS should get a COVID-19 vaccine

The science has shown us that the COVID-19 vaccines are safe and effective. Like other medical decisions, the decision to get a vaccine is best made in partnership with your healthcare professional. You should get a COVID-19 vaccine as soon as it becomes available to you. The risks of COVID-19 disease outweigh any potential risks from the vaccine. In addition, members of the same household and close contacts should also get a vaccine as soon as they can to maximise protection against COVID-19.

Most of the COVID-19 vaccines require two doses, and where this is the case, you need to follow your country's guidelines on the timing of the second dose. Following full vaccination (both doses), it may take up to at least 2 weeks for the vaccination to achieve full effect.

If you have had COVID-19 and recovered, you should also get the vaccine, because prior infection does not appear to protect from future COVID-19 infection indefinitely. It is normal practice to wait until you have recovered from an illness before being vaccinated. But you should still get vaccinated as soon as you can after recovery, following the government guidelines in your country.

We do not know how long a person is protected from COVID-19 after being vaccinated, although clinical trial data indicate that protection is high for at least multiple months. Repeated doses of the COVID-19 vaccines may be required in future, similar to the flu vaccine.

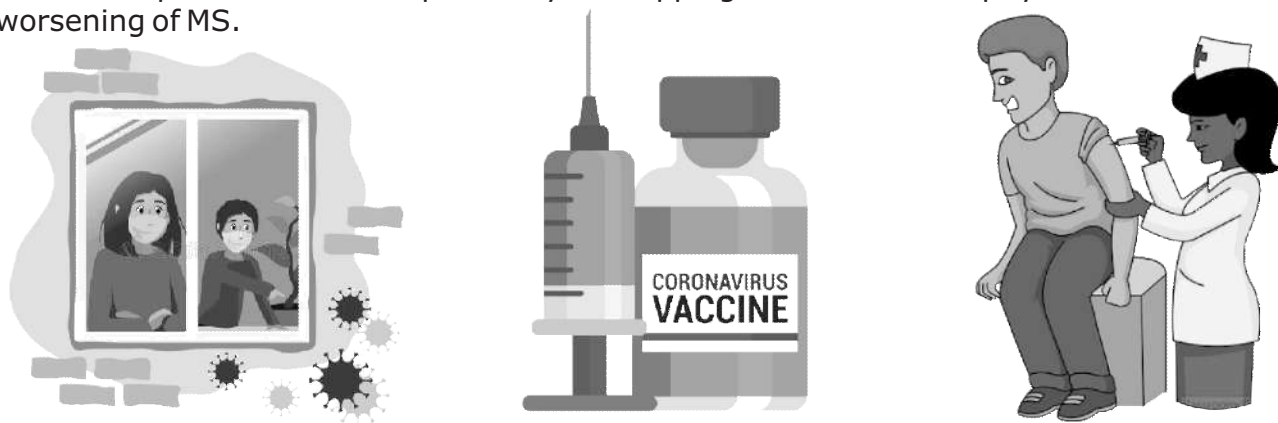
Even once you have received the vaccine, it is important to continue to take precautions against COVID-19, such as wearing a face mask, social distancing, washing your hands and following any local rules about getting tested for COVID-19 when necessary.

The mRNA, non-replicating viral vector, inactivated virus or protein COVID-19 vaccines do not contain live viruses and will not cause COVID-19 disease. These types of vaccine are not likely to trigger an MS relapse or to worsen chronic MS symptoms.

6. You do not need to self-isolate after the vaccination. The vaccines can cause side effects, including fever or fatigue, which should not last more than a few days after vaccination. A fever can make your MS symptoms worse temporarily, but they should return to previous levels after the fever is gone. Even if you have side effects from the first dose, it is important to get the second dose of the vaccine (for vaccines requiring two doses) for it to be fully effective. Having side effects, such as fever, muscle discomfort and fatigue are a sign that the vaccine is doing its job (it is getting your body to mount a response against the virus, and therefore is starting to protect you).

The COVID-19 vaccines can be administered to people with MS who are being treated with MS therapies

Continue taking your disease modifying therapy (DMT) unless you are advised by your MS healthcare professional to stop or delay it. Stopping some DMTs abruptly can cause severe worsening of MS.



- **It is safe to receive a COVID-19 vaccine when you are on MS therapies (DMTs)**
- **Delaying the start of a DMT, or altering DMT timing, is not a safety issue – it is a strategy to allow the vaccine to be fully effective**

If you are able to plan when you receive your vaccine, please discuss with your MS healthcare provider how and whether to coordinate the timing of your vaccine with the timing of your DMT dose – if you are on a DMT where this is relevant (see below). This should help ensure the vaccine is still effective at generating antibodies to the coronavirus.

The decision of when to get the COVID-19 vaccine should include an evaluation of your risk of COVID-19, (see the list near the beginning of this advice on groups who are more at risk), and the current state of your MS. Work with your MS healthcare provider to determine the best schedule for you. If the risk of your MS worsening outweighs your risk of COVID-19, do not alter your DMT schedule and get the vaccine when it is available to you. If your MS is stable, consider the following adjustments in the administration of your DMT to enhance the effectiveness of the vaccine:

All of us have a personal responsibility to slow the spread of the pandemic and eliminate the virus as quickly as possible.

**Interferons, Glatiramer Acetate,
Teriflunomide, Monomethyl
Fumarate, Dimethyl Fumarate,
Diroximel Fumarate, Natalizumab**

If you are about to start one of these DMTs for the first time, do not delay starting it for your COVID-19 vaccine injection. If you are already taking one of these DMTs, no adjustments to your DMT administration are needed. It is safe to take your vaccine.

**Fingolimod
Siponimod
Ozanimod**

If you are about to start alemtuzumab or cladribine, consider getting the COVID-19 vaccine so that the second vaccine injection is done at least four weeks before starting alemtuzumab or cladribine. If you are already taking alemtuzumab or cladribine, consider starting the vaccine injections at least 12 weeks after the last alemtuzumab or cladribine dose. When possible, resume alemtuzumab or cladribine at least four weeks after the second vaccine injection. This suggested scheduling is not always possible and getting the vaccine when it becomes available to you may be more important than timing the vaccine with your DMT. Work with your MS healthcare provider to determine the best schedule for you.

**Alemtuzumab
Cladribine
Ocrelizumab
Rituximab**

If you are about to start ocrelizumab or rituximab, consider getting the COVID-19 vaccine so that the second vaccine injection is two to four weeks before starting ocrelizumab or rituximab. If you are already taking ocrelizumab or rituximab, consider getting the vaccine injections at least 12 weeks after the last DMT dose. When possible, resume ocrelizumab or rituximab at least 4 weeks after the second vaccine injection. This suggested scheduling is not always possible and getting the vaccine when it becomes available to you may be more important than timing the vaccine with your DMT. Work with your MS healthcare provider to determine the best schedule for you.

Ofatumumab

If you are about to start this DMT, consider getting the COVID-19 vaccine so that the second vaccine injection is two to four weeks before starting your DMT. If you are already taking ofatumumab, consider getting the vaccine injections four weeks after your last ofatumumab injection. When possible, resume ofatumumab injections at least four weeks after the second vaccine injection. This suggested scheduling is not always possible and getting the vaccine when it becomes available to you may be more important than timing the vaccine with your DMT. Work with your MS healthcare provider to determine the best schedule for you.

High Dose Steroids

Consider getting the vaccine injections three to five days after the last dose of steroids.



#myMSstory: Aniruddha

Some people become a source of inspiration for others in the way they face challenges that come their way in the journey of life. One such person is Aniruddha Konar. Having lost his father at the young age of 7 he was brought up by his mother who was teaching Botany in Maitreyi College in Delhi. Being an only child, Aniruddha's mother was his only friend, guide and companion during his childhood.

After completing his schooling from St. Xavier he did his graduation from Khalsa College and wanted to follow his passion of becoming a Lawyer. Being determined and intelligent he could secure a seat in the prestigious Law faculty in Delhi University and completed his degree in 1996. He started working as a Civil Lawyer in Tis Hazari Court. He was a man of wisdom and strength and remained focused in his profession. He got married in 2001 with a beautiful lady who was also a teacher by profession. Life was good and they had their son Aditya in 2004. Life was extremely busy and he was enjoying both his personal & professional life.



From 2012 onwards there was a perceptible difference in his speed. Unaware of what that could mean, he continued his practice in the Court. In 2014, he finally decided to get an MRI done and see a neurologist. Then began his struggle with the disease. He was diagnosed with PPMS. It was an enemy he didn't know. He was getting a new surprise everyday. With a belief to get a cure he tried every treatment available to him. His family and friends were of great support and helped him in every way they could.

Very soon he got connected with MSSSI and discovered MSPs as his new family and WhatsApp his new friend. His movements were getting restricted and it was becoming difficult for his family who had to pick him up every time he felt down. The physio was the next problem as getting one was difficult as they were too expensive or unreliable. Here too MSSSI helped him in different ways. He had been a very social person but MS cut that. So now the phone was all he had to retain his sanity. Slowly his life completely transformed as his movements got more restrictive but his passion to stay updated and be involved in every matter remained intact.

Aniruddha still enjoys watching news and keeps himself updated. He is still in touch with all his friends who are successful lawyers and Judges now. Nothing could steal his passion of staying connected with people. With just one hand working he continues to encourage and inspire others. He cheers up everyone through his messages. Not only that he still gives strong opinion on things around him. He feels blessed to have a loving family and friends.

Whenever we see him we see him smiling with joy. He is unafraid and strong in spirit, challenging his life to test him, A source of inspiration for all of us.

Interview by Nidhi Gaur

TIPS TO IMPROVE MEMORY

Effective learning can only be achieved if you're able to focus your complete attention on what you are trying to learn.

by Acadoceo | Acadoceo.com

1 READ, READ, READ

Reading your textbook, academic articles and journals will broaden your understanding. Make shorter notes for yourself and then study your own notes.

2 LISTEN TO AUDIO

Listen to audio on the topic and write down some key notes on what they're saying that can help you better understand the subject you're learning.

3 WRITE THINGS DOWN

Make your own notes from what you have read in the textbook. Write questions and answer them later. These can be questions from your textbook or even questions that you think are likely to come up on the exam. This is a good way to test your understanding of what you learnt and help you remember it.

4 TALK OUT LOUD

You can read the topic out loud, or try to teach the topic to someone else.

5 MIND MAPPING

Mind maps are a great way to break down information into a simple diagram that can be remembered more easily. They're also a good way to test whether you know the subject matter. You can redraw the diagram and deliberately leave blanks to see can you fill them in again or whether you can discuss the topic in more detail by only looking at the key headings on the mind map.

6 TEST YOURSELF

Use past exam papers. This is great for not only testing your knowledge but also familiarising yourself with the exam format and structure, which will help you settle into the exam much quicker and easier on the day. Use questions from the textbook.

7 PRACTICE

To improve memory it is important to keep going back over information that you learn, using different formats of learning.

8 EAT PROPERLY

Fuelling the mind is an essential element of increasing focus and concentration. Research has indicated that students learn much better when they're well nourished. How often you eat can also have a powerful effect on your energy levels.

MEMORY LOSS: 7 TIPS TO IMPROVE YOUR MEMORY

Try these simple ways to improve your memory.

Can't find your car keys? Forget your grocery list? Can't remember the name of the personal trainer you liked at the gym? You're not alone. Everyone forgets things occasionally. Still, memory loss is nothing to take lightly.

Although there are no guarantees when it comes to preventing memory loss or dementia, certain activities might help. Consider seven simple ways to sharpen your memory- and know when to seek help for memory loss.

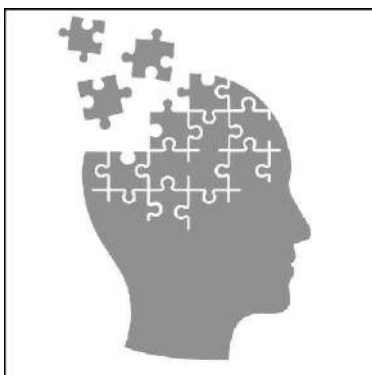
1. Include physical activity in your daily routine

Physical activity increases blood flow to your whole body, including your brain. This might help keep your memory sharp.

For most healthy adults, the Department of Health and Human Services recommends at least 150 minutes a week of moderate aerobic activity, such as brisk walking, or 75 minutes a week of vigorous aerobic activity, such as jogging-preferably spread throughout the week. If you don't have time for a full workout, squeeze in a few 10-minute walks throughout the day.

2. Stay mentally active

Just as physical activity helps keep your body in shape, mentally stimulating activities help keep your brain in shape-and might keep memory loss at bay. Do crossword puzzles. Play bridge. Take alternate routes when driving. Learn to play a musical instrument. Volunteer at a local school or community organization.



3. Socialize regularly

Social interaction helps ward off depression and stress, both of which can contribute to memory loss. Look for opportunities to get together with loved ones, friends and others- especially if you live alone.

4. Get organized

You're more likely to forget things if your home is cluttered and your notes are in disarray. Jot down tasks, appointments and other events in a special notebook, calendar or electronic planner. You might even repeat each entry out loud as you jot it down to help cement it in your memory. Keep to-do lists current

and check off items you've completed. Set aside a place for your wallet, keys, glasses and other essentials. Limit distractions and don't do too many things at once. If you focus on the information that you're trying to retain, you're more likely to recall it later. It might also help to connect what you're trying to retain to a favorite song or another familiar concept.

5. Sleep well

Sleep plays an important role in helping you consolidate your memories, so you can recall them down the road. Make getting enough sleep a priority. Most adults need seven to nine hours of sleep a day.

6. Eat a healthy diet

A healthy diet might be as good for your brain as it is for your heart. Eat fruits, vegetables and whole grains. Choose low-fat protein sources, such as fish, beans and skinless poultry. What you drink counts, too. Too much alcohol can lead to confusion and memory loss. So can drug use.

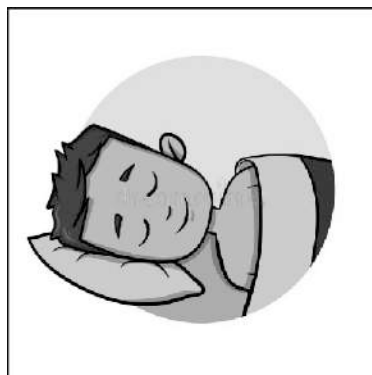
7. Manage chronic conditions

Follow your doctor's treatment recommendations for medical conditions, such as depression, high blood pressure, high cholesterol, diabetes, obesity and hearing loss. The better you take care of yourself, the better your memory is likely to be. In addition, review your medications with your doctor regularly. Various medications can affect memory.

When to seek help for memory loss

If you're worried about memory loss-especially if memory loss affects your ability to complete your usual daily activities or if you notice your memory getting worse-talk to your doctor. He or she will likely do a physical exam, as well as check your memory and problem-solving skills. Sometimes other tests are needed as well. Treatment will depend on what's contributing to your memory loss. Effective study can only be achieved if you're able to focus your complete attention on what you are trying to learn. If you are unable to concentrate fully on what you are doing because you're constantly being distracted, or your thoughts are going elsewhere, your process of learning will be interrupted. This makes it almost impossible to retain the very information you need when it comes to setting exams.

Memory and concentration go hand in hand. Concentration is the ability to focus all attention on the activity at hand and block out all other unnecessary thoughts and distractions. So, what can we do to increase our concentration and therefore improve our memory? Luckily they are skills that can be developed, you just need to know the right techniques. The Tips to Improve Your Memory Infographic details 8 essential tips when it comes to improving our memories. Make sure you take them all into account when you're preparing for an important exam!



TIPS TO IMPROVE CONCENTRATION

Mindfulness, cognitive training, and a healthy lifestyle may help sharpen your focus.

You're trying to concentrate, but your mind is wandering or you're easily distracted. What happened to the laser-sharp focus you once enjoyed? "Older people tend to have more difficulty filtering out stimuli that are not relevant to the task at hand," says Dr. Kirk Daffner, a neurologist and director of the Center for Brain/Mind Medicine at Harvard-affiliated Brigham and Women's Hospital.



What's fogging up focus?

Like a computer that slows with use, the brain accumulates wear and tear that affects processing. Dr. Daffner says this can be caused by a number of physiological stressors such as inflammation, injury to blood vessels (especially if you have high blood pressure), the buildup of abnormal proteins, and naturally occurring brain shrinkage.

The following factors can also affect your Concentration

Underlying conditions. Depression or sleep disorders (such as sleep apnea) can undermine your ability to concentrate. So can the effects of vision or hearing loss. "You waste precious cognitive resources when you spend too much time trying to make out what's

written on a page or just hear what someone is saying," Dr. Daffner notes.

Medication side effects. Some drugs, especially anticholinergics (such as treatments for incontinence, depression, or allergies), can slow processing speed and your ability to think clearly.

Excessive drinking. Having too much alcohol impairs thinking and causes interrupted sleep, which affects concentration.

Information overload. We are bombarded with information from TVs, computers, and messages such as texts or emails. "When there's too much material, it burdens our filtering system and it's easy to get distracted," Dr. Daffner says.

Try this focus exercise: Want a way to boost your attention and focus? Neuropsychologist Kim Willment of Harvard-affiliated Brigham and Women's Hospital suggests a single-task exercise like reading. "Read something for 30 minutes, setting a timer to go off every five minutes. When it goes off, ask yourself if your mind has wandered.



If so, just refocus on what you're reading," she says. "By training your brain to monitor if your mind is wandering, you strengthen the monitoring process and the ability to maintain focus on a single task."

To improve attention, consider the following strategies.

Mindfulness: "Mindfulness is about focusing attention on the present moment, and practicing mindfulness has been shown to rewire the brain so that attention is stronger in everyday life," says Dr. Kim Willment.

She recommends sitting still for a few minutes each day, closing your eyes, and focusing on your breathing as well as the sounds and sensations around you.

Cognitive training: Computerized cognitive training games aim to improve your response times and attention. Evidence that this works has been mixed. "The goal of playing these games is not to get better at them, but to get better in the cognitive activities of everyday life," Willment says.

"But there is evidence that a person's ability to pay attention can be improved by progressively pushing the person to higher levels of performance. So if you reach a certain level of sustained attention, pushing it to the next level can help improve it, and this may translate to everyday life."

A healthier lifestyle. Many aspects of a healthy lifestyle can help attention, starting with sleep and exercise. "There is a direct link between exercise and cognitive ability, especially attention," Dr. Daffner says.

"When you exercise, you increase the availability of brain chemicals that promote new brain connections, reduce stress, and improve sleep. And when we sleep, we reduce stress hormones that can be harmful to the brain, and we clear out proteins that injure it."

Aim for seven to eight hours of sleep each night, and 150 minutes per week of aerobic exercise, such as brisk walking.



Other healthy steps to improve focus: eat a healthy balanced diet, which has been shown to support brain health; treat underlying conditions; and change medications that may be affecting your ability to focus.

"Getting older is out of your control," Dr. Daffner says, "but healthier living is something you determine, and it may improve concentration."

MSSI DELHI : CHANGING WITH THE TIMES..



What a year 2020 has been! It has turned our world upside down, it has made us look at our values differently and it has made us realise more than ever before the importance of staying in touch with those whom we love & cherish. It taught us even though we are locked up in our homes that distancing need not isolate us or make us feel isolated.

Social Media, in all its varied forms, came to our rescue and very soon we were all chatting, Zooming, Whatsapping, video calling each other and spending a lot more time communicating with all those who are a part of the MS World far & wide.

VIRTUAL HOME VISITS:

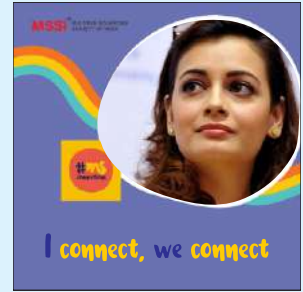
Our Home visits were always among our most popular programmes. Our MSPs always looked forward to the visit from our volunteers and welcomed them into their homes.. We looked forward to getting a first-hand glimpse of their home situations and towards getting a chance to talk to them personally on a one-to-one basis. However, during Covid and the lockdown this program had to be replaced by Virtual Home Visits.

We tried to time our Virtual Visits to the birthdays or special occasions of our MSP's. We chatted with some of them online, often had a video tour of their homes and they and their families shared experiences and thoughts with us. It was not equivalent to a physical Home Visit, but for the time being this will have to suffice. However, we were able to 'visit' homes of some of our members from other towns across India , which we would not have been able to otherwise.

Do you want to visit us in our home?

Video call us & introduce us to your family.. and we would love to chat with you !

WE FOUGHT COVID BY GOING DIGITAL



In the treatment of RRMS

Rx

Denop
Teriflunomide 14 mg Tablets

Designed t

Teriflunomide vs IFN

ARR

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in treatment naive patients

34%

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in recently treated patients



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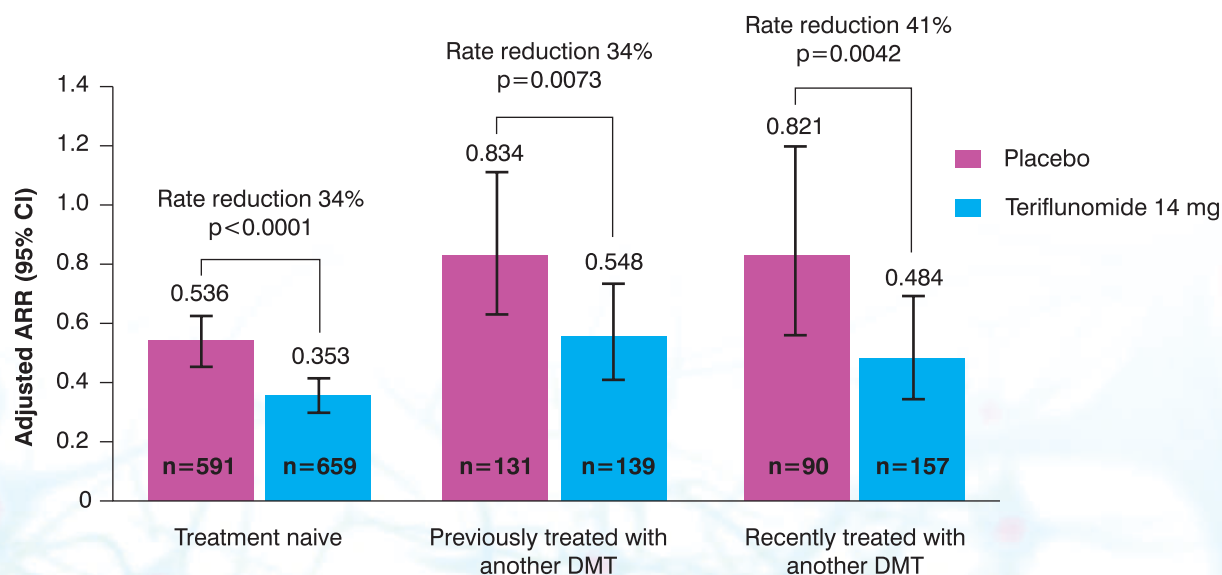


to Quiescent MS



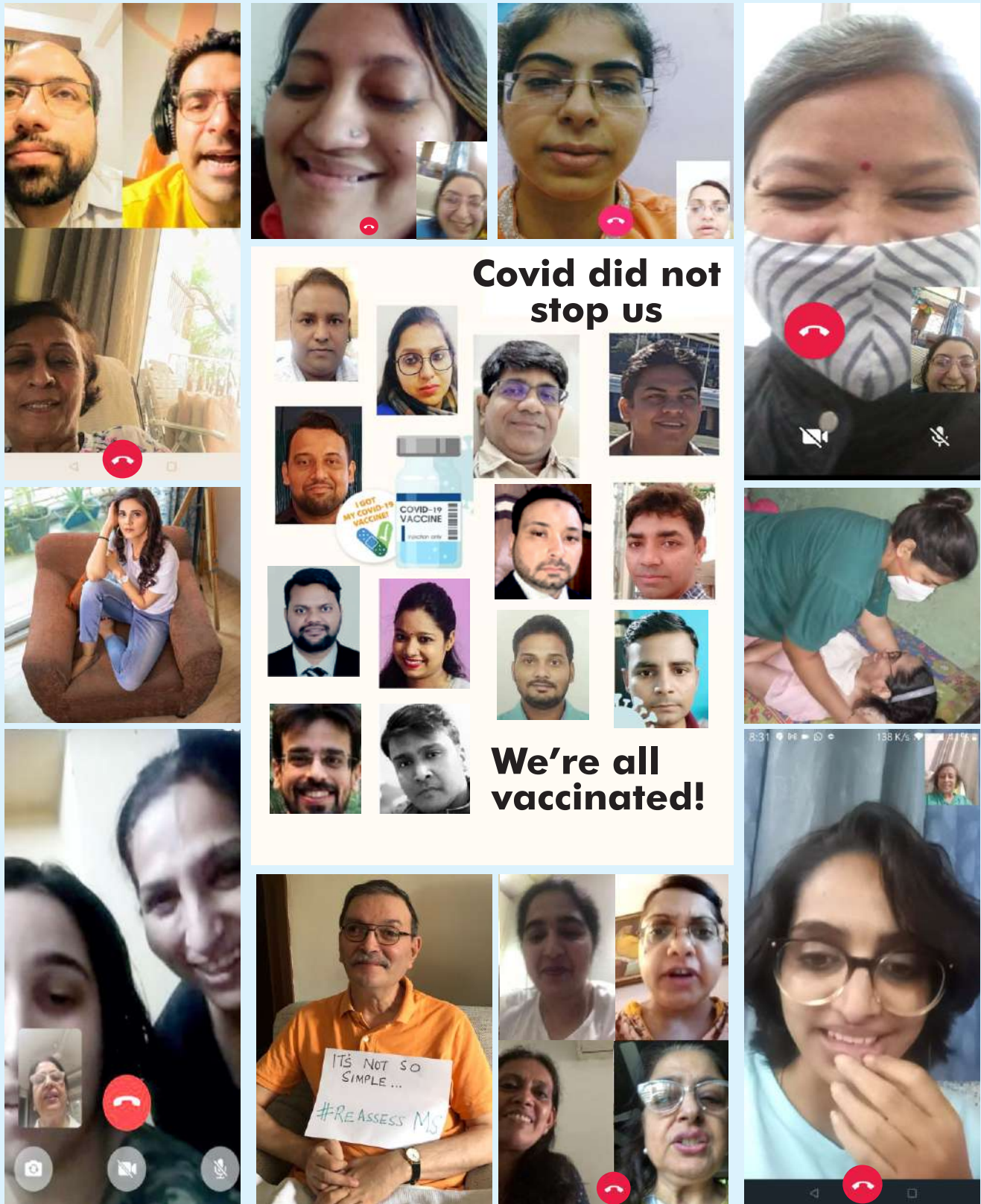
IFNB-1a, IFNB-1b, GA

Adjusted ARR with teriflunomide 14 mg or placebo



Orally
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with or
without food

We thrived during Covid through Digital Transformation



Face to face chats & counselling

Actual Site Photo





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*T & C Apply

BIRTHDAY GREETINGS:

Earlier, we made sure that we sent a birthday greeting card to all our patients. It was just our way of wishing you and remembering you on your special days. Now, we try to combine our virtual home visits with your birthdays, so that we can wish the best of everything on your very special days, and occasionally get a glimpse into your birthday parties or special occasions. It makes us feel as if we are a part of your family, .

WHATSAPP:

WhatsApp revolution has really changed our world.. just a few years ago we could not have believed that we could do so much on this simple app. It has become our main means of communication even more so now. Everyone connects immediately. Photos and videos, chats and tables, information, and news, even Zoom seminars. its all happening on WhatsApp !

JOIN THE CONVERSATION!



Youth MS Group (YMSG) on WhatsApp – If you are between the ages of 21-35 years, you will meet many other like minded people of your own age.

These are area-based groups. We have eight groups from different areas headed by a young PwMS. They all interact with each other regularly and enjoy the camaraderie that exists among all of them. They have learnt that they are not alone, there are others who share their pain and joys, and are happy to share advice and anecdotes and experiences.. During Covid days, the number of members who became members of these groups increased rapidly, and now are chatting frequently. Have you joined yet ?

MSSI DELHI VIDEOS:

These videos are immensely popular! They cover various topics and show us a talented side of our patients which many of us were unaware of!! There are three categories of these videos.

#myMSstory–as the words themselves tell, these are the personal depictions of our friends–PwMS as well as caregivers can contribute their short stories. They make the video themselves, tell us in their own words about what they have achieved even in adverse circumstances and provide a guiding light and inspiration for others. Painting and music, travel and beauty competitions, so many aspects of their lives are depicted in these short but delightful videos. Please do realise that making a video is not really that simple! It requires practising the words again and again, a lot of editing, many mishaps and laughter while the video is being filmed. There is many a slip between the thought and the final video but the process of making it is always fun.

So watch some of these on our MSSI FaceBook page , and send us one of yourself now!

Shivangi Bhardwaj – Winner of Mrs. India Beautiful Voice – a very popular video, it told us the story behind Shivangi's win. We always knew that she was beautiful, but now we also learnt about the new things she had to learn in order to compete in this contest. Congratulations Shivangi, we are proud to know you.

Jyoti Setia started painting only recently and was reluctant to show us her handiwork. But with encouragement from her daughter **Lakshita**, she made a video about her paintings and how she overcame her shyness and shared her art with everyone. Lakshita's video about her mother was so heart-touching. Her pride in her mother's achievements made us proud of her also.

Sukhmani's video on a good diet was another very popular video. She showed the correlation between diet choices and remaining healthy with MS. Yoga, staying positive and losing weight were the hallmarks of **Anju Bhatia's** video. Her enthusiasm for life and her very practical advice for our members was a great hit!

#MSSIDelhicares- these are videos from us-the managing committee. Here we showcase what we do and how we help you and provide various types of assistance to our members. Shagufta's various activities when she visits the patients at home were beautifully documented in her video. The Physiotherapists video was about the various exercises they do and the amazing effort they put in to look after their patients. This is our way of saying *#MSSIDelhicares*.

#staypositivewithms – Rashmi Narula presented a video on how to stay positive with MS. Once again, the visuals cheered up our MS persons and once again the words of a member made more sense and touched their hearts.

Major Sumit Thakral's testimonial was proof of the fact that the social media interaction during the pandemic days did not stop us from helping each other and making sure that we were there for all of you.

But there is so much more on social media than just WhatsApp- even though it occasionally seems like it is everywhere! **INSTAGRAM** provided exercise videos made by our physiotherapists. They were not able to go their patients for quite some time, but they made sure that they sent them videos of the exercises so that they do not stop doing them. We could not celebrate World MS Day in May 2020 or **India MS Day this February.. Although we could not meet physically**, once again Social Media came to our rescue. We organised **Webinars** – with doctors and counsellors. We had a **Zoom** meeting with music-attended by almost 100 MSSSI Delhi members. Songs and discussions intermingled together.

FACEBOOK helped in sharing platforms of ideas such as **Mandalas**! The response to the request for Mandalas was overwhelming ! The colours, the designs-it was as if there was a burst of colour all around. **Find your MS Connection**-this campaign had responses from the family members of MS persons. After all-the idea was to connect and here was an opportunity to truly connect!

Social Media has proven to be much more than just a conversation media for our MS persons. They, like the rest of the world learnt to use it to share information with a click , to watch the others as they taught them new things, or practised old ones, and above all to realise that the world is one and it rests in the palm of your hand !

Our Scholarship Stars



I have been suffering from progressive MS since 2006 Over time, because of severe adverse developments in my physical condition, my entire family went through significant mental and financial stress & crisis. My two kids had to change their schools 4 times because of which their studies suffered. My wife was the only working member in the family and hence the breadwinner & home maker.

Now, in this pandemic caused by COVID-19, my wife has lost her job. My children are still in school, daughter Aarushi in class XI and son Aarush in class VII. He had to change schools again because the family could not afford the fees. With the household income decreased, the education of the children, the future of our country & my family took a blow. With the help from MSSSI Delhi scholarship I am certain things will improve as I have been given hope as well as support for my children education. I am extremely thankful to Ragini Ma'am for her kind initiative of taking personal care to understand the difficulties of the MS patients and their families.

Regards

Rakesh Kumar from Gurgaon



I was diagnosed with MS in 2010 and after that struggling on finance side due to high cost of medicine. I am also not in a position to work due to my physical condition and being confined to a wheelchair. This educational support /scholarship to my Kids Bhawana and Shivansh, has surely helped in a big way to pay their overdue school fees. I pray MSSSI should continue and enhance this further to other needy people as well. I again want to thank MSSSI Delhi for continuous support and I don't have enough word to express my gratitude.

-Sanjeet Singh



I'm deeply grateful to Team MSSSI for providing scholarship to MS patients. I was diagnosed with MS when I was 14 years and 7 months old. After getting MSSSI study scholarship I didn't get any problem with my School fees. Before this, due to the high cost of medicine my parents were unable to submit my fees regularly. With this assurance from Bipasha Ma'am I can now go ahead in life.

-Sahil Phougat



Hi, Thanks to MSSSI for giving the scholarship to my son so that he can pursue his education flawlessly.. Information was shared by Bipasha ma'am which has given the light in darkness. Thanks a ton to her and MSSSI.

-Aditi Minocha



I'm very thankful to Team MSSSI for providing scholarship to MS patients.

I am Sandeep Singh. I am an MS patient. Thanks MSSSI team for your Scholarship being provided for my kids Khushnoor and Warisveer Singh for enabling the continuation of their studies After getting study scholarship I didn't face any problem regarding their schooling. I'm very thankful for all the help I have got from you all !

Sandeep Singh



When I got MS, I lost my job, my income and also most of my savings over a period of time. In this situation it became very difficult to ensure a good and uninterrupted education to my children. Thanks to MSSSI's regular support of Scholarships to both my children Meghjeet and Peehu I have the confidence & security that my children can get the best education I would like to give them. Moreover even in the scenario of Corona when governments and employers were reducing salaries and jobs. MSSSI continued to send scholarships in a timely way, and they have not compromised even one inch to help us MS patients and their kids. Apart from that I would also like to thank MSSSI Delhi for providing health and nutritional supplements to me which I share with my children Thanks MSSSI.

Sujeet Upadhyay



मैं सम्पूर्ण MSSSI Team का सहज दिल से आभार व्यक्त करती हूँ जब मुझे MS की problems हुई, मैं समझ न पाई कि क्या किया जाए? क्योंकि financial problems होने की वजह से बच्चों की पढ़ाई की चिन्ता होने लगी। Website से MSSSI संस्था का पता चला कि ये एक ऐसी संस्था है जो निःस्वार्थ भाव से निःशुल्क सेवा प्रदान करती है। यही नहीं बिपाशा जी रागिनी जी स्वयं मुझे देखने आई उस समय मेरा और मेरे पति की खुशी की सीमा न रही। अब हम बच्चों की पढ़ाई के लिए निश्चित हो गए कि इनकी school fees में कोई परेशानी न होगी। इतना ही नहीं Dr. Akash को भी मेरी exercises के लिए नियुक्त किया गया। ये इस तरह के Dr. है कि निराशापूर्ण व्यक्ति भी आशानुरूप हो जाता है। मैं पूरी Team का तहेदिल से आभार व्यक्त करती हूँ शगुफ़ता जी भी अपने निश्चित समय पर आकर सेवा प्रदान करती हैं। ये भी हंसते मुस्कुराते अपने काम को तन्मयता से करती हैं। ईश्वर से प्रार्थना है कि सदा यह संस्था निरन्तर सफलता की ओर बढ़ती रहे।

सधन्यवाद, मनिंदर कौर



WHAT INFLUENCES QUALITY OF LIFE?

Many factors can influence a person's quality of life, both inside and outside their direct control. These factors vary from person to person, from place to place and change over time. Multiple sclerosis (MS) can have an impact on these factors at any time.

Seven principles to improve quality of life

The seven principles below are based on the insights and experience of people affected by MS and agreed by the MSIF movement. There is no priority amongst the principles – it is for individuals and organisations to decide what is most important to them at any time. No country can claim to have achieved them all. They are our call to action for continuous improvement in every country.



We invite everyone in the MS movement to use the principles in their own way:

- **as individuals:** to think about our own quality of life and what we can do to enhance it, whether we have MS ourselves or know someone who does
- **as MS organisations:** in shaping and evaluating our strategies, programmes, advocacy and research

and we call on others to join us....

- **Healthcare professionals and providers of services to people affected by MS:** to understand how what they do and how they do it affects quality of life
- **Researchers and product developers:** to shape their investigations and the way they carry them out
- **Governments and health authorities:** to help shape laws, policies and actions.

The MSIF movement's call to action on quality of life with MS

In 2005, MSIF published a set of principles—a kind of “gold standard”—setting out what any person with MS should expect in order for them to have a good quality of life.

In 2016, MSIF reviewed the principles and carried out an extensive consultation with people from over 30 countries, learning more about what influences quality of life for people with MS, their caregivers, family members and friends closest to them.

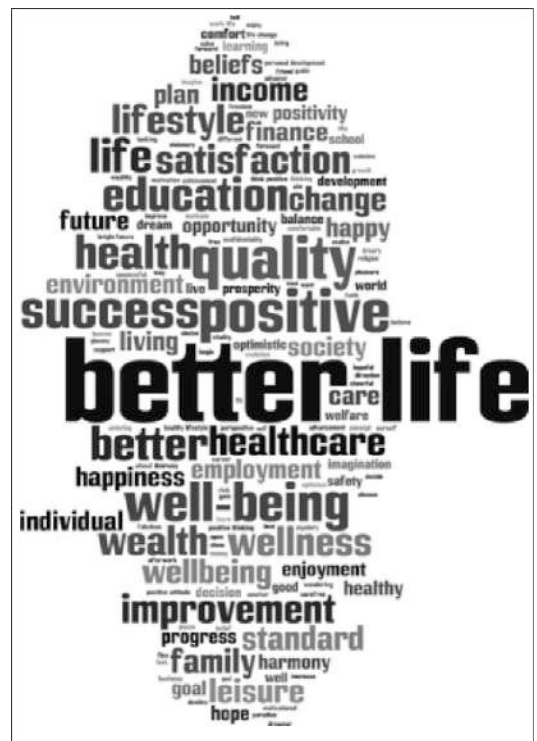
This consultation produced a refreshed set of principles identifying the main areas in which every bit of progress can make a real difference to individuals. It recognises that quality of life is highly personal and changeable, with many interdependencies, and that it is for individuals to determine what matters to them.

Empowerment, independence and a central role for people affected by MS in decisions that affect their lives.

Why is this important?

This principle affects every aspect of quality of life. It includes freedom of thought; personal beliefs and values; the rights of every individual to self-determination. Its influence is broad, including social, professional and intimate relationships and opportunities to participate in society. It draws on insights from numerous health, welfare and political settings showing that quality of life is enhanced when people can participate fully in decisions that affect their lives and take responsibility for themselves. This means having the right information, skills, opportunities and a supportive context that recognises diversity in all its forms. Whilst independence and empowerment can mean different things to different people, they are often the first thing a person affected by MS talks about when considering quality of life. *Some key features*

- People affected by MS realise their full potential in all the aspects of life that are important to them
- People affected by MS participate in decisions about their treatment, care and lifestyle in line with their personal beliefs and values
- Services take into account the needs and priorities of the individual and are designed to be user-friendly
- Information about MS is trustworthy, up to date and directly accessible by people affected by MS
- People affected by MS shape and fulfil their roles and responsibilities within the family, community and wider world
- People affected by MS have leadership roles throughout the MS movement
- Personal wellbeing (including diet, exercise, sleep) and resilience-building are directed by the person affected by MS
- Spiritual support is accessible in line with individuals' beliefs and practices



Some key features

- Family members are recognised as individuals with their own quality of life needs
- People have access to support with personal and sexual relationships and their changing dynamics
- The care-giving role is understood, acknowledged, valued and financially supported
- Child and adolescent caregivers get special attention to protect their education, health, social and personal development
- Care and respite services are designed in ways that respect the personal time of family members
- Individuals' personal privacy, confidentiality and sensitivities are respected
- Funding is available for professional assistance with personal care
- People with MS and people affected by MS each have opportunities to expand their own social networks
- Health policy research addresses the composition of the support network and strategies to enhance it

Work, volunteering, education and leisure opportunities that are accessible and flexible.

Why is this important?

This principle focuses on some of the links between aspects of the external environment and elements of quality of life that contribute to a person's sense of self-worth, independence and belonging. Rights to education, work and leisure are recognised human rights. Participating in these activities as equals empowers and enables people with MS to contribute as valued members of the family and wider society. Participation also enhances visibility and public understanding of MS, which in turn contributes to removing stigma and discrimination.

Some key features

- Rights to work and study are protected
- Educated and informed employers; accessible workplaces and flexible working practices
- Access to career advice, training and professional development opportunities
- Educational institutions are accessible and have flexible approaches to learning and assessment processes
- Leisure, sport and social facilities are accessible and welcoming (encouraging, promoting participation)



Accessible public and private spaces, technology and transport

Why is this important?

This principle enables participating in many of the other principles – getting around easily at home and outside is important for participating in society, relationships, education, work and leisure activities. Physical barriers or complex systems for accessing buildings and transport are common, even in health facilities, and having to rely on other people for assistance compromises independence. Online or virtual public spaces are increasingly important and require similar attention to accessibility.

Some key features:

- Rights to choose where to live and to decide when to move to accessible accommodation
- Housing that is designed or adapted and equipped to suit changing needs and preferences
- Transport that is accessible for a range of needs-not just for wheelchairs: seating, support rails, trained operators
- Public buildings-civic, commercial, healthcare, leisure, places of worship-that are designed or adapted and managed to be accessible for a range of needs-not just for wheelchairs: toilets, rest spaces, door design, trained staff
- Welcoming and non-discriminatory attitudes
- Digital and mobile technology and services that provide increased opportunities for people affected by MS, and are accessible and usable by people with a range of impairments

Financial resources to meet the changing needs and costs of living with MS.

Why is this important?

This principle is relevant to almost every aspect of quality of life. People affected by MS experience substantial financial costs – for medicines, care, adaptations (such as walking aids, assistive computer software, adaptations around the home) and transport. Many household budgets cannot cope with these impacts and other expenditure suffers. In many countries, households that rely on government benefits often remain on the poverty line. These financial strains can impact on family relationships and increase isolation.

Some key features

- The full financial impact of MS is researched and understood, including underlying factors and implications for policy and practice
- People with MS can earn their own living and manage their own finances
- Financial services (banking, investment planning and borrowing advice) are available for people affected by MS
- Government assistance and insurance programmes are designed to meet the variable financial needs of those with and affected by MS
- MS is recognised as a qualifying condition for government assistance and other relevant benefits such as subsidised public transport

Positive, supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination

Why is this important?

This principle focuses on the role of the external environment in affecting quality of life, emphasising the importance of explicit attention to equality issues. MS is relatively uncommon, poorly understood by policy makers and service providers and often has invisible symptoms, increasing the likelihood that needs will be overlooked. Many countries lack even basic data on MS prevalence. Lack of societal understanding of MS increases vulnerability especially for people already facing risk related to gender, sexuality, poverty, race or social status.

Some key features:

- Health professionals, support workers, employers, educators and the general public are aware of MS and understand their role in promoting the Principles
- Legislation and policy that promotes dignity for all
- Investment of public resources in reducing inequalities associated with MS
- Inclusion on electoral registers and accessible voting systems
- Inclusive approaches to innovation in communications, infrastructure and other technology development
- Attention to vulnerability and exclusion issues in research and policy-making



Immunity is the need of the hour with constant warnings of the 3rd wave of COVID-19.

Our immune system is our body's basic defence mechanism. In order for it to work well, we need to ensure that we take care of our body. So here are some tips on how you can change your diet to boost your immunity.

Consume protein as it helps build antibodies. Foods such as lentils/ dal, legumes/ chana & rajmah, dairy, nuts, seeds, eggs, fish and chicken are all rich in protein. Ensure you're getting your dose of vitamins and minerals. Fruits like amla, lemon, berries and green leafy vegetables are rich in Vitamin C. Omega 3 reduces inflammation. Thus, one needs to have walnuts, fish & flaxseeds (alsi). Iron is important for oxygen and blood production. Good sources of iron are beetroot, dates, pulses, meat and green leafy vegetables. Finally, herbs such as turmeric (haldi), pepper, cinnamon/dalchini and garlic are great for fighting pathogens.

Together with a healthy diet we should exercise and have good sleeping habits. Taking care of our body helps build our immunity but it does not make us invincible. It is still possible to get sick, especially with so much uncertainty around us. This is why we should also ensure that we are always protected in case of an unfortunate event.

Healthy Eating and MS

Although there's no solid evidence to suggest that any one diet influences the risk or progression of multiple sclerosis (MS), healthy eating may help ease some symptoms of the disease. But what exactly does this mean for people with MS?

A healthy and balanced diet combined with daily exercise may help alleviate symptoms such as fatigue, and bowel and bladder issues. It can also improve the health of the skin, bones, teeth, and gums, as well as strengthen the heart and increase muscle strength and flexibility. A healthy diet can also help control weight gain and lower the risk of heart disease and osteoporosis. Some studies have shown that certain foods may lower the risk of MS or slow the progression of disability, but researchers have not yet established a direct link between diet and MS.

Here is some general guidance on foods to eat and those to avoid as an MS patient. It's important to consult your physicians before making any major dietary changes.

Fruits and vegetables

Several studies have shown that eating more fruits and vegetables may help reduce symptoms such as fatigue, pain, and depression.

Fruits and vegetables contain a wide variety and relatively high concentration of antioxidants. Antioxidants can help decrease the formation of molecules called free radicals that can cause damage to tissues in the body.

The National MS Society recommends consuming five servings a day of antioxidant-rich fruits and vegetables. Eating fruits and vegetables in as many different colors as possible, sometimes called "eating the rainbow," can help increase the number of different antioxidants and other nutrients in your body.

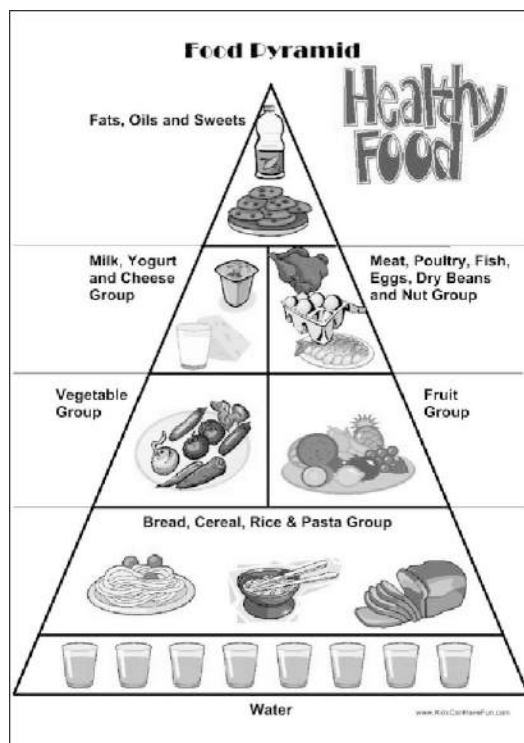
Vitamin C and vitamin E are some of the more familiar types of antioxidants. Plant foods rich in vitamin C include broccoli, Brussels sprouts, sweet potatoes, strawberries, leafy greens, citrus fruits like oranges, tomatoes, and bell peppers. Vitamin E is present in leafy greens, peppers, avocados, and nuts and seeds such as almonds and sunflower seeds. Fruits and vegetables may also be helpful for weight loss and control. Since they are high in nutrients and fiber, they can help with cravings and help you feel fuller for longer. At the same time, they are usually much lower in calories.

Fats

Saturated fats

Whether or not you have MS, it is a good idea to avoid saturated fats as much as possible. Saturated fats have been linked to several health issues such as heart disease, stroke, high blood pressure, and some forms of cancer. Some studies have also suggested that saturated fat intake may be related to the risk of MS relapses and disease progression.

These fats are found primarily in animal-based foods such as meat, eggs, milk, chicken skin, and cheese. Some plant-based foods such as coconut oil, palm oils, and cocoa butter are also high in saturated fat.





Trans fats

In general, trans fats should also be avoided, as they have no known health benefits and can contribute to conditions such as heart disease. These fats are typically man-made and, like saturated fats, are solid at room temperature. Examples include margarine and vanaspati ghee. They can also be found in fried foods, cookies, and other processed foods.

Unsaturated fats

Unsaturated fats are commonly known as "good" fats. Contrary to saturated fats, they may lower blood cholesterol levels, thereby decreasing the risk of heart

disease or diabetes. They could also help ease inflammation. There are two types of unsaturated fats: monounsaturated and polyunsaturated fats. Good sources of monounsaturated fats include olive and canola oil, avocados, and many types of nuts and seeds.

Polyunsaturated fats can be found in sunflower and corn oil, walnuts, flaxseed (Alsi), and fish.

A type of polyunsaturated fat called omega-3 fatty acids, commonly found in fish, has been studied in MS with mixed results. One study found that a fish-rich diet contributed to a lower risk of MS, while another found that taking daily omega-3 supplements had no effect on disease activity. These differences could be due to the source-food versus supplements-of omega-3, but more research is needed. The National MS Society advises caution with omega-3 supplementation, as its interaction with certain medications has not been fully studied and may decrease their effectiveness. Consult your doctor before starting any supplements including omega-3.

Proteins

In general, you should limit protein sources to those low in saturated fat, such as lean meats and fish. Red meat, poultry, and processed meats, sausage, and bacon may lead to a higher risk of heart disease. Because MS patients may already be at risk of heart disease, you should limit your consumption of these meats. You may want to consider plant-based protein sources, such as tofu and soya nuggets, as they do not contain saturated fats and are higher in fiber than meat, poultry, and fish.

Dairy

Some evidence suggests that MS patients should avoid dairy products, particularly those from cow's milk, as their consumption may increase disease activity. Two ideas are proposed about how milk may contribute to the development of MS. One is that cow milk protein butyrophilin can cause the body to produce antibodies against it. These antibodies could also recognize a protein with a similar shape, called myelin oligodendrocyte glycoprotein, that is found on nerve cells, leading to their damage. Another theory is that the calcium in dairy may reduce the body's production of the active form of vitamin D.

Full-fat dairy products are also often high in saturated fat, which should be avoided as part of a healthy diet. Several alternatives to dairy products are available such as those made from soy, almond, oats among others.

Sugar

For people who experience fatigue, it is often tempting to turn to sugar. However, while sugary foods may provide quick bursts of energy, they often lead to energy crashes and may ultimately increase fatigue.

Sugar also increases the number of calories you are consuming and can contribute to weight gain. The energy crashes may make you crave more sugary foods to help increase blood sugar levels again.

Artificial sweeteners such as aspartame can irritate the bladder and cause problems, so you may want to avoid these as well.

Salt

People should generally reduce the amount of salt they consume as it can lead to health problems such as high blood pressure. You should try to limit your consumption of processed and prepackaged foods as these often have high salt content. Fast food and food from restaurants often contain a lot of salt as well.

Beverages

Water

Drinking enough water is important for MS patients as it is for the general population. Water is necessary for many essential functions in the body including digestion, brain function, regulation of body temperature, and the movement of blood and nutrients. MS patients may experience fatigue and trouble thinking clearly if they are not getting enough water. Water intake needs may vary from person to person.

Alcohol

For people with MS, alcohol can worsen balance and coordination issues. Drinking too much alcohol can also exacerbate symptoms of anxiety or depression, as well as have a negative effect on fatigue.

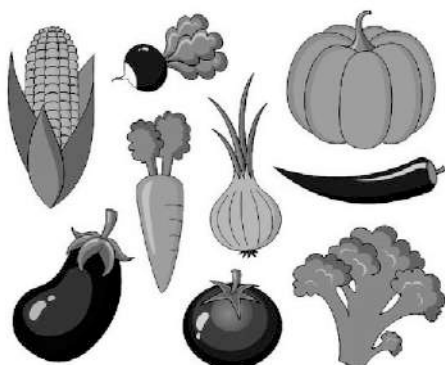
One study has also shown that alcohol use, abuse, and dependence may be significantly related to an increased risk of developing MS.

Vitamin D

Vitamin D has long been a topic of interest among the MS community, with several studies suggesting that vitamin D may provide a protective effect against the risk of MS. However, a 2020 mouse study also found that vitamin D in high doses may actually contribute to disease progression.

Vitamin D can be found naturally in foods such as some fish, mushrooms, or fortified foods such as cow or soy milk, orange juice, oatmeal, and some cereals.

Research continues into the impact of vitamin D on MS. You should consult your doctor before starting any vitamin D supplementation to determine safe levels of intake.



#myMSstory: DEEPSHIKHA GAUBA ARORA

A new Chapter of my life begun in Feb' 2012. I was so nervous, thrilled, amused and what not with the swiftness at which the developments had happened. After 2 months of meeting him to be precise.. we were *husband and wife*..

I was as thunderstruck as any ordinary girl would be... but I was contented. Anyone could easily make out with my sparkling face. The best part was that I was doing good on professional front as well. I was working as Assistant Professor IT since 4 years and cleared my PhD exam with Rank 46 PAN India and was just a step away from getting enrolled when similar to any *Bollywood masala movie* came a sudden jerk - 10 months into marriage and I was diagnosed with Multiple Sclerosis (MS). I was to be admitted the very same day I had to attend my PhD interview and on top of that on 25th December...

I never knew what this so called auto immune disorder MS (as told by my neurologist) even meant. Primarily the pain of not attending my interview and furthermore to do away with my *chooda* (*bridal wear* in punjabi brides) for a MRI scan was so upsetting that I didn't even bother to Google what MS was. Goodness gracious! when I did my research I was startled.

I was admitted for a regular 3 days solumedrol procedure and the first thing that came to my mind at that time was "*why me... why am I the chosen one for this... why is God so unkind to me*" and after lots of pondering and sulking, I got my answer when my inner voice whispered "*If you want to be strong learn how to fight*". Since then I am combating this disorder.

I started yoga and taking care of my health but after a MRI in 6 months my lesion load increased and I was asked to start injecting Interferon.

It was a tough call but my husband convinced me to go for it. At this point of time, I was even advised to consider my decision again as I might not be able to conceive and start a family. But I am glad that we stood firm for the decision we made and got through an entire year peacefully with teeny-weeny symptoms. After one year of taking the shot, I wanted to plan for my baby. My neurologist was not sure but my homeopathy doctor (*I started visiting him when I started Interferon*) whom I consulted convinced me to go ahead. Fortunately we did and in next year i.e. July 2015 I was blessed with a baby girl.



One year I had back to back 3 relapse and it was very exasperating. My doctors asked me to wean off my daughter and start on Interferon dosage again as soon as possible. After 1.5 year I again started with my injections and it's been 3.5 years that I am still taking it.

Although the best part is that I started working from home again as a freelancer in education sector and also for a LLP assisting in a government project . I am enjoying my life and love every bit of it and take life as it comes. I won't say life is smooth but it certainly is beautiful and worth living and dreaming for.

Recently I prepared my daughter for a rhyme for her school activity and it has changed my aspect to look at life with a positive note yet again

"Koshish karne walon ki kabhi haar nai hoti... toofan se darr ke nauka paar nai hoti"

Though I keep motivating myself by filling my **bucket list**, this poem has illuminated me again. As they say "**Stop dreaming about your bucket list and start living it**". I keep striking off from my list and updating it yet again trying to achieve gradually.



DON'T WORRY BE HAPPY

De-stress & Stay Healthier

The prolonged stress of living with a chronic illness, like multiple sclerosis can lead to frustration, anger, hopelessness, and depression. People with MS are especially at risk of becoming depressed. And, for good reason Since people with MS face many stressors.

To better cope with the disease, it is important to learn how to manage stress. The first step is to recognize when you are stressed and then you can take steps to reduce your stress.



What Are the Warning signs of Stress?

- Are you unable to concentrate?
- Do you worry, feel sad, and have frequent mood swings?

What Can You Do to Feel Better?

- The key is keeping a positive attitude.
- Accept that there are events that you cannot control.
- Be assertive instead of aggressive. Assert your feelings, opinions, or beliefs instead of becoming angry, combative, or passive.
- Learn relaxation techniques
- Exercise regularly. Your body can fight stress better when it is fit. But talk to your doctor before starting an exercise program.
- Eat well-balanced meals.
- Rest and sleep at regular times
- Don't rely on alcohol or drugs to reduce stress.

Access to Comprehensive and Effective Treatments and Care for Changing Physical & Mental Health Needs of Life with MS.

-Dr. Manish Mahajan, Senior Consultant Neurology, Artemis Hospital

There are complex and numerous direct impacts of MS on physical and mental health. These impacts can be visible and invisible, and they can in turn affect other aspects of quality of life. The impacts and symptoms of MS vary from person to person both in nature and in severity, and they change over time. They can interact with a person's other health conditions. Treatments themselves can have side effects. For many people affected by MS, the mental and emotional health impacts are as important as the physical impacts. Managing all MS symptoms effectively and promoting good general health through a personalised package of care can help people affected by MS to minimise the overall impact.

Some key features

- Early diagnosis, monitoring and review
- Multidisciplinary, integrated care planning with services provided close to where people live
- Age-appropriate and gender-sensitive information about MS and what to expect, including the specific needs associated with MS in childhood and adolescence
- Choice of effective, accessible and affordable treatments to meet the varying needs, preferences and priorities of individuals with MS
- Service providers who listen to individuals' needs and respect the expertise that comes from lived experience
- Research for more effective treatments that have fewer side effects and are easier to use as well as research to find ways to prevent, slow, stop or reverse the accumulation of damage and disability associated with MS
- Research on the barriers and facilitators to access including financial, cultural, administrative, and geographic barriers
- Accessible general healthcare, screening and preventive services including mental, sexual and reproductive health
- Psychological and emotional support as required including around diagnosis and decisions about the future
- Rehabilitation and palliative care services appropriate to the stage of life
- Individuals' personal privacy, confidentiality and sensitivities are respected

Support for the network of family, friends, loved ones and unpaid caregivers

Why is this important?

This principle recognises that the quality of life of a person with MS is closely linked to that of their families and other loved ones. When one is affected, so is the other. People affected by MS—spouses, partners, family members, close friends and unpaid caregivers—experience health, emotional, social and financial impacts of their own, which are usually under-recognised and poorly addressed in public policy and services. People with MS and people affected by MS can both become vulnerable to abuse, exploitation, discrimination and stigma. The principle also acknowledges that people with MS often have caregiving roles themselves.

Breakdown of Costs

Investigations

- I. Contrast enhanced MRI brain and cervical spine (Rs. 26000/ \$416).
- II. Visual evoked potential (VEP) (Rs. 2000/\$32).
- III. Lumbar puncture (CSF analysis) (Rs. 8000/ \$128).
- IV. Ancillary investigations like autoimmune encephalitis panel (Rs. 40000/ \$464).

Treatment Costs

Pulse IV steroid therapy x 5 days (Rs. 70000/ \$1120).

Hospital Stay Costs

Room cost plus ancillary expenditure (Rs. 70000/ \$1120).

It is important to remember that this is the financial burden borne out of pocket by an average middle class patient admitted to SGRH. Patients who live below the poverty line cannot afford such costs and the financial burden forces family members to take loans or at times sell their home and property to pay for the treatment. Unlike a case of post infectious myelitis, a patient with MS may suffer an acute exacerbation or relapse leading to another hospitalization and additional costs. The various MS disease modifying agents are so expensive that few patients in India can afford the drugs. Many as a result discontinue treatment regimens and self medicate with medications such as oral steroids.

We also calculated the average cost to the patient of various disease modifying agents available in India.

- I. Injectable DMT's like Avonex (beta interferon) given at a dose of 30mcgI/M once a week costs Rs. 30000/ \$480 dollars monthly.
- II. Copaxone (glatiramer acetate) Rs. 20000/ \$320 monthly.
- III. Mitoxantrone Rs. 400/ \$5 per vial.
- IV. Tysabri (natalizumab) costs a whopping Rs. 1,40,800/\$2184 monthly.
- V. Oral DMTs like fingolimod costs around Rs. 3,00,000/\$4790 dollar for 30 capsules, teriflunomide Rs. 2,90,000/ \$4500 for 1 month supply, and dimethyl fumarate Rs. 3,40,000/ \$ 5300 for 1 month supply.
- VI. Azathioprine costs Rs. 600/ \$9.6 per month.

The per capita income in India is estimated at just short of Rs. 6000 per month which equals \$90 per month. That means the per capita income for a family of 4 would be less than \$400 a month, but the reality is that most people live on much less than that and struggle to provide for the basic needs of food, clothing and shelter. Both the interferon's and the oral DMTs are accessible to only a few in India due to their exorbitant cost. As a result, many Indian MS patients cannot afford treatment and are left behind untreated with significant neurological disability impairing their quality of life. In India, where it is estimated that around 100,000-200,000 people have MS, finding cost effective treatment options is very important.

What are the Solutions?

I. Methylprednisolone (Solumedrol) is an effective drug used to treat an acute attack of MS. Once the diagnosis of MS is confirmed, and patient presents to the hospital with an acute exacerbation, first dose of methylprednisolone can be administered in the emergency department followed by rest of the doses at home. The outpatient administration can be carried out by trained nurses via patient outreach programs. This will greatly reduce the cost of treating an acute attack of MS without requiring admission.

- ii. An initial MS diagnostic and treatment package should be constituted, including all the necessary initial investigations and treatment. This shall help drive down the initial costs incurred by patients and family members.
- iii. A MRI package should be constituted. This should include the cost of MRI brain and cervical spine imaging at least once a year and help in reducing the diagnostic cost associated with repeated neuroimaging in patients with MS.
- iv. A National Health Insurance scheme geared towards chronic neurological diseases such as MS should be formulated. While many good insurance schemes have been recently launched by the government, unfortunately they remain on paper only.
- v. Pharmaceutical companies manufacturing and marketing MS drugs should be approached by the government and the cost of MS drugs should be negotiated so that more patients can afford these medications and avail their benefits. Recently 3 Indian pharmaceutical companies have launched generic versions of Tecfidera (dimethyl fumarate) costing under Rs.4000/month. Intas pharmaceuticals generic version of Aubagio (teriflunomide) costs only Rs. 2000/month.
- vi. There are various studies documenting the effectiveness of azathioprine in MS patients. A multicentre randomized non inferiority trial was conducted comparing azathioprine vs beta interferon's for relapsing remitting multiple sclerosis and it was found that efficacy of azathioprine is not inferior to that of beta interferon for patients with relapsing remitting multiple sclerosis. Massacesi et al.[1]conducted a study evaluating the efficacy of azathioprine therapy on new brain lesions evaluated using magnetic resonance imaging and concluded that azathioprine administered at lymphocyte suppressing doses, is effective in reducing MS new brain inflammatory lesions and is well tolerated [2]. In a study by Casetta et al.in 698 patients with MS, it was concluded that azathioprine is a fair alternative to interferon beta for treating MS patients [3]. In SGRH, we have around 20 patients with MS who are on azathioprine for the past 10 years, doing well and tolerating the medication well. Considering the convenience of oral administration, low cost and good efficacy, azathioprine may represent an alternative to interferon and oral DMTs. This should be studied further in the Indian context.

Conclusion

In India, there is a large unmet disease burden of MS. We can't afford not to afford the treatment of MS in India as it affects our young population who are the backbone of our nation. To tailor to the requirements of the Indian population, drug trials with large sample size using cheaper drugs such as azathioprine are needed. Large academic medical centers in India should take the lead in this initiative and run head to head trials of azathioprine against more established injectable and oral DMT's.

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CORPUS PUBLISHERS

Concepts in Neurology and Research (CNR)

Volume 1 Issue 1, 2020

Article Information

Received date: May 04, 2020

Published date: May 15, 2020

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Keywords

Multiple sclerosis; Drugs;
Treatment; Cost; India

Editorial

Can we Afford not to Afford Treatment of Multiple Sclerosis in India?

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Introduction

Multiple sclerosis (MS) is a chronic neurological disease which affects men and women in the prime of their youth, he disease can present in relapsing-remitting, secondary progressive, progressive relapsing and primary progressive forms and leads to increasing disability during the course of the patient's lifespan. Symptoms such as muscle weakness, gait and balance problems, coordination problems, visual impairment, diplopia, bladder and bowel disturbances, sensory symptoms, cognitive dysfunction and fatigue can be disabling at times and lead to poor health related quality of life, neurological disability and high health care costs. Progressive disease can be particularly disabling leading to a wheel chair dependent on caregivers for activities of daily living. In India; till a few years ago, MS was thought to be rare and a disease of the Western hemisphere. It is unclear why now we are seeing more and more MS patients in India. Is it because with advances in health care and diagnostics, we are diagnosing more cases which earlier remained undiagnosed or is the incidence of this disease actually increasing in the Indian population? his still needs to be determined and it would behoove us well to start a national MS registry and keep a track of MS cases and co-register with dietary and environmental variables. Many low and middle income countries such as India have a huge population with limited accessibility and affordability to health care facilities. About 70% of India's 1.3 billion population lives in rural areas with 30% living below the poverty line. In a country like India, a disease like MS can have a particularly devastating impact not just because of its chronicity and propensity to affect the young but also due to its high treatment cost burden.

A study published in April, 2015 found that the cost of first generation disease modifying medications for MS increased from between \$8000 to \$11000 annually in the 1990's to approximately between \$60000 to \$90000 per year currently. Newer disease modifying MS drugs cost even more. In the west, patients with MS commonly pay for their MS treatment in one of the following ways:

- I. Job (employer) based health insurance plan.
- II. Individual health insurance plan.
- III. Medicare.
- IV. Medicaid or state children's health insurance program.
- V. Other state and federal government funded programs for the uninsured and underinsured.

In India, where illiteracy, unemployment and poverty remain major social problems, state and federal supported health insurance schemes benefit only a small fraction of the population. As in India at present there is no National Health Insurance program, patients have to pay out of pocket for health care. The purpose of writing this commentary is to draw attention to the cost burden associated with a chronic disease like MS and start a discussion on treatment solutions that may benefit our MS population without causing unbearable financial burden. We calculated the average health care cost to a patient who is first time admitted for any demyelinating disease, in a corporate health care institution. A patient with spastic paraparesis was admitted to Sir Ganga Ram Hospital (SGRH) with provisional diagnosis of acute myelitis later confirmed as MS. We found that the entire hospitalization cost him around Rs.1.8 lac (\$2560).

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Citation: Sethi PK, Pandita N, Batra A and Sethi NK. Can we Afford not to Afford Treatment of Multiple Sclerosis in India?.

Concepts in Neurol and Red. 2020; 1(1): 1003.



#myMSstory: Puja

She did what she could for as long as she could and when she could no longer do that, she did the next best thing. This is who Puja Chadha Chaudhry is. She is a fighter; she is a survivor and she never gave up no matter how tough the journey was. Not only did she overcome the challenges in her life, but Puja also voluntarily chose to work for others and help them sail through tough times.

Born and brought up in an Army family, Puja had a wonderful upbringing and was a very pampered child at home. Loving parents and a sister seemed like the happiest family she could ask for. They had everything to make her life feel complete. Already a brilliant student and an over achiever throughout, she had a keen desire to learn and explore and enjoyed being the head girl of her school. She spent most of her childhood in small towns due to her father's profession. When she grew up, she pursued hotel management from Jaipur and moved to Delhi thereafter. Puja had grown up to be a very charming, confident, and friendly individual.

As eligible as she was, suitable marriage prospects started pouring in and she soon got married in the year 2003, into a family where both her husband and father-in-law were lawyers. Life was kind and she was eventually pregnant with her first child. As it was a complicated pregnancy, she was advised to be on a complete bed rest. She however had a keen desire to study and learn something new. Being a go getter, nothing could stop her from pursuing what she set her eyes on and went on to study Law. She gave birth to a beautiful child and named him Purab and continued to study and take care of her baby. She had just started to enjoy being a mother but when Purab turned 22 months, she experienced loss of sensation in the right side of the body and had her first encounter with Multiple Sclerosis in 2006.

Completely shocked as a natural reaction to first time MS patient, Puja went ahead with her treatment, but MS kept progressing. She was now having relapse after every 8 to 10 months. Doctors advised Disease Modifying Drugs, but she was adamant as she wanted to have another child. Her husband and other family members understood and trusted the doctor's decision against that, so they started with the DMD Glatimer acetate in 2008 for the next 6 years. She used to take one injection every day, but the relapses never stopped. Her stomach turned blue because of the pricking of injections but her father was always very encouraging and supportive of her and went to every single hospital with her. He shadowed her through the treatment, MRIs, tests, and everything that was needed, and she never felt alone in this journey.

In 2014 she switched her DMD. Though it was a more aggressive treatment, the silver lining on the cloud was its oral intake as opposed to daily injections and that pain that came with it. The relief soon brought with it anxiety and depression. To top it all, due to the possible drug side effects, she had to deal with many skin problems resulting in one full year of recovery.

Life kept moving and she kept becoming more determined but sometimes no matter how tough you become, life becomes even tougher.



Finance has always been a concern for all MS people as the treatment is quite expensive. She however felt blessed to have a father like hers who not only gave her moral and mental support but also took care of her medical expenses and planned better to secure her future. Unfortunately, on the other hand, her in-laws could not understand the invisible symptoms of MS. This sometimes made her sad, but she decided to move on with dignity despite periodic anxiety, depression, limping imbalance, bladder issues and voice slurring. A believer in hard work, she was not the one to give up easily. Much before MS entered her life, she worked in the hospitality sector with celebrated hotels like ITC Maurya. She eventually worked as a trainer for soft skills and hospitality with giants like HCL and Frankfinn too. She recalls how MS was too stubborn and that she lost her voice while delivering a lecture. That did shake up her confidence a bit, but she was determined. She took the long road ahead and did everything to help her come out of this uninvited guest. She continued to take lectures and speaking eventually became easier. Till date, talking for long makes her lose her voice. But she chooses it no other way.

The biggest setback was just around the corner and she almost lost a part of herself with her younger sister Payal's demise in the year 2013. Payal left behind a beautiful one year old daughter Chahat and Puja knew she was to mother her while also dealing with the loss and helping her parents through such pressing times. But she now had two children, Purab and Chahat and her life instantly started to revolve around both.

MSSI brought a ray of sunshine and helped Puja by encouraging her to work for other MS patients. With constant encouragement she started working for MSSI while trying to keep herself occupied and fill her empty days with something constructive. However, what happened in 2018 was something she had not imagined in her wildest dreams. Her pillar of strength shattered with the death of her father. She felt like a thirsty person in the desert with no one to run to or talk to. She decided to fill in that vacuum and stand up again for her children and mother. She held her head high and lighted her father's pyre along with her 13-year-old son. This was by far the toughest thing she had done, and she was broken from inside.

In 2018, she along with her mother decided to stop the DMDs, as her condition was getting worse and she eventually shifted to ayurvedic treatment. This started helping her with symptoms like pain, sleep, speech etc. Though she could not overcome the loss of her father, I always saw her paying gratitude to MSSI. One of her friends, Arun who is a Life Coach along with another patient supported her unconditionally, made her believe in her potential and encouraged her to fight back.



Going through a very rough patch in her married life, Puja was terribly missing her father and always longed to be understood. After her father's death, no one who could understand her state of mental and physical being except her mother and her son. Her husband and other family members could not understand her shortcomings because of her ailment, and she knew this was the story of every MSP. Living under the constant pressure of divorcing her husband for more than a decade, she again had a relapse in 2020. It was also the time when her son was appearing for his pre boards and she found herself alone at her in-laws with no one to take care of her. Seeing her through such difficult times, her son encouraged her to move base to her mother's house as he was too scared to lose her. He just wanted to see her happy and taken care of. She moved back to Delhi and is now living with Chahat and her mother. Purab stays with his father and comes often to stay with her too. This was a tough decision, but it seemed the best bet in everyone's interest.

Learning from her own experiences, she was determined to not let others suffer and started to help MSSSI by becoming an active volunteer for the organization. Her involvement with MSSSI gave her immense strength and working for this cause gave her wings beyond what she could imagine. MSSSI Delhi too showed a lot of confidence in her ability to work which really helped her to get her confidence back.

With joy comes good health and this happened with Puja too. Her condition improved after she shifted her focus from her personal problems to benefitting others. Her mother also came out of a phase of depression post her husband's demise and her condition also improved.

Her kids are her strength and she had found a bigger purpose in life. Her son, Purab is 16 and her daughter, Chahat who also happens to be her niece by birth, is 9. Her coach, Arun is family now and her mother cannot thank him enough for helping them at the crucial phase of their life. Puja often says that MSSSI has given her purpose to live and the confidence to fight back. She has immense gratitude for all the team members of MSSSI Delhi and she finds comfort in helping many others by making them realise their capabilities and true potential.

She believes her mentors Bipasha Mam and Meenakshi Mam who supported her unconditionally and trained her to handle MSSSI work and personal issues too have been her guiding light and were always just a phone call away whenever Puja needed them. She feels she has found her father in Prabal Sir as his beliefs and working style reminds her of her father. She says, "I can ask for hugs anytime and this MSSSI family of mine will stand by me."

Someone has rightly said 'Do what you can, with what you have, where you are'. This is what she swore by and has been leading by setting examples for all of us. She concludes by saying, If I can, you too can.

Thank you Puja for inspiring us

-Interview by Nidhi Gaur
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DO YOU HAVE CAREGIVER BURN OUT

A caregiver helps another person with their medical and personal needs. Unlike a paid healthcare worker, a caregiver has a significant personal relationship with the person in need. Usually the person being cared for is a family member or friend who's chronically ill, has a disabling condition, or is an older adult who can't care for themselves.

A caregiver helps with daily activities, such as:

- preparing meals • running errands • bathing • performing medical tasks and giving medications

Being a caregiver for someone you know and love can be very rewarding, but it can also be exhausting and frustrating. It's often emotionally, physically, and mentally draining. It tends to limit your social life and can cause financial problems. Caregiver burnout occurs when the stress and burden from these negative effects become overwhelming, negatively affecting your life and health.

What is caregiver burnout?

A caregiver with burnout has become overwhelmed and is physically, emotionally, and mentally exhausted from the stress and burden of caring for their loved one. They may feel alone, unsupported, or unappreciated.

They often haven't been taking good care of themselves and may be depressed. Eventually, they can lose interest in caring for themselves and the person they look after.

Almost every caregiver experiences burnout at some point. If it does happen and it's not addressed, the caregiver eventually becomes unable to provide good care. For this reason, caregiver burnout can be harmful to the person receiving care as well as to the caregiver. There are warning signs before burnout occurs. Being aware of them helps you know when to take steps to manage or prevent the stress you're experiencing.

General warning signs and symptoms for caregiver burnout include:

- feeling anxious • avoiding people • feeling depression • feeling exhausted • feeling you're losing control of your life • being irritable • having a lack of energy • Losing interest in the things you like to do • neglecting your needs and health

When it happens, caregiver burnout has both physical and emotional signs and symptoms. Physical signs and symptoms include:

- body aches and pains • fatigue • frequent headaches • increased or decreased appetite • unusual changes in weight • insomnia • weakened immune system

As burnout progresses and depression and anxiety increase, a caregiver may use alcohol or drugs, especially stimulants, to try to relieve the symptoms. While burnout occurs over time as a caregiver feels overwhelmed by the stress of caring for a loved one, compassion fatigue happens suddenly. It's the loss of the ability to empathize and have compassion for other people, including the person you're caring for.

It's caused by the extreme stress that comes with empathizing with the suffering and traumatic experiences of the people you care for. It's mainly been studied in healthcare workers, but it also happens to caregivers.

This can lead to mental deterioration, which increases the risk of harm to the person receiving care. It can become a very dangerous situation. A caregiver should stop providing care until they're no longer under the influence of drugs or alcohol.

Treatment and prevention

It's important to be aware of the warning signs of caregiver burnout so you can recognize when you have them. There are a number of things you can do to take care of yourself, stay healthy, and prevent burnout, including the following:

- **Ask others for help.** Remember that you don't have to do everything. It's OK to ask friends and family to do some of your caretaking tasks.
- **Get support.** Talking about what you're going through and getting support from family and friends or a support group helps you process your feelings and emotions. Holding everything in can make you depressed and contribute to feeling overwhelmed. Consider seeking professional counseling, if necessary.
- **Be honest with yourself.** Know what you can and can't do. Do the tasks that you can, and delegate the rest to others. Say no when you think a task will be too stressful or you don't have time to do it.
- **Talk to other caregivers.** This helps you get support and allows you to give support and encouragement to others going through something similar.
- **Take regular breaks.** Breaks help relieve some of your stress and restore your energy. Use the time to do the things that relax you and improve your mood. Even 10-minute breaks can help.
- **Attend social activities.** Meeting with friends, continuing your hobbies, and doing things you enjoy are important to maintain your happiness and avoid isolating yourself. The activity should be something that gets you away from the daily routine and setting of caregiving.
- **Pay attention to your feelings and needs.** It's easy to forget to take care of your needs when you're a caregiver, so be sure to take time for yourself.
- **Take care of your health.** Keep your regular doctor appointments, including for preventive care, take your medications, and see your doctor when you feel sick. If you aren't healthy, you can't take care of someone else.
- **Eat a healthy diet.** Eating nutritious meals keeps you healthy and improves energy and stamina.
- **Exercise.** Exercising is a great way to relieve stress, increase energy, and take time for yourself. It can also improve depression.
- **Maintain your sleep schedule.** Getting enough rest is important for your well-being and to maintain your stamina.

- **Take family leave.** If you work, make use of family leave benefits available to you. Removing the stress of work can reduce your responsibilities and free up more time for yourself.
- **Consider respite care.** When you need a break, using respite care for a few hours to a few weeks is an option in most places. When you need a few hours or a day for yourself, in-home services, such as a home health aide or an adult day center, can take care of your loved one. A residential care facility provides overnight care if you need a longer break. Do not feel guilty if you have to go away, the break will help you to come back relaxed and refreshed. Maintaining a healthy mind, body, and spirit is essential for the well-being of both you and your loved one.
- **Burnout vs. depression.** Burnout and depression are similar but separate conditions. They have many of the same symptoms, such as fatigue, anxiety, and sadness, but there are some differences too. These include:
 - **Cause.** Depression is a disorder of your mood or state of mind. Burnout is a reaction to exposure to severe stress in your environment.
 - **How you feel.** When you're depressed, you may feel like life has lost its happiness. With burnout, you feel like all of your energy has been used up.
 - **Effect of removing stress.** If getting away from caregiving and stress for a while doesn't improve your symptoms, depression is more likely. If your symptoms improve with time away, you most likely have burnout.
 - **Treatment.** Depression usually gets better with medication and sometimes psychotherapy. Burnout usually gets better by getting away from the stress of caretaking and focusing on your own health and needs.



Takeaway

Caregiver burnout happens when the stress and burden of caring for a loved one becomes overwhelming. This causes a decline in your mental and physical health. Remember that burnout is a common occurrence in caregivers - you didn't do anything to cause it.

The most important thing is to know the warning signs of caregiver burnout so you can recognize and even prevent them. Following the tips for preventing burnout and using the many resources available to caregivers will help you get to a healthier place.

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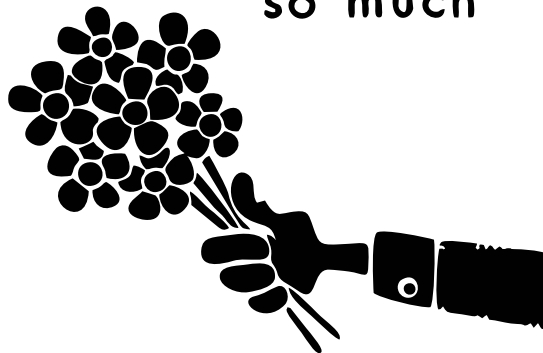
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Neuro Sciences Centre, AIIMS &
Indian Spinal Injuries Center.

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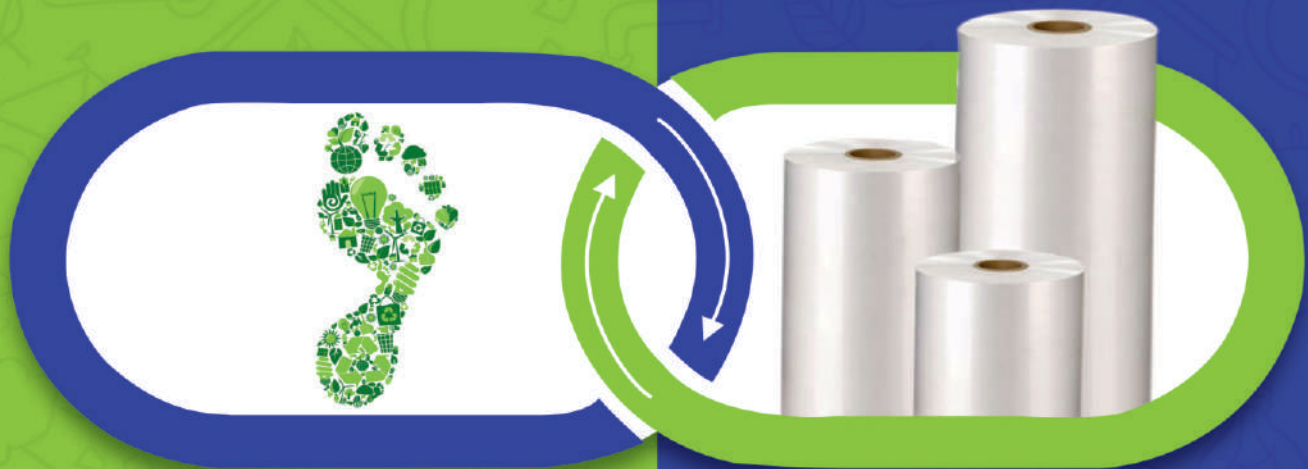
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