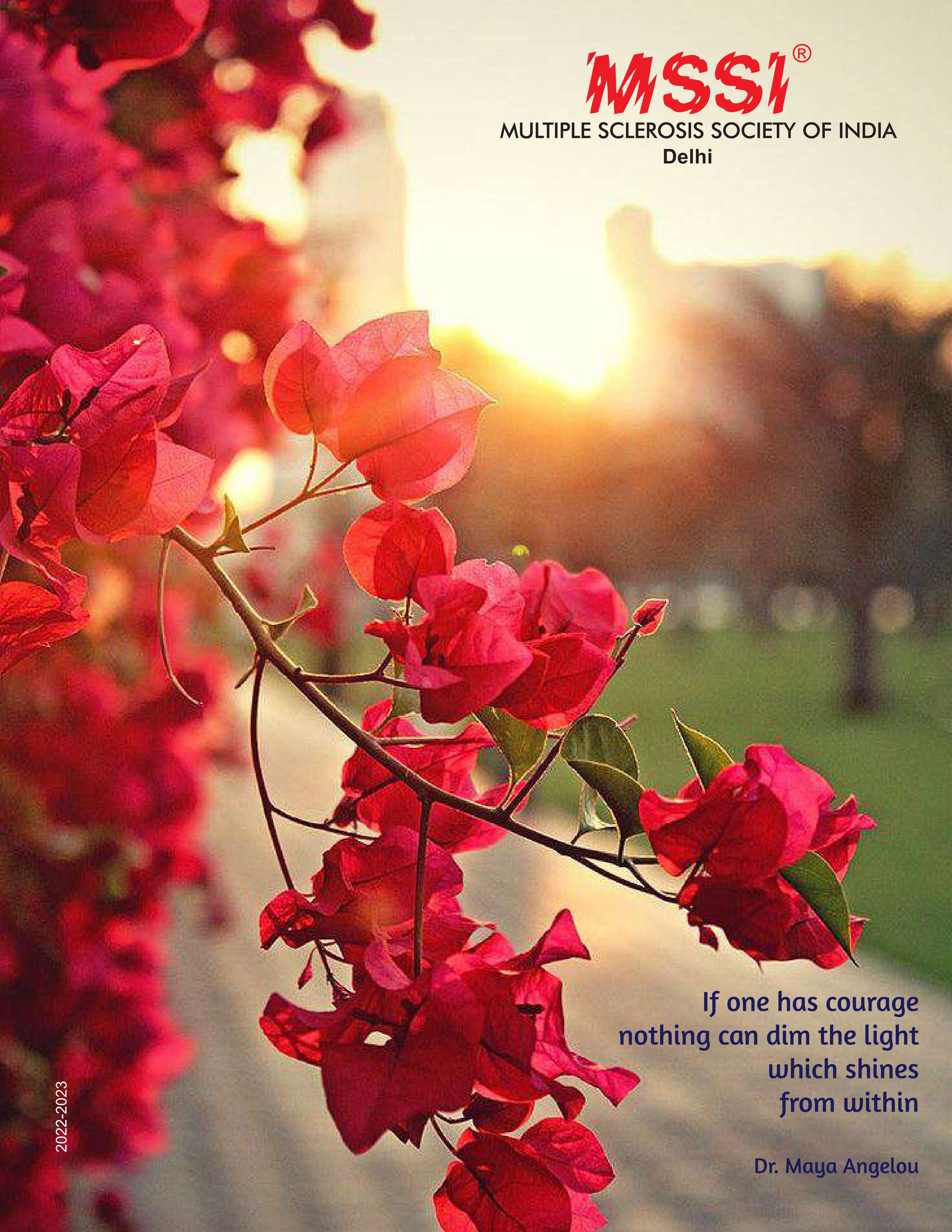
MSSI®

MULTIPLE SCLEROSIS SOCIETY OF INDIA

Delhi



If one has courage
nothing can dim the light
which shines
from within

Dr. Maya Angelou

2022-2023

LycoRed

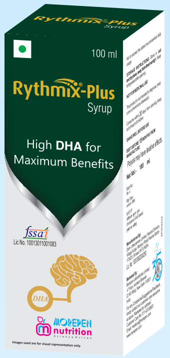
For Nutritional Supplementation

Rx

Rythmix®-Plus

DHA 100 mg + Fat soluble vitamins

Syrup



100% Veg. DHA (Algae) Supplementation

Fortified with fat-soluble vitamins

Additionally Vitamin D 400 IU

Available in delicious

Guava Flavour

Dose

5 ml once or twice daily
for children above 4 years of age

Nutrition intervention studies suggest that diet (Use of **Vitamins**, **Proteins** & **Omega 3**) may be considered as a complementary treatment to control the progression of the **multiple sclerosis (MS)**.[1]

For High Protein supplementation

HIGH PROTEIN
14 gm
PER SERVING

Blend of Pea, Whey & SMP

13 Vitamins & 11 Minerals

MOREPEN

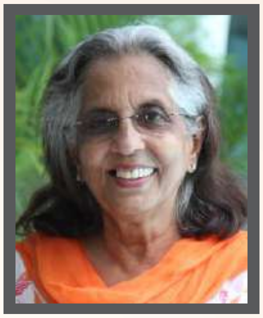

SHARK TANK INDIA
JUGAADISTAN
Welcome
SONY liv
LIONSGATE PLAY
eros now
ultra
hoichoi
hungama Play
manorama MAX
shemaroo
Dollywood
divo
SHORTSTV
FLIX
KLiKK
EPIC ON
HOUSEFULL
BAJIRAO MASTANI
JOHN 3 WICK PARABELLUM

MSSI®

MULTIPLE SCLEROSIS SOCIETY OF INDIA
Delhi

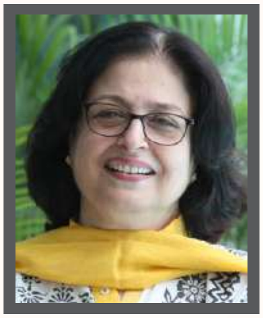
MEET YOUR MSSI DELHI MANAGING COMMITTEE

Bipasha Gupta
Hony. Chairperson

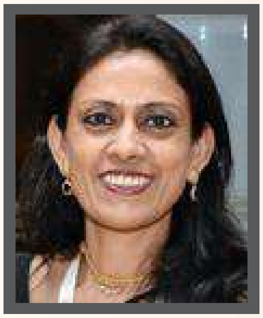


Mridula Murgai
Hony. V Chairperson

Prabal Malaker
Hony. Secretary

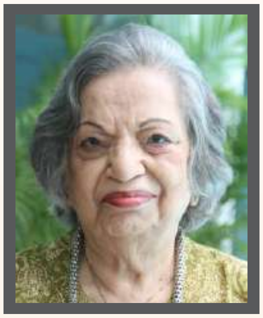


Meenakshi Bhujwala
Hony. Treasurer



Ragini Mathur
Hony. Joint Secretary

Praveen Khetarpal
Executive Member



Meera Pinky Hora
Executive Member

Nina Kochhar
Executive Member

Office: 87-A, Ground Floor, DDA Flats, Shahpur Jat, New Delhi-110049
Tel: 91-11-26490087, Mobile: 9871596452

Website: www.mssocietyindia.org

Affiliated to Multiple Sclerosis International Federation (MSIF)
www.msif.org

MSSI®

Delhi

MSSI Delhi proudly presents it's much awaited 18th Annual Souvenir & Handbook. It is our effort to research & share new & relevant topics with you every year.

Not only do we work hard to bring you interesting information, we also raise money every year through advertisements so that we can send this information far & wide, absolutely free. Money raised through this effort is used for various walking aids, wheelchairs and services to those MSps who need it most.

This year we had a large number of young MSPs registering with all the chapters and specially Delhi Chapter as it covers a huge area of 8 highly populated states of North India.

This year too Covid continued to play havoc in everyone's lives, but at MSSI Delhi we never stopped working. We continued to create awareness through social media, our staff & volunteers switched to the online mode for distribution of aids & supplements, Webinars, telephonic and video/Face Time counseling only increased manifold.

Our volunteers & Committee Members continued to work towards raising funds, reaching out to MSps & their families in innovative ways, keeping in touch with our doctors, at the same time diligently completing the mountain of reports & paperwork to send our donors & sponsors to maintain the highest level of transparency in our work.

All our EC members are all totally dedicated volunteers, giving so much time selflessly as most are either MSps themselves or have a close family member with MS.

We do still need to pay our office staff, pay the physiotherapists & attendant and meet the overhead expenses of the office, so we really appreciate it when some of our members come forward with contributions or donations or help us get advertisements from their contact circle, in spite of their own troubles.

We need more & more people to join this cause.. Our appeal to all of you is to come forward and help us to help you, strengthen our hands in our fight against MS which is disrupting the lives of so many young men & women – they are the future of the country and they need our support to manage their life with dignity. Help us grow & expand our work.

Last but not the least, my sincere and deep gratitude to our advertisers, donors, EC members and volunteers who work relentlessly and selflessly for the cause.

Bipasha Gupta
Hony. Chairperson
MSSI Delhi

Editorial Team:
Meenakshi Bhujwala, Mridula Murgai
Designed & Printed by: Anil Saini
Email: anilsaini67@gmail.com

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.

KYA MATLAB ?

While reading this Handbook some words may sound difficult & complicated-here's a quick guide!

Access, accessibility	ability to enter or visit some place
Aggravate/ flare	to increase (symptoms)
Ambulation/ ambulatory	walking / able to walk
Anti Oxidant	Substance that avoids spoiling or deterioration
Bladder	organ related to urine
Bowel	organ related to stool/lower part of intestine
Chronic	Long lasting, continuous
DMD	Disease modifying Drugs
DMT	Disease modifying Treament
EC/ MC	Executive Committee/ Managing Committee
Fatigue	Feeling very tired all the time
Generic	Non branded
Immobility	not able to move
Incontinence	lack of control (eg of bladder or bowel)
Inflammation	Swelling
Intervention (medical term)	to come in between, to avoid or delay
Laxative	medicine for easing stool motion (Julaab)
Mobility	ability to move freely
MS	Multiple Sclerosis
Msp	MS patient/ person
Musculoskeletal	related to muscles and bones
Neuropathy/ Neuropathic	Pain of the Nerves , numbness
PWD , PwD	Person with Disability , divyangjan
PwMS	Person with MS
Spasticity	Muscle spasm, uncoordinated movement
Stimulant	that which raises level (eg BP or sugar)
Urgency	desire to pass urine urgently

10 TIPS FOR PEOPLE NEWLY DIAGNOSED WITH MULTIPLE SCLEROSIS

Recently diagnosed with MS? These tips can help you prepare for what's ahead.

Educating yourself about MS can ease your fears and help you better manage the disease. A multiple sclerosis diagnosis can be frightening and overwhelming, but while you may feel very much alone, you are by no means the only one dealing with this condition.

Multiple sclerosis is the most common disabling neurological disease in young adults, usually striking between ages 20 and 40, according to the National Institute of Neurological Disorders and Stroke. Nearly one million people in the United States are living with MS, per the National Multiple Sclerosis Society (NMSS), as are more than 2.3 million/ 23 Lakh people worldwide. The good news: Most MS symptoms can usually be managed successfully, says Anthony Reder MD, a multiple sclerosis specialist and professor of neurology at the University of Chicago.

"Symptom management gets better every year with new drugs, techniques, and lifestyle information," he explains.
If you've been newly diagnosed with MS, these tips can help you manage the disease.

1. Learn as Much as Possible About MS

There are many myths and misconceptions about multiple sclerosis, and without the facts, your MS diagnosis can be scarier than necessary.
MS is a chronic inflammatory disease affecting the central nervous system. It occurs when the immune system causes inflammation that damages myelin-the protective insulation covering nerve fibers in the brain and spinal cord-as well as the nerve fibers themselves and the cells that make myelin. This damage to the myelin or nerve fibers is what causes MS symptoms to occur.
But MS is very rarely fatal (life threatening) it is possible to live a fulfilling life with the disease.

2. Be Sure Your MS Diagnosis Is Definitive

Various strategies are used to make a diagnosis of MS, including a neurological exam, MRI, spinal fluid analysis (spinal tap), and blood tests to rule out other conditions.
In some cases, getting a definitive MS diagnosis can take quite some time, partly because other causes of neurological symptoms must also be ruled out.
According to the latest criteria, your physician must do all the following to make an MS diagnosis:

- Find evidence of damage in two separate areas of the central nervous system
- Find evidence that the incidents of damage occurred at different points in time
- Rule out all other possible look alike diseases and diagnoses

3. Understand That MS Symptoms Can Be Unpredictable

No two people have exactly the same MS symptoms, and you may have different symptoms from time to time. Common MS symptoms include numbness or tingling, spasticity, vision problems, walking difficulties, weakness, slurred speech, fatigue, bladder dysfunction, cognitive changes, and more. But these symptoms can be unpredictable.

“Over the course of the disease, some MS symptoms will come and go, while others may be long-lasting," Dr. Reder says.

4. Don't Delay MS Treatment

Because permanent neurological damage can happen even in the earliest stages of MS, it's important to start treatment as early as possible

"All disease-modifying therapies for MS (DMTs) may reduce chances of the disease becoming progressive," says Dr Reder.

There are quite a few FDA-approved disease-modifying therapies for MS that have been found to reduce the number of relapses, slow the progression of disability, and limit new disease activity. These medications for MS include injectable medications, oral medications, and infused medications.

Other medications are also used to treat MS symptoms including bladder and bowel symptoms, depression, dizziness and vertigo, emotional changes, fatigue, itching, pain, sexual changes, spasticity, tremors, and walking (gait) difficulties.

5. Track Your MS Symptoms

Keeping a record of your MS symptoms and how you are feeling can help you update your doctor on your progress. Tracking your symptoms can also help you prepare a claim for disability benefits, if necessary. It can also help you stay on top of your symptoms if you're experiencing memory problems or having trouble making connections, says Reder.

6. Avoid MS Symptom Triggers

Certain triggers, like stress, lack of sleep, infections, viruses, and hot baths or anything else that can lead to overheating, can cause a temporary worsening of MS symptoms, says Reder.Drinking alcohol in excess is discouraged for people with MS because intoxication causes poor coordination and slurred speech, which can add to existing MS symptoms, he says.

7. Find the Right Doctor for You

MS is a lifelong disease, so it's important to be under the care of an MS specialist who is a good match for you. The neurologist who provided your initial MS diagnosis may not be the specialist you want to stick with for life.

MSSI can help you locate neurologists in your area with expertise in treating MS. Support groups for people with MS are also helpful for getting doctor referrals suited to your circumstances.

8. Consider Complementary and Alternative Medicine (CAM)

In addition to taking medication to control your MS symptoms, you may want to consider complementary and alternative treatments.

Research is beginning to support the role of some CAM treatments in comprehensive MS care, including vitamin D, Yoga & exercise, acupuncture, and cooling strategies. Most people who have MS use some form of CAM as part of their MS management plan Acupuncture may provide relief for some MS-related symptoms, including pain, spasticity, numbness and tingling, bladder problems, and depression, and a few small studies suggest that it may help with fatigue, pain, mood, and quality of life, However here is no " one size fits all" remedy in any area of treatment. What works for you may not always work for someone else. Many people with MS also use massage to prevent or relieve spasticity, pain, poor circulation, and pressure sores.

9. Think About Whom You'll Tell

You may be concerned that telling your employer that you have MS could affect your job security, employment options, and career path.

Before disclosing the disease at your workplace, learn about your rights under the Disabilities Act 2016. Please reach out to MSSI for details.

You'll likely want to tell your closest family members and friends, particularly those who know you well enough to notice any changes. While there is no shame in sharing, you are not obligated to share news of your MS diagnosis with everyone in your life. Instead, pick the people who will be most supportive and helpful as you learn to live with the disease.

10. Don't Give Up Hope

Depression is one of the most common symptoms of MS. If you're struggling with depression or other mood changes, ask your doctor for a referral to a mental health professional who understands the challenges you are facing with MS and can help.

Although currently there is no cure for MS, newer treatments can slow the progression of the disease, improving your quality of life and helping to prevent disability. And research is ongoing, with the goal of developing even better treatments in the near future that will stop progression and even restore functions and abilities that have been lost.

Your doctor can help you understand more about MS and stay up to date on new treatments and lifestyle tips, including the importance of a healthy diet, establishing and maintaining a healthy weight, exercise, and quitting smoking if you have MS.

MSSI Delhi-Finding Innovative Programmes To Help You..

YOUR MENTAL HEALTH AND MULTIPLE SCLEROSIS

A diagnosis of multiple sclerosis or a new symptom or complication of the disease is upsetting and can provoke feelings of anxiety. It can also lead to grief, which may include feelings of shock, anger, guilt, and sadness. With MS, the experience of grieving can happen over and over as the disease progresses and causes new losses.

But grief is not the same thing as depression, which is a prolonged feeling of being down, depressed, or hopeless, often accompanied by a loss of interest in doing things that were once pleasurable.

Depression is one of the most common symptoms of MS. At least half of all people with multiple sclerosis will experience major depression at some point in their lives, according to Rosalind Kalb, PhD, a psychologist and a consultant to the National Multiple Sclerosis Society in New York City. It's not just a result of the challenges and worries that come with MS; there's also evidence that the inflammatory changes in the immune system are associated with depression, says Dr. Kalb.

Managing Depression and Multiple Sclerosis

Taking steps to manage your fatigue, stay connected with friends and family, get enough rest and regular exercise, and follow a healthy diet can improve your mood. But even the best self-care may not be enough to treat depression.

If you feel depressed or weighed down emotionally, ask your primary care doctor for a referral to a psychotherapist, preferably one who is familiar with MS. You can also find sources of social and emotional support by going online to email or live chat with a MSSI resource.

Managing Anxiety and Multiple Sclerosis

Working with a professional therapist can also be helpful in managing the anxiety that often comes along with MS. And there are strategies you can employ on your own to relieve anxiety, such as practicing mindfulness, exercising regularly, and strengthening your social support network.

How Multiple Sclerosis Can Affect Your Relationships

When you have multiple sclerosis, it changes the way you relate to your family, friends, and spouse or romantic partner -or potential partners, if you're single. Your role in relationships or the way you view yourself may change because of MS symptoms like fatigue or depression. If you have to stop working or begin working from home, that can impact the dynamic in your family, too. Navigating this new territory takes time and patience-both with yourself and your loved ones.

Your Family Relationships

A good rule of thumb with MS and family relationships is: Don't assume anything. Talk to your family about how much help you want and what you'd like to do for yourself. If there are ways you want to maintain your independence, let your loved ones know.

Make sure you are taking care of yourself, and encourage your family members to do the same. Remember to insert lightness and fun in your life whenever possible; <u>focus on what you can still do together as a family rather than what you've lost.</u>

Sometimes you may feel guilty or worry that MS has taken over your family life. Finding ways to carve out "MS free" zones or time can help give everyone a break. Look for ways to take the MS out of family life; reserve time, money, and even actual physical space in your home where you all can focus on the present moment. Putting MS and MS-related concerns on the back burner, even for a short period, can be good for you and your family.

Your Friendships and Multiple Sclerosis

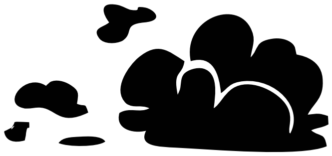
Many people with MS (and without) don't have great relationships with their "next of kin," or perhaps their family members live far away. Friends, or our "chosen family," can provide invaluable support when you have MS. But even a well-meaning friend can say or do the wrong thing at times.

To keep your friendships strong, let your friends know what you need from them. Maybe you need someone to just hang out with you and chat or do something you both enjoy. Or maybe you need a specific type of help, such as being picked up for an outing if you can't drive. The clearer you can be about your needs, the easier it is for your friends to provide for them.

Your Romantic Relationships and Multiple Sclerosis

A diagnosis of MS can create shock waves in even the most stable relationships. Many unknowns are immediately introduced, with no easy answers. How fast will the disease progress? What will the impact be on our children? Should we have children? How will we afford the medical costs? It's common for either partner to feel stress and maybe even depression. Communicating with each other and getting professional support through a therapist or by connecting with an organization like MSSI and is many member groups can be invaluable.

Not all storms come to
disrupt your life
Some come to clear your path



MY SPOUSE WAS DIAGNOSED WITH MS. NOW WHAT?

It's not a question of if but how MS will change your relationship with your partner. Personality traits can become exaggerated, or dynamics can be reversed in ways both large and small. A diagnosis of MS might mean a shift in who the "breadwinner" is or who picks up the kids and does the grocery shopping. Even small changes can create misunderstandings and even resentment if couples don't communicate.

There's no doubt that having MS is hard, but being the partner of someone with MS is challenging, too. Although partners don't have the symptoms and physical issues that come with MS, they do have to routinely adjust their expectations and behavior. It can add to their work day, impact their time management, and as a result the partner (or caregiver) could end up going through the symptoms with you !

So you need to be patient too-cooperate with them, and stop throwing the victim card at them all the time. You're both in it together. So if you feel you need help & support, it's worth seeking out together.

Money Matters: The Cost of Living With Multiple Sclerosis

It's estimated that the cost of living with MS could impact your budget 20-50 % This figure can include medication, doctor visits, rehabilitation, mobility aids, and home and auto modifications or a paid helper/ caregiver. The ability to work-or loss of that ability- is also a factor in the financial burden that MS can cause; depending on your symptoms and disease progression, keeping a full-time job can be difficult.

The family, partner or caregiver may have to step up with financial support, so sit down as a family unit & discuss these issues openly.

You can approach MSSI to help you work out some solutions, or provide the right perspective to families coping with the issue.

Managing Your Work Life With MS

Over a period of time, it could become difficult to continue to work when you have MS, but there are many potential benefits to remaining employed if it's possible, For many people, work can provide self-esteem and identity-even their main social support.

If, when, and how you disclose that you have MS to your employer is up to you. Although you're not legally required to share your diagnosis, if you begin to have noticeable symptoms, your employer or coworkers might become concerned. If you decide to share your diagnosis, you may also want to request certain " accommodations" or adjustments so that you can continue to contribute at work. Many people with MS find that they can stay employed by asking for a few accommodations at work, which is protected under the PwD Act 2016. Examples of these sorts of accommodations would be a flexible schedule, the ability to work from home sometimes, changes to your workstation, accessible office, being seated close to the toilet or even modifying your assignments.

Even with accommodations if you find that holding a traditional full-time job isn't possible anymore . there are other ways to make ends meet, including starting your own business or applying for disability benefits. To learn more about this, contact your local MSSI Office for details.

#MyMSstory: Shruti Kaushik

The new year started with yet another challenge. Isn't a new year meant to be a fresh start with a promising future? But this seemed to be a new beginning of new trials. This was becoming a pattern so I thought, "why not do something different."

I decided to stop cribbing, feeling sorry for my state
(I am overweight, sour, grumpy, crying over the past, etc) when one day I realized it wasn't giving any joy or comfort to moan and groan.

I needed to take stock of my life.
As I do know, intrinsically, I am a lively, peppy, resilient person. So the real me thought of attempting to get back to my original self.
Just as I took these small steps (they take a lot of energy, effort and manoeuvering to get to the correct path with a proper intent) I began feeling I am on my journey, akin to climbing the mighty Everest.

I need to mention here that I am attempting to NOT agonize over how I, effortlessly climbed up and ran down the steep hills of my beloved home town, Simla in my hey days but to make the most of whatever I have in terms of mobility, inner strength. The die hard spirit resurfaced when I began walking DAILY on our colony ground. The winter sunshine added to the warmth in my heart. The sunny vast empty ground welcomed me as I took small steps into my new found freedom.
Freedom to start believing in myself, my ability to walk unhindered (atleast for fifteen minutes) the freedom to connect to nature, to admire the daily punctual routine of the local dogs. In the last few weeks I've noticed how they keep their timings to meet each other, play, protecting their territories. It's a lesson in discipline alright.

They find love and joy amongst themselves. In these animals I found a message and also a reason to maintain a schedule. I may change my walking time, but they stick to theirs. Surviving all vagaries and hurdles which strays encounter continuously.

I look forward to the meetings. A little tail wagging, a paw extended in friendship all this without expecting any reward except love and kindness. I notice this daily.

Selfless love coupled with a certain discipline is the mantra.

I started believing in myself. I did drive my car. Though a short distance yet it gave me immense confidence and joy.
One more regret was overcome.
The complaint of how I drove all around, to my school, kids classes etc and how I couldn't drive now finished too. Not because I drove but I the understanding and acceptance that I may not be able to do so regularly and to not to justify or fight with this reality . If you note the difference,
I am NOW accepting that I need to let go of things not under my control.
Recently I watched a video on how some MS warriors overcame their individual hurdles. Their stories which showcased their victory and joy resonated with my emotions and feelings. The joy of achievement and being winners could be felt by each one.
The win was in admitting, accepting and then managing and doing something about the disability and its consequences. The joyous feeling of achieving a milestone was the topping on the cake.

How many would appreciate and laud each MSp's efforts for accepting their challenges with a smile.

If one really wants to, one can take lessons from their experiences. Disability or the setbacks in our lives can be the biggest motivators. I have decided to move ahead, with a positive mindset as that's a doable target as compared to dealing with the long list of challenges thrown our way constantly.

The joy of reaching the target of hundred steps in 15 minutes as compared to clocking the fastest in the 400m race in my better racing years is what I am learning to make the benchmark for me.

Why not?

I WAS grappling with medical, emotional, social, financial, personal issues. Most caused by the disease, covid and life.

Focusing on achieving the targets of my daily routine is what I am doing now. So many around to learn from

Animals and humans both.

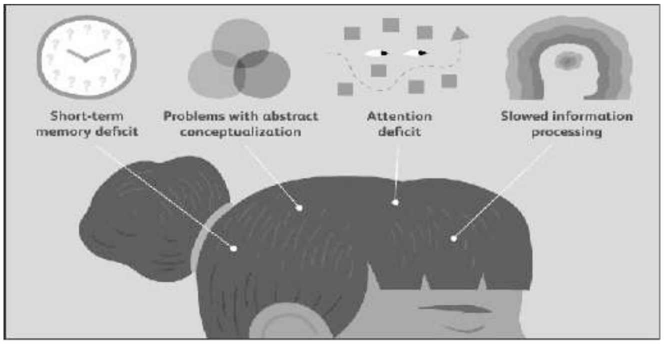
The journey begins.

Every day may not be good ...but there is something good in every day

COGNITION & MS

When we think of progressive MS, we tend to imagine ourselves unable to walk or move. But that may no always be the case. MS can also affect our brain capacity or cognitive skills & ability. Cognitive ability is defined as **a general mental capability involving reasoning, problem solving, planning, abstract thinking, complex idea comprehension, and learning from experience.**

Cognitive abilities are brain-based skills we need to carry out any task from the simplest to the most complex. They have more to do with the mechanisms of how we learn, remember, problem-solve, and pay attention, rather than with any actual knowledge. For instance, answering the telephone involves perception (hearing the ring tone), decision taking (answering or not), motor skill (lifting the receiver), language skills (talking and understanding language), social skills (interpreting tone of voice and interacting properly with another human being).

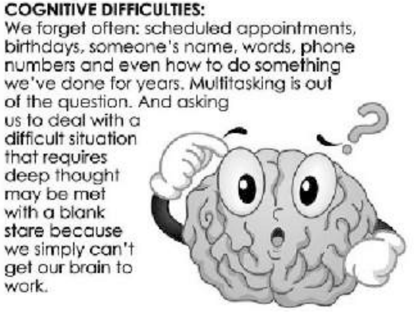


The 8 Core Cognitive Capacities

- Sustained Attention.
- Response Inhibition.
- Speed of Information Processing.
- Cognitive Flexibility.
- Multiple Simultaneous Attention.
- Working Memory.
- Category Formation.
- Pattern Recognition.
- Advanced cases of MS experience memory loss or sometimes face difficulty performing with everyday tasks. Eg They can find it difficult to follow a movie or TV series if it has a complicated story line or too many characters . Some face concentration problems as they get tired easily, subsequently losing interest even in activities they enjoyed most like watching TV or listening to music.
- You can definitely avoid this happening or stall the process. It will require the help & cooperation of caregivers or even professionals.

Small changes may really add up: Making these a part of your routine could help you function better.

- Take Care of Your Physical Health.
- Manage High Blood Pressure.
- Eat Healthy Foods.
- Be Physically Active.
- Keep Your Mind Active.
- Stay Connected with Social Activities.
- Manage Stress.
- Reduce Risks to Cognitive Health.



COGNITIVE DIFFICULTIES:
We forget often: scheduled appointments, birthdays, someone's name, words, phone numbers and even how to do something we've done for years. Multitasking is out of the question. And asking us to deal with a difficult situation that requires deep thought may be met with a blank stare because we simply can't get our brain to work.

- Reading is an entertaining activity that doubles as an exercise for your brain. Start with light reading or short stories. Read the newspaper if current affairs interest you. **Reading increases your knowledge and makes you think**. Watching television shows on the other hand is a passive activity and does not stimulate the brain cells in the same way. Reading, in general, **can boost cognitive functioning**, improve memory, and is even linked to a longer life.

You will also find **'brain teasers'** online that will help you exercise the cognitive abilities .. Search them under 'tips to improve concentration...'

- **Practice meditation**. Multiple studies have shown that meditation can be a good brain training tool to improve attention/ concentration skills.
- **Be proactive, not passive**: If talking with someone: ask questions. If reading a book, ask yourself how you would summarize what you just read.
- **Do not multitask**, since this will divide your attention. Attention is limited, so when you try to do several things at once you concentrate less on each individual task and, worse, you waste some of your limited attention and processing power in switching from one thing to the next and then back (there is a clear "transaction cost" when multi-tasking)
- **Make Lists** :Use a notepad, make daily 'to-do' lists.

Tips to Improve Memory

Start by improving concentration

- **Personally relate to the information** you are processing. Ask yourself where else you have heard this, whether there is something in your life related to this new piece of information, how it makes you feel.
- **Repeat the information**: Come back to it more than one time. This has been found in many studies: repeated information is easier to recall -remember that "cells that fire together, wire (connect) together".
- Spaced retrieval (a method with which a person is trained to recall a piece of information at different intervals) is one of the rare methods that show results even with Alzheimer's patients.
- **Elaborate on the information**: think about it, build on it. Things that are concrete and have a clear meaning are easier to remember than abstract and vague ones. For instance, try to picture the information in your head, since pictures are easier to memorize than words.

Putting it all together: Tips to better remember names Yes, we all forget names, and often in the few seconds after we hear them. Most of the time this phenomenon is due to a lack of attention or concentration. Also, most names have no specific meaning and are thus hard to memorize.

Say you are introduced to someone called Kiran today:

- **Pay attention to the name**: Ask Kiran to repeat her name if you have not heard it very well. Make a conscious effort of trying to memorize the name: Focus on it ("Her name is Kiran. I want to remember it.")
- **Repeat it**: Use the name several times in the conversation. ("What do you think of this, Kiran?") If relevant, use the person's business card later on to read her name and reflect, just a few seconds, on the conversation. And picture her face later on in the day as you repeat her name.
- **Relate and elaborate on the name**: Do you know someone else named like this? ("She seems quite happy, like the other Kiran I know from college.") Or relate the name to previous information ("Kiran, as in Kkkk- Kiran from Sharukh Khan's movie ! Well, she surely doesn't look like Kkk Kiran!").

Hope this helps!

FACTS Vs MYTHS

The rapidly developing science behind multiple sclerosis (MS) changes so fast that people with the condition, their families, and even their doctors can be forgiven for not knowing all of the latest news about it. But holding on to outdated myths and misconceptions about the disease may mean limiting your activities unnecessarily or missing out on the best treatments. With more accurate, up-to-date knowledge of MS, people who live with it can have a higher quality of life. Here are some of the most common MS myths-and the truth about each one.

Myth 1: People With Multiple Sclerosis Can't or Shouldn't Be Physically Active
Fact: At one time, experts believed that physical activity would worsen multiple sclerosis, so they advised against an active lifestyle. Doctors now know that staying active is one of the best ways to stay healthy with MS and delay disability. Dr. Conway a neurologist at the Cleveland Clinic in Ohio, encourages his MS patients to exercise regularly. "In my experience, it can make fatigue worse at first, but if a person can get over the initial hump, it can actually improve fatigue”

Studies have found that exercising regularly significantly reduced fatigue in people with MS. The authors concluded that a regular exercise routine is "strongly recommended" as part of an overall MS management program.

To get the most benefits from exercise, choose activities that suit your interests and your physical abilities, and make sure you're active on most days of the week. If you're not sure how to get started with exercise, or you need some help identifying exercises that will improve your fitness without wearing you out, try working with a physical therapist or a personal trainer who is knowledgeable about MS.

Myth 2: Multiple Sclerosis Doesn't Cause Pain
Fact: Many people living with multiple sclerosis can tell you the truth about this MS myth: They do feel pain. Though some healthcare providers may not consider pain a symptom of MS , Multiple sclerosis clearly does cause pain. A study published in July 2017 in Scandinavian Journal of Pain confirmed that people with multiple sclerosis not only experience long-term chronic pain but also report increased pain over time.

There are three main causes of pain in MS - These include neuropathic pain, pain related to spasticity, and musculoskeletal pain due to immobility and fatigue.

Because chronic pain in MS can present differently from one person to the next, it can be especially hard to treat, but it's important that it's addressed, says Dr. Anna PhD, associate professor of physical medicine and rehabilitation "People with MS need help with their pain," she says. Unfortunately, there isn't a silver bullet that works for all chronic pain problems. "You may need to try a few different things, often in combination, to find out what works for you".

Myth 3: I Can't Do Anything to Help My MS
Fact: There are many steps people with MS can take to improve their quality of life and possibly slow the progression of the disease. Not smoking, being at a healthy weight, exercising regularly, and making sure you aren't deficient in vitamin D have all been shown to help people with MS manage their condition.

Because illnesses such as diabetes and hypertension may worsen MS, keeping focused on wellness is truly important. Doctors always emphasize the importance of a healthy lifestyle; it can be empowering for people to realize that they have some control over their disease.
Taking your medications as prescribed can make a difference. While these medications don't cure MS, they can reduce the number of relapses a person has and help slow the progression of the disease later on. If you're feeling powerless over your multiple sclerosis, talk to your medical team about others you can take.

Myth 4: I Can't Work With MS
Fact: MS is usually diagnosed between the ages of 20 and 45, a time in life when most people are working on building a career. Although MS progresses differently in everyone, symptoms such as fatigue and trouble concentrating can eventually make a keeping a traditional job difficult: It's estimated that 70 percent of people with multiple sclerosis leave their job within 10 years of their diagnosis.

Even though it is sometimes necessary to leave your job, continuing to work can have many benefits besides the regular salary !

We know that MS affects women more than men, and when we study women-not just women with MS-who are in the workforce, they value their work less because of prestige and the financial gain. For them, it's more about their self-esteem and identity-even their main social support.
If you are currently working or looking for a job, do some research about what would enable you to continue working before you quit your job or give up your job search. For example, if fatigue is an issue, ask your employer about accommodations such as flexible working hours or the possibility of working from home. The Persons with Disabilities Act 2016 protects your right to stay employed and requires your employer to work with you on reasonable accommodations.

Myth 5: Multiple Sclerosis Is Not Associated With Cognitive Impairment
Fact: Multiple sclerosis is typically thought of as a condition that affects mobility, but the fact is that it can also affect your cognitive functioning, such as thinking and memory.

How much MS impacts your cognitive abilities can vary from person to person, Some people with MS have no deficits or difficulties, , whereas others have brain fog symptoms, such as difficulty with short-term memory, multitasking, or concentration.
This could be due to inflammatory activity in the brain, but there could be other causes as well. We can now screen for other things that could be contributing, including vitamin deficiencies or the medications the person is using. For example, sometimes medications for neuropathic pain can affect cognitive abilities.

Myth 6: Multiple Sclerosis Treatment Should Start With Less Powerful Drugs
Fact: "The highest risk of developing irreversible problems is right after you are diagnosed," says Dr Corboy. In spite of that, some people with MS-and their doctors-prefer to begin treatment with drugs that are less powerful and have fewer side effects. He attributes this to a cultural preference for waiting and seeing how things progress, an approach that could be harmful for those with multiple sclerosis. A study found that, in people with relapsing-remitting MS, initial treatment with the highly effective disease-modifying therapies fingolimod, alemtuzumab, or natalizumab was associated with a lower risk of conversion to secondary-progressive MS, compared with people who started on the lower-efficacy drugs glatimer acetate or interferon beta.

If you have doubts about whether you're on the most powerful medication suitable for your situation, ask your doctor.

There is a wealth of options, and Doctors are almost always able to find a medication that works with a patient's lifestyle and with a side effect profile that's manageable.

Myth 7: Women With MS Shouldn't Get Pregnant

Fact: Experts emphasize that women with multiple sclerosis can get pregnant and might even find some relief from MS symptoms during pregnancy, according to a paper However, it's not uncommon for a woman to have a relapse in the months following delivery, so being prepared & lining up sources of help and support ahead of time is recommended.

It must be noted that women who have MS are not at any increased risk of preterm delivery, stillbirth, birth defects, cesarean delivery, or miscarriage. It is safe to get pregnant or have children.

Although the majority of MS medications have not been well-studied during pregnancy and are therefore not recommended, there are other treatment options for women who need to continue their therapy during pregnancy. If you have MS and want to have a baby, talk with your doctor about all of the medications you're taking, including those for MS, to find out the best options for you.

Myth 8: Multiple Sclerosis Is Contagious

Fact: This myth may continue to circulate in part because a relationship with the Epstein-Barr virus (EBV) does exist, but there's never been any evidence that MS is contagious (infection through touch) or in any way transmissible," says Dr Corboy.

MS is neither infectious, nor will it travel by touch.

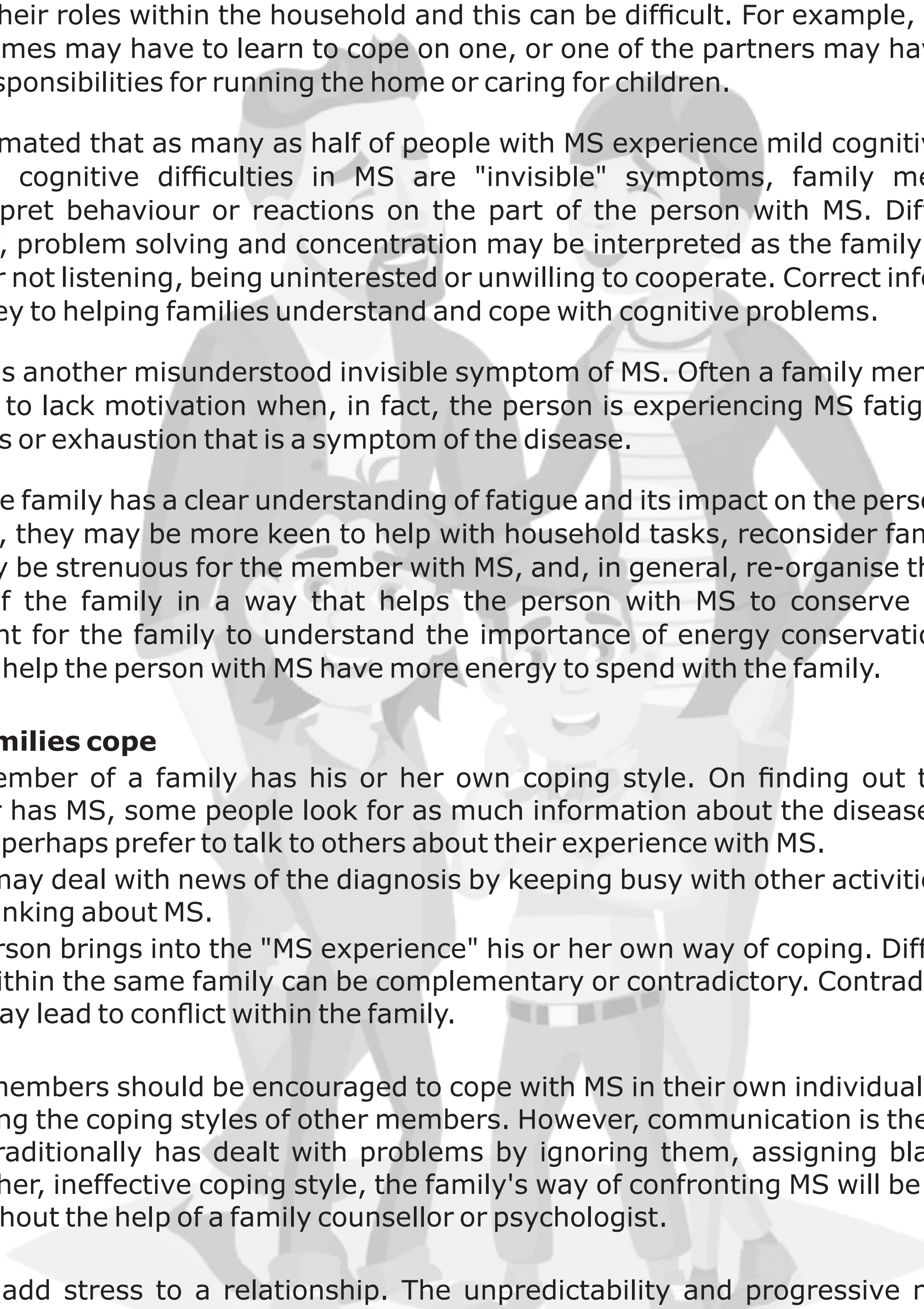
Myth 9: I'm Going to Be Physically Disabled

Fact: Some people with MS do experience severe disability, but it's difficult to predict the rate of progression of the disease or the eventual degree of disability for any one person. A previous study found that 15 percent of people with MS reported a need for ambulatory aids like a walker or wheelchair in the year following diagnosis; but after 45 years of living with MS, 76 percent required ambulatory assistance. That is most people were able to manage with just some help and did not require a wheelchair.

Advancements in MS medications, combined with a healthy lifestyle and the use of tools like physical therapy, will continue to improve the prognosis for many people. When MS does affect your physical functioning, there are a wide variety of mobility aids and other devices, as well as physical therapy know-how, available to assist you in living your life as you want to.

THE IMPACT OF MS SYMPTOMS ON FAMILY LIFE

MS can affect many aspects of daily family life, particularly if a person has symptoms such as fatigue, eyesight problems and cognitive changes. Couples may find that they have to review their roles within the household and this can be difficult. For example, a family with two incomes may have to learn to cope on one, or one of the partners may have to take on extra responsibilities for running the home or caring for children.



It is estimated that as many as half of people with MS experience mild cognitive problems. Because cognitive difficulties in MS are "invisible" symptoms, family members may misinterpret behaviour or reactions on the part of the person with MS. Difficulties with memory, problem solving and concentration may be interpreted as the family member not caring or not listening, being uninterested or unwilling to cooperate. Correct information can be the key to helping families understand and cope with cognitive problems.

Fatigue is another misunderstood invisible symptom of MS. Often a family member with MS appears to lack motivation when, in fact, the person is experiencing MS fatigue, a type of tiredness or exhaustion that is a symptom of the disease.

When the family has a clear understanding of fatigue and its impact on the person's ability to function, they may be more keen to help with household tasks, reconsider family activities that may be strenuous for the member with MS, and, in general, re-organise the house and habits of the family in a way that helps the person with MS to conserve energy. It is important for the family to understand the importance of energy conservation strategies that can help the person with MS have more energy to spend with the family.

How families cope

Each member of a family has his or her own coping style. On finding out that a family member has MS, some people look for as much information about the disease as they can find and perhaps prefer to talk to others about their experience with MS.

Others may deal with news of the diagnosis by keeping busy with other activities in order to avoid thinking about MS.

Each person brings into the "MS experience" his or her own way of coping. Different coping styles within the same family can be complementary or contradictory. Contradictory coping styles may lead to conflict within the family.

Family members should be encouraged to cope with MS in their own individual styles, while respecting the coping styles of other members. However, communication is the key, and if a family traditionally has dealt with problems by ignoring them, assigning blame or using some other, ineffective coping style, the family's way of confronting MS will be the same, at least without the help of a family counsellor or psychologist.

MS can add stress to a relationship. The unpredictability and progressive nature of the disease, the changes and sacrifices that might be required and the impact of some symptoms are all obstacles that make it difficult for both the person with MS and their partner to cope. It may be useful for a couple to seek help from a counsellor.

MS affects every member of the family. Learning about the disease and its possible effect on the family can help people face challenges as they arise. Families that are informed about the different resources available can choose those that best suit their needs and lifestyle.

Unpaid caregivers play a vital role in the lives of people with MS, but being a caregiver comes with its own set of challenges.

Even the term 'caregiver' is difficult. For many people it feels like an awkward and inaccurate way to describe the relationship with a partner, friend or family member who also happens to have MS.

Caregiving' could range from getting the groceries to helping someone with their basic needs. Often caregivers fit these tasks around other responsibilities like a job, house work, school, or childcare.

Going from being a partner, family member, friend or child to also being a caregiver can impact your relationship. Talking to other caregivers and getting support from MS or caregivers organisations can help with this.

Caregivers need to be recognised and supported. Family support is critical ,friends should also help out by providing the caregiver a break, and of course MSSI counselors & volunteers are always by your side. These are all support systems that a caregiver can rely on.

Culture and circumstance play a huge role in the experience of caregivers. Finances, stigma and social care vary hugely between countries and different social groups.

MSSI has published a very useful Caregivers Guide in English &some regional languages as well. Please call the office for a copy.

All our events and programmes are also open to the families of people with MS as well as caregivers. Caregivers are also part of the local support & connect groups.

TIPS ON LIVING WITH MS

A healthy diet is one part of living well with multiple sclerosis.

If you have multiple sclerosis (MS) or know someone who does, you know that a big piece of living with the condition is the increasing uncertainty of what each day may bring; the ups and downs of the condition are well beyond what most healthy people can understand. Even if you've grown to accept your "new normal," that doesn't necessarily make it any easier. Learning about the additional challenges that may come along and how to navigate them can make a huge difference in quality of life, both for you and those around you.

The following tips, tools, and resources can help you to live well with multiple sclerosis.

Managing Daily Life and Complications of MS

To stay healthy when you have MS, it's crucial to pay attention to your symptoms and how your body feels. Pushing too hard for too long can lead to a worsening of symptoms or even a flare-up, or relapse. But adhering to a healthy lifestyle can be easier said than done when many of the challenges of MS-lack of mobility, financial strains, or even depression- make it even harder to do what you know you should do. Figuring out what works for you-and what doesn't-can help you live your best life with MS.

Healthy Eating Habits

It's a good idea to discuss any specific dietary changes you'd like to make with your doctor; some popular diets could have a negative impact on MS. Currently, the diet recommended for MS is similar to what's recommended for everyone: lots of fiber, fruits, and vegetables, and limits on the amounts of unhealthy fats and sugar you eat.

Staying at a healthy weight is important for everyone, but that's particularly true if you have MS. Obesity (severely over weight) can increase your risk of fatigue and depression, and obesity in children and teens has been associated with an increased risk of MS later in life.

How food can improve or worsen various chronic illnesses is a growing area of research. Although some people with MS may experience symptom relief when they eliminate or add certain foods to their diet, there's no evidence yet that any particular diet can affect disease progression in MS. Almost all of us know what foods to eat & what to avoid.

Follow the Golden Rule of Moderation: Avoid sugars, avoid excessive fatty & fried foods, reduce your intake of carbohydrates & cereals, eat fiber rich foods, fruits & vegetables rich in proteins & minerals.

We need not start searching for exotic fruits and unfamiliar foods like quinoa etc. In India, our own traditional foods & some regional foods provide adequate healthy options.

There are no do's & don'ts with regard to cereals or milk products or certain foods, unless the individual has medically proven restrictions like dairy or gluten allergies or suffers from diabetes.

Managing Your Prescriptions for MS

When it comes to medication to treat MS, there are more options than ever before-currently, there are 20 approved disease-modifying therapies. Once you're diagnosed and you and your neurologist decide the best medication for your situation, you'll want to start treatment as soon as possible. "Whether you have a slowly or rapidly progressing form of MS, a disease-modifying therapy will reduce the relapse rate by up to 50 percent," says Michael Hutchinson, MD, PhD, an associate clinical professor of neurology at Mount Sinai in New York City. Once your doctor decides what therapy is right for you, you'll be shown the correct way to take your medicine. It can take time to determine if the drug is working appropriately or whether or not you should switch medication. In many cases, you'll need to have periodic blood tests to make sure your body is absorbing and responding to the medication appropriately.

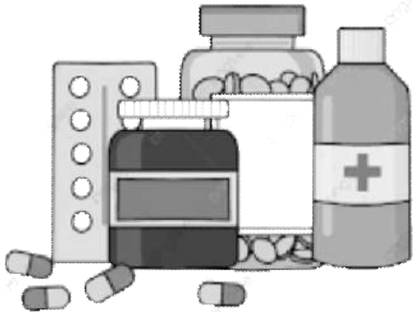
Finding the " right" Doctors for Multiple Sclerosis

Most people who successfully manage MS have a team of medical professionals to help with different aspects of the condition. But because multiple sclerosis is a chronic illness that affects the central nervous system, it's primarily treated by a neurologist, a doctor who specializes in treating diseases of the brain, spinal cord, and nerves.You may need to meet with several different neurologists to find one with whom you feel comfortable. Keep looking until you find the right fit-you'll need to follow up with these specialists for the rest of your life. When you meet a new neurologist, ask all your questions : how many patients they see with MS, or if they are involved in research. Tell them all your problems. Always try to locate a Doctor you are comfortable with, close to your home. Ask her/him who to call in case of an emergency. Note down that number, and share it with your family. **But remember**- our Drs are busy people. In India we have lakhs of patients, but specialists could be in 100s, not even 1000. So unless there is an emergency, keep all your questions for when you meet them. Do not keep calling them to trouble them. Remember next time it could be YOU he is unable to meet, because some other patient is taking up all his time !

If you're not sure where to start, ask the volunteers at MSSI to guide you.

In addition to your neurologist, you may consult with several other healthcare providers for MS.

- **Primary care doctor** Sometimes called a family doctor or internal medicine doctor, a primary care doctor takes care of your non-MS health needs.
- **Physical therapist (PT)** These health professionals can teach you exercises to increase flexibility and strength and improve your balance.
- **Occupational therapist (OT)** An OT can give you MS "life hacks" or tips to help you conserve energy and function better with daily activities like driving, cooking, and grooming.
- **Ophthalmologist** Having a vision specialist on your team can help you with any potential vision loss and help you preserve your sight.
- **Urologist** A urologist can help with urinary tract issues and sexual concerns for men.
- **Speech language pathologist** These experts can help with difficulty swallowing or problems with speech.
- **Nutritionist** or dietitian Although there is no "MS diet" that will control or cure MS, these experts can help you ensure you're eating the right amount of healthy foods.



COMPLEMENTARY AND ALTERNATIVE MEDICINE FOR MULTIPLE SCLEROSIS

Many people with MS seek out natural remedies and complementary therapies to augment their disease-modifying therapy. Before you try out any new vitamins, herbs, or supplements it's important to talk with your doctor first.

- Vitamin D There is evidence and several ongoing studies that show a connection between vitamin D and MS. If you haven't had your vitamin D levels tested, ask your doctor; they may recommend a supplement if you're deficient. Too much vitamin D can be toxic and cause serious side effects, so it's best to take it under the supervision of a doctor who can monitor your level.

- Green Tea: Although there's no proof that green tea helps MS symptoms, it is rich in antioxidants and other healthy compounds. It will not do you any harm.

- Turmeric (Haldi) a common spice and a key ingredient in Indian food. You can even fill the haldi powder into capsules and take it once or twice daily. Although there have been many animal studies that show turmeric can have anti-inflammatory properties, most experts agree that it needs to be studied further before it can be recommended as an alternative treatment for people with MS.

- **Ayurveda:**

Ayurveda is an alternative medicine system with historical roots in the Indian subcontinent. The theory and practice of Ayurveda has become very popular lately and many people are attracted to it due to advertisements promising " cure for MS" & also due to hearsay.

However, MSSI does not endorse any practioner of Ayurveda (or Homeopathy) as in our experience we haven't seen any proof of disease reversal or total cure till date. Certain alternate therapies may help in relieving some symptoms of the disease, but prolonged use of Ayurveda has also resulted in side effects arising from some of the ingredients (like 'bhasma' or metals)which could potentially damage organs.

#MyMSstory: SONALI

THINGS I WISH I KNEW WHEN I WAS DIAGNOSED WITH MS

My name is Sonali. I'm 29, live in Delhi and I was diagnosed with Multiple Sclerosis (MS) in 2009 at the age of 19.

It's quite a funny thing when you're diagnosed with an incurable disease that leaves you looking fine on the outside but wreaks havoc on the inside.

Your brain controls your body through nerve impulses, and MS attacks the nerves that send those messages. This, in turn, alters how your body functions. So, I'm sure you can imagine just how inconvenient this disease is.

The inconvenience of this disease continues with involuntary muscle spasms. I've kicked people under tables, tipped my coffee on people, and looked like I was auditioning for a horror movie in the middle of the shopping center. I also look like I'm part of a zombie apocalypse on the regular from the horrific fatigue it causes.

Jokes aside, an MS diagnosis is a lot to handle, especially at the young age of 19. Here are all of the things I wish I knew sooner.

I want to share 6 points so that we can live with MS with better resilience.

1. Treatment will help

When I was first diagnosed with MS, there weren't many forms of treatment available. I had to inject myself four times a week while not being able to feel the right side of my body.

I used to cry for hours, not being able to inject myself with medication because I'd anticipate the pain. I wish I could go back and tell that girl who would sit with the injector on her leg-which was covered in welts and bruises from the needles-that treatment would come so far that you won't have to inject yourself anymore. And it has come with introduction of oral DMTs. Even very reasonable generic drugs are available which are now very popular. It'd improve me so much that I'd regain the feeling in my face, arm, and leg.

2. Strength comes from challenges

I wish I knew that you learn your greatest strengths when you're faced with the worst of life's challenges.

I experienced mental and physical pain from injecting myself, I've lost feeling in my limbs, and I've lost overall control of my body. Out of these things, though, I learned my greatest strengths. No university degree could teach me my strengths, but the worst of life's challenges could.

I have a resilience that can't be beat, and I have a smile that doesn't fade. I've experienced real darkness, and I know how lucky I am, even on a bad day.

3. Join support groups

I wish I could tell myself that I absolutely need support, and it's more than OK to accept it and ask for it.

My family are my absolute everything. They're the reason I fight so hard to be well, and they help me with cooking, cleaning, or gardening. I didn't want to burden my family with my fears, though, so I turned to an occupational therapist that specializes in MS and never looked back. Being able to talk to someone other than my family helped me really accept the cards I'd been dealt and deal with the emotions I was feeling. I have a whole community of people to share my good and bad days with.

4. Don't compare your diagnosis to others with MS

I wish I could tell myself not to compare my diagnosis to other people's diagnoses. No two people with MS will share the same exact symptoms and experiences.

Instead, find a community to share your concerns and find support. Surround yourself with those who understand exactly what you're going through.

5. Everyone copes in different ways

At first, my way of coping was to pretend that I was fine, even though I became a figure of myself that I didn't recognize. I stopped smiling and laughing and buried my head in my studies because that was the best way I knew how to cope. I didn't want to burden anyone with my illness, so I lied and told everyone I loved I was fine.

I lived like this for many years until one day I realized I couldn't do it alone anymore, so I asked for help. Since then, I can truly say I've found my way of living well with MS.

I wish I knew that coping is different for everyone. It'll happen naturally and at its own pace.

One day, you'll look back and know you're the **strong warrior** you are today because you walked through that war and continue to fight that battle. You'll come out stronger and wiser each time, ready to conquer again.

6. Everything will be OK

I wish that my 19-year-old self knew to truly believe that everything would be OK. I would've saved so much stress, worry, and tears.

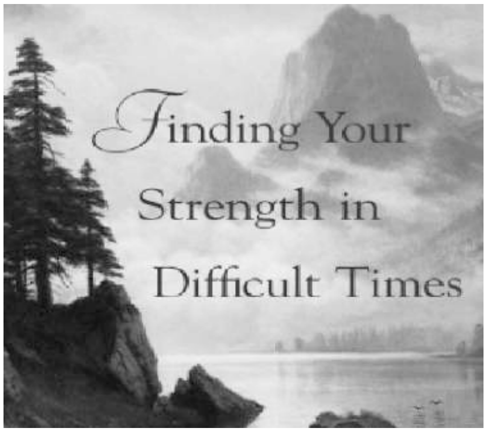
But I know it's all about the process. Now, I can help those who are dealing with some of the same experiences I went through and give them the information they need.

It really will be OK-even through all the storms- when it's too dark to see the light and when you think you have no more strength to fight.

Takeaway

I never thought something like an MS diagnosis would happen to me, and yet I was wrong. It was a lot to comprehend at the time, and there were many aspects of the disease that I didn't understand.

Over time, however, I learned how to cope. I learned to see the good in every bad. I learned that perspective is your best friend, and I learned how important it is to be grateful for the simple things.



I might have seen tougher days than the average person, but I'm still so lucky for all I have and for the strong woman this disease has forced me to be. No matter what life throws at you, with a good support system and a positive mindset, anything is possible.

FIVE HABITS FOR HAPPINESS...

1. Note three good things every day

Science shows that grateful people tend to be happier and healthier. Gratitude can be a stress-buster and can even have a beneficial effect on heart rate. Consciously nurture the habit, by noticing three good things each day. For example: " I really enjoyed my chat with my friend today - I'd forgotten how much he makes me laugh," or "Going out to the market (or a walk) made me feel so good today”

2. Volunteer your time, energy and skills

Research indicates that we can get as much out of volunteering as the people we give our time to. The 'helper's high' is associated with reduced depression and anxiety and improved well being. Volunteering is also a way to get in to social and community life – another thing that is strongly associated with life satisfaction.

3. Look for the good in people

It's easy to take our nearest and dearest for granted and criticism can come easily, especially in long-established relationships. Psychologist John Gottman recommends aiming for five positive interactions for every negative one you have with a person. These can range from showing affection, to thinking about what we value about them.

4. Use positive reinforcement techniques

If you're a parent, try to show your child how to find constructive solutions to conflicts.

All families argue, and sometimes it's in front of the patient. But try to let them also see resolutions: how you can resolve your differences like mature adults and return to a caring, supportive relationship, despite difficult emotions

5. Find your strengths and use them

When we put our strengths into practice, we're usually energised and feel at our best. Identify your best traits-with the help of friends and family if necessary-and use them. Try to do different things, or do things differently !

A TRIBUTE TO DIANA KHAMBATTA

On behalf of MSSI Delhi

Diana was a much loved, much respected member of MSSI for close to 30 years.
When I joined the MS Society I was introduced to Diana by her first name by some the then founder members, as she was already associated with MSSI. In spite of all of us new committee members being quite a lot younger than her we always addressed her as Diana.
Even though my own association with her was also through the Parsi community which I married into, I really got to know her closely through her work with MSSI, so like everyone else I called her by her first name too, though she was almost my mother's age.

She soon joined the managing committee as a volunteer and added so much value to our work through her experience and advice .
She was smart, efficient, responsive and often ended some noisy discussions with a firm and decisive " bas ho gaya, khatam !"
But above all she was compassionate & soft hearted. She connected with our patients many of whom came from simple under privileged backgrounds, and always kept the weakest ones in mind to quietly do something extra for them and their families.

As Secretary and then Chairperson, she attended all our meetings, seldom walking into our little office without some snacks and goodies - but one thing was certain, come 5 pm, she had to rush back home for tea with her dear husband Jim!
Diana helped us raise funds mostly through her large circle of friends-simply because they all believed in HER. Soon our work was recognized and the society gained from her personal credibility and goodwill. Never flaunting her connections, in fact almost circumspect about them, she chuckled when we teased her about being the Society's " Lakshmi".
It was thanks to her that we had the pleasure of holding our annual fundraiser courtesy the Hotel Lalit for an unbroken spell of 10 years - till just before Covid came in the way.

Several lasting relationships with our donors and supporters are all thanks to Diana. She made countless contributions to the Society over her almost 30 year association that helped us get established-and we knew that she also gave her time and the same energy to her other Charities as well-be it the Guild of Services, the Najafgarh home for women, the Vrindavan widows or the annual community weddings which we all attended.

The last couple of years had been hard on her health, but her son Veraf made it a point to bring her to the office or invite us home each time he came in to town. All of us at the MS Society will always miss her, and she will be remembered fondly-not only by us here in MSSI Delhi, but by our colleagues in other cities as well.

Meenakshi Bhujwala

HOW CAN WE DESCRIBE MULTIPLE SCLEROSIS IN 10 WORDS?

Multiple sclerosis is a difficult disease to understand, even if you live with it. Trying to explain it may take more than a sound bite. It can be difficult to keep things short and sweet when describing life with multiple sclerosis.

I've heard it said that the ideal response in a recorded interview is the 10-word answer. It's a short snippet of information that fits perfectly as a media sound bite, and is short enough to stick in our memory. It's like a diverting billboard advert that catches our eye as we pass by on our 70-miles-per-hour lives.

Some 10-Word Descriptions Are Factual, but Not Informative

"MS is a degenerative disease of the central nervous system.”

There are 10 words that perfectly describe MS. They say it all, but say nothing at the same time. (Incidentally, this is the kind of 10-word answer politicians love to use in debates!) While the statement is 100 percent factual, it's far from informative.

"Degenerative" how? Is this "disease" contagious? If it's in the "central nervous system," does that mean it's a brain tumor or something?

While many of us may think it a clear description of the disease with which we live, that's likely because we've lived with the information (and the condition) for long enough that because we understand what we're really trying to say, others will also..

It's Important to Convey the Frustration of Living With MS

So what *is* answer to the question "what is MS?":

Now we're on to the mechanics of the thing. These 10 words begin to explain not only what MS is, but what it does. They draw back the curtain so people can see some of the frustration of living with this disease. I think it's important to introduce some element of the MS experience when crafting such a short response.

"Unpredictable" is a good descriptor to add to our 10 words. But it leaves questions: unpredictable how? ("In every way" is the answer, but you can very little information in 10 words.)

A Brief Response May Feel Like Small Talk

While it may seem like a small talk answer to a rather complicated question, sometimes a question about MS is really just that: polite conversation or small talk.

I have found that personalizing my response helps to inform people that I'm open to giving more information if they're interested in it, as well as making it more relatable.

What MS, the disease, is to me is the same as it is to everyone living with it. But what MS and its symptoms do to me-to each of us-ranges as far and wide as one can imagine, and even beyond that.

For Now, I Have My 10-Word Answer Ready..

No answer, whether it be 10 words or 100, could give the full story of life with MS. But then again, no one asking is likely to want the full story. My 10-word answer would hopefully convey the complexity of the disease, what it means to me personally, and-importantly- what it does not.

My answer has changed through the years, and it will probably change again. For now, though, when asked "what is MS?" my 10-word answer is:

“Complicated and unpredictable. But it's my disease, not my definition."

HOW WELL IS YOUR MS TREATMENT WORKING?


MS treatments can take time to start working-and can eventually stop working. Here's how to know if it may be time for a change.

Most people who have multiple sclerosis (MS) are first diagnosed with a type called relapsing-remitting MS (RRMS), marked by defined episodes of increased nervous system symptoms and impairment followed by periods of remission. Currently, nearly all people who have RRMS are treated with a class of drugs called disease-modifying therapies (DMTs). DMTs help reduce relapses, delay the progression of MS, and prevent future nerve damage, but they don't improve existing damage or alleviate symptoms.

There are now over two dozen DMTs used to treat MS, so there are a lot of options to choose from. "There is no one best disease-modifying therapy for everyone," says Barbara Giesser MD, a neurologist and MS specialist at Saint John's Health Center in Santa Monica, California. "Choosing a DMT is not an easy conversation between the patient and the neurologist. You have to consider a number of factors." This includes how aggressive your MS is and any other health conditions you have, as well as your lifestyle, financial condition and personal preferences. DMTs can be administered by mouth, injection, or intravenous (IV) infusion.

Unlike, say, a headache medication that provides immediate relief, DMTs can take many months to start working. "These treatments don't make people feel better, and they don't treat symptoms," Dr. Giesser says. Instead, DMTs are designed to lessen the immune system's attack on the nervous system, which can help decrease the number of flares you experience and their severity.

The effectiveness of a DMT is primarily assessed by how well it reduces flares and whether your doctor can see new or inflamed lesions on magnetic resonance imaging (MRI). Most people with MS require therapy with a DMT along with other medications or strategies to help manage symptoms.

But you probably won't be on the same DMT forever. There are many reasons you might eventually change to a different treatment, and switching is common.

Answer these questions find out if your treatment plan is as effective as it could be-and what you can do if it isn't.

This assessment is part of a series aimed at helping you check in on your MS before your next checkup with your doctor. There are no right or wrong answers – it all depends on your personal response & life style Then, schedule an appointment with your neurologist to discuss your results.

Question 1

How long have you been on your current MS treatment?

- A. Less than 6 months
- B. More than 6 months

Question 2

Do you take your medication exactly as prescribed?

- A. Yes, always
- B. Most of the time
- C. Sometimes
- D. No, I often forget

Question 3

Do you experience any bothersome side effects from your medication?

- A. Yes
- B. No
- C. Not sure

How much is MS affecting your daily life?

- A. A lot — I'm really struggling.
- B. Somewhat. There are things that could be better.
- C. Things are generally pretty manageable.
- D. It's not. I'm doing well.

Question 5

How often do you experience severe flares?

- A. Rarely or never
- B. A few times a year
- C. Every few months or more often

Question 6

True or false: I've noticed a significant change in my physical abilities over the past several months.

- A. True
- B. False

Question 7

On your last MRI, did your doctor detect new lesions in your brain or on your spinal cord?

- A. Yes
- B. No
- C. Not sure

Based on your responses, depending on how you're feeling overall, it might be good to explore other treatment options. Share this information with your neurologist. Let them know what your quality of life is like, plus any concerns you have about your current treatment.

These other treatment tips can help, too:

- **Talk to your neurologist before stopping any treatment.** Even if you're experiencing side effects or having trouble sticking to your dosing schedule, it's important to carry on with your treatment plan. That's because DMTs help slow nervous system damage, which is not reversible once it occurs.
- **Consider tracking your symptoms.** This can help you get an objective sense of how your MS affects you over time. You can keep a notebook or use an app

- **Learn about other treatment options.** If you're unhappy with your current treatment, remember that there are many other choices. Talk to your doctor about anything you dislike about your current medication and what other options might be a better fit.

Being on the right treatment is the single most important thing you can do to slow the progression of MS and keep flares to a minimum.

EXERCISING WITH MS

Although the fatigue and pain that often comes with MS can make physical activity difficult, exercise can improve mobility and make you feel better. A physical therapist or specially trained exercise professional can share specific exercises designed to improve foot drop, walking, balance, and going from sitting to standing.

It's also possible to increase your strength, flexibility, and level of fitness when you have MS. Although exercise can lead to soreness and fatigue, working with an expert can help ensure you don't overdo it. A regular program that builds your strength and stamina can actually help reduce fatigue in the long run.

Taking measures not to get overheated during exercise is also important for individuals with MS, because getting too hot can cause MS symptoms to worsen. Some options for avoiding overheating include exercising in an air-conditioned environment, exercising outside during the cooler parts of the day, and taking breaks to cool off during workouts. We also recommend keeping a bowl of cold water & a wet face towel by your side while exercising.. dip it, squeeze it and wipe your forehead, neck arms & underarms with it frequently to bring down your body temperature

MOBILITY ACCESSIBILITY AND MS

For some people, the impact of MS on balance and leg strength can make getting around a challenge; many people with MS eventually need to rely on a walker, scooter, or wheelchair in their home. Outfitting your living space to accommodate your assistive device may mean modifying areas like your entryway, kitchen, and bathroom.

If you aren't quite ready for a home modification project, just clearing away clutter and removing decorative accessories like rugs or baskets and flowerpots can go a long way in creating space and helping to prevent falls.

Mobility Aids for MS

Fatigue and balance issues are common in MS, and eventually you might opt to use a mobility aid. It is a good idea to get professional evaluation with a physical therapist who can help you select the device that's right for your needs. There are many options to consider:

- **Canes**/ Walking Sticks: There are two main types of canes: a single point cane; and a four-point cane, in which four pegs connect to the main shaft. Some people even choose to use two canes, one in each hand.
- **Walkers** A walker is a good choice if you notice that you're beginning to stumble more. A standard walker has rubber grips on the bottom to help with stability.
- **Rollators** Instead of flat rubber grips on the bottom, rollators (as the name suggests) have wheels on the bottom.
- **Trekking poles** These devices are good for people with balance issues, as they encourage a more upright posture compared with a cane.

Some people with MS resist or put off using a walking aid, but it can actually improve your independence and take some of the stress out of getting from here to there. If you have MS, whether to use a wheelchair or not can be a big decision. It may mean that your disease has progressed to the point where you don't feel safe getting around using other mobility devices. But it's not an all-or-nothing choice; many people decide to use a wheelchair for certain activities or environments but not full-time.

There are manual wheelchairs, which require arm strength or others where someone is required to push you, and powered scooters and wheelchairs, which move automatically with buttons or levers you can control.

Although many people - specially young persons- avoid using a wheelchair because they do not want to appear disabled or dependent , using one can actually provide freedom and new opportunities for activities that aren't feasible with a cane or a walker. Just like we do not hesitate to use specs if our eyesight gets weak, we should consider using a wheelchair if our legs are weak and it stops us from going out comfortably.

Travelling With MS

You might think that because MS can flare up unexpectedly amid stress, fatigue, heat, or an infection, travelling would be off-limits, but that's not the case. Most people with multiple sclerosis have no travel restrictions, says a neurologist who specializes in MS at Cleveland Clinic.

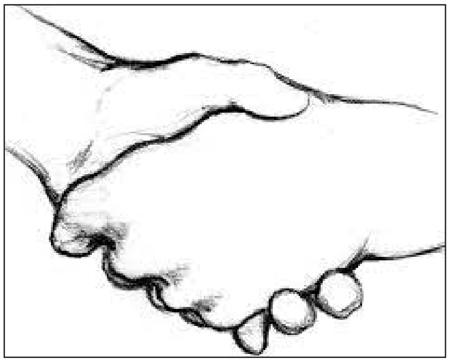
There are things you can do to raise the chances that your trip goes smoothly. For one, make sure you have all the medication you need, and don't forget to bring a way to store it at the needed temperature. Bring any relevant medical information, and check ahead to see if there is medical care available at your destination. Finally, build in extra time to take breaks, and schedule activities so you don't have to rush or be stressed during your journey.

MILESTONES ACHIEVED BY MSSI DELHI – 2021-2022

After a long difficult year of trying to understand Covid, a couple of months into 2021 we were all relieved that the worst was behind us, and with the vaccine coming out , we all heaved a sigh of relief ! So we started planning many programs, only to be hit by the worst Delta wave by mid year 2021. Like the rest of the world we had to put many of our plans on hold and change the way we had been doing things. However, we still achieved a lot, and above all we kept in constant touch with all our members and to the best of our ability provided all the services they needed.

Here, in no particular order, are the activities we completed and services that we provided.

- **OUR PROGRAMMES**- Our special events like India MS Day & World MS Day, our regular Day Care programmes as well as Doctor's sessions had to be taken online yet again, as personal meetings were cancelled. These covered subjects like Medical Seminars, Doctor's lectures, Rights of Persons with Disability, Yoga, Mental Health, Physiotherapy, Alternate medicine and Diet Programmes along with music, Antakshari, & performances by our talented members! We organised & participated in around 25 Zoom Webinars through the year, with an average attendance of over 75 persons at each session. That's almost one session every 2 weeks !



- **COUNSELLING-24/7**- Online Counselling is a speciality of the MSSI Delhi Chapter and one of our most popular and appreciated services. 3-4 members are always available for this. This includes FACE to FACE Video counselling also. During the lockdown days this was our primary means to interacting with our MSP's, as well as their families.

- **HOME VISIT-** All of us at MSSI Delhi really enjoy meeting you all in your homes-unfortunately that was not possible this year either, so we ramped up our Video calling and found ourselves making 'virtual visits' to your homes! That way we were visiting our members not only in Delhi/ NCR, but as far as the cool & beautiful Kashmir & Uttarakhand, colourful Jaipur and other places in Rajasthan, meeting families in Punjab & Himachal

- **MEDICAL AND WELFARE**-Once again going digital, we have been sending wheelchairs, walking aids, air mattresses, diapers, & even a Hospital bed directly to our members in need in far flung towns & villages through Amazon. Each item is sourced very carefully, taking into consideration the size of the doors, the measure of disability and the level of financial need of the MSP's.

Last year we supplied10 wheelchairs, 10 walkers, 5 toilet chairs, 15 walking sticks and 1 hospital bed.

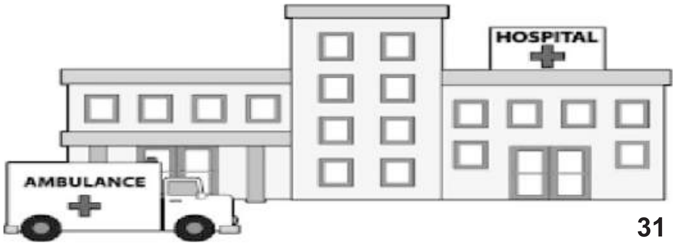
- **BIRTHDAY CARDS**-Each year we send specially designed birthday cards to over 700 MSP's by post. Occasionally, we also make video calls on their birthday and talk to their family members, enjoying the virtual birthday sweets & cakes! Our EC Members have been handwriting cheerful personalised messages in the cards since last 15 years. No amount of Whatsapp greetings can match the joy of receiving a personal card in the post!

- **MEDICINES & NUTRITIONAL SUPPLEMENTS** - For two years we were being supplied regular health supplements by one of our sponsors, Morepen Laboratories Ltd for over 100 MSPs. However, during this Financial Year 2021-22 due to the Covid crisis they were unable to continue with the project. We did not let this setback deter us! From our own funds we continued with the distributions. Today we continue to supply these supplements to approximately **80 needy MSPs.**

- Cod Liver Capsules
- Vitamin D3 and Calcium
- Vitamin C with Zinc
- Vitamin A to Z
- Protein Drinks

This time consuming exercise ensures that supplement packs & tablets are packed carefully, each recipient is called to confirm the address & again to confirm receipt of the same. These MSPs have been identified & assessed personally by a senior MC member as deserving candidates facing poor health due to lack of a balanced diet. This supplement project is essentially for MSP's who earn Rs.20,000 or less every month from all sources and are found lacking in right nutrition.

- **HOSPITAL ADMISSIONS AND APPOINTMENTS WITH LEADING NEURO DOCTORS:** Priority based emergency hospital admissions are organised with the help of senior consultants at RML Hospital and AIIMS. Appointments on a priority basis with leading neurologists, urologists & other consultant doctors are regularly fixed at AIIMS, Artemis, RML, Max, Apollo, Gangaram, Paras, Vimhans, GB Pant and Fortis.



- **HOME CARE ATTENDANT-**Shagufta, our home care attendant for home bound women MSP's is very popular among her patients who are spread right across Delhi /NCR . She helps bathe them, wash their hair, makes up their room keeping it fresh & tidy. She often even treats the ladies to a face massage, hair cut or a mini pedi & mani ! She makes them look and feel better, and this allows their caregivers some time off as well. She visits each of her lady MSps for 2-3 sessions per week, averaging **50 visits a month**.

Care, Comfort, Convenience@home

- **PHYSIOTHERAPY**–Our flagship project is running successfully and effectively since 2003 & growing day by day, sometimes at a pace we find hard to keep up with! Our team of over 12 highly motivated & trained PTs buzz around the entire city of Delhi & the suburbs on their motorbikes, completing **450-500 sessions every month**. These experienced and qualified doctors have now grown to be more than just MS physiotherapists or occupational therapists; they are like family members to many . They frequently go above and beyond their call of duty.They cheer them up, counsel and motivate them; they discreetly share details of difficult family circumstances, enabling us to reach out with any further assistance we can provide. These physiotherapists take the MSPs out for a walk occasionally or with the cooperation of the MSp's families even take small groups of MS friends to a mall or a park for an outing.

This is our most popular project and our immense thanks to our sponsors & donors , and kudos to our consultants & trainers, with a special mention of **Dr Jasmine Anandabai** for her regular training refresher sessions, her personal consultations & guidance in difficult cases & her time which she gives to MSSI Delhi so generously. We spend about **28-30 Lakhs per year** on this project and currently we have 14 physiotherapists on our panel. At the moment our Home Services are available in Delhi &NCR but we have plans to reach out to our Meerut and Varanasi MSPs in the near future.

- **ADULT DIAPERS**-most of our members need adult diapers for their daily use. We source these diapers from suppliers who provide us the best quality at the best price. We supply these diapers free of cost to our members who need them but are unable to afford it.

The MSSI Delhi Spring Celebration

The last 2 years have been the most difficult that most of us have faced in our lives. it left us feeling low, depressed, isolated and confined to our homes & indoor spaces. All of us were longing to get back to our friends, to meeting people, enjoying the outdoors & generally to reclaim our lives.

Earlier this year, when we saw a sustained reduction in Covid cases and feeling reassured with our vaccines, we thought it was time to start thinking about resuming our regular programmes & interactions.

In Delhi we are blessed to have vast well maintained parks & public spaces. February & March are traditionally the best months in Delhi-gardens are in full bloom, the weather is perfect and so we gingerly floated the idea of a Day in the Park on 9th March. The venue was the Sunder Nursery Park, a wonderful park in the heart of Delhi, dotted with 12th century monuments, waterways and an astounding variety of trees, birds & butterflies. We planned it midweek, and we thought we would have a small turn out, but we were delighted with the enthusiastic response-We were 80 people in all!

The Sunder Nursery park is fully accessible, (Entry free for PwD) has excellent clean toilet facilities including a special needs toilet , abundance of flowers, wide open spaces. We had planned games, prizes, sumptuous lunch & snacks, and enough chairs & durries to complete the picnic atmosphere. Since it was just a day after International Women's Day, we also felicitated the brave young women present (PwMS as well as female caregivers) with a little gift pouch containing feel good nik-naks like a floral hair tie, some 'bindis', lip balm etc to make them feel special!

We all had a great time and spent the day catching up, chatting, laughing & soaking in the beautiful atmosphere. Our cover page this year is inspired from this picnic. It was decided there & then that this is one event we must repeat every year !

In the treatment of RRMS

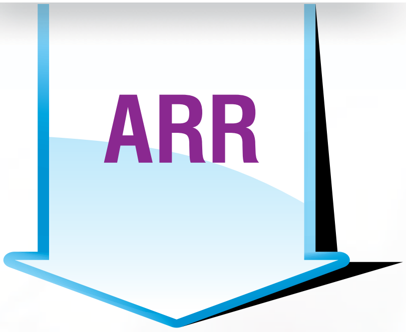
℞

Deno

Teriflunomide 14 mg Tablets

Designed

Teriflunomide vs IFN



ARR

34% **in treatment naive patients**

34% **in previously treated patients**

41% **in recently treated patients**

$ patients recently treated with another DMT, # patients previously treated with another DMT
Ref: Comi et al. BMC Neurology (2020) 20:364

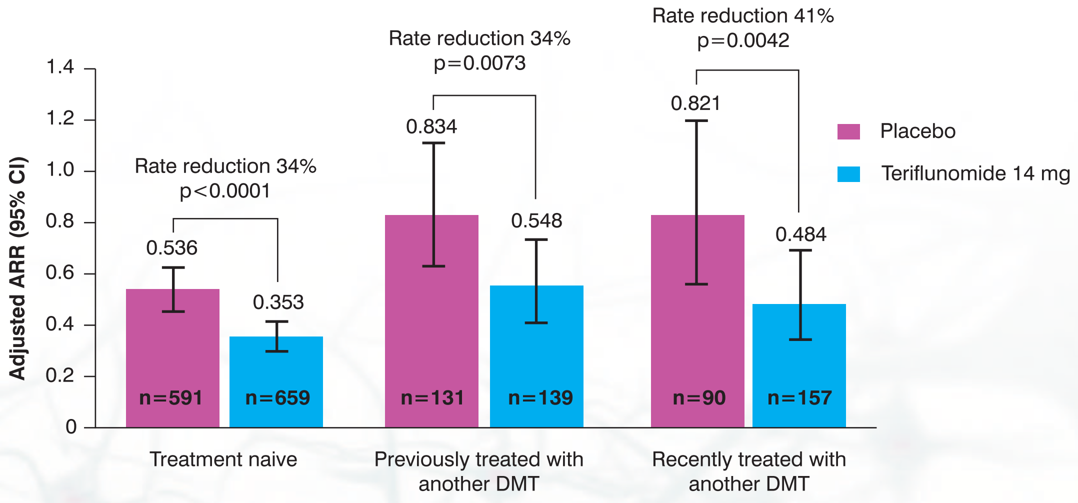
psy

ESTABLISHED ★ BIO-EQUIVALENCE* ★

to Quiescent MS

B-1a, IFNB-1b & GA

Adjusted ARR with teriflunomide 14 mg or placebo



**Orally
Once Daily
with or
without food**

For the use of a Registered Medical Practitioner or a Hospital or a Laboratory only.

NATCO PHARMA LIMITED
NATCO HOUSE, Road No. 2, Banjara Hills, Hyderabad - 500 034, India
Ph: 040-23547532, e-mail: pharma@natcopharma.co.in







MSSI



- **VIDEOS OF EXERCISES**: During Covid 19 we helped all our members by going digital. We shared videos of exercises by trained PT and OTs so that Caregivers could help the MS persons at home and make sure that their exercise routine is not broken. We also shared videos from other international MS organisations & websites to help our MSps stay active.

- **SCHOLARSHIPS**–This project has been growing by leaps and bounds every year. Currently MSSI Delhi is supporting 40 students–who are either MSps or children of MS persons who have been facing financial difficulty in continuing their education. MSSI Delhi provides a fixed monthly grant or scholarship allowance to ensure that no child is left behind. It is our effort to cover the monthly school fee of these children, and based on the average fee bills we receive from them, we have capped it at a maximum of Rs 1500 pm. Once again, a meticulous & painstaking process of checking each & every fee bill, if required we cover the cost of books as well if it falls within the monthly limit set by the Managing Committee. The success of this programme is also visible in the number of donors who wish to contribute to this project. There is nothing more fulfilling than watching these young children thriving & making us & their parents proud. We currently spend around **Rs. 6 Lakhs** per year on this project. This year we will have the invaluable support of a new sponsor- **Swarn Lata Motherson Trust.**

- **NEW MEMBERS**– We welcomed almost 100 new members to MSSI Delhi. This year we registered the maximum number of new members in any year because of our enhanced Social Media presence and activities. We can now be contacted via almost all leading social media platforms, apart from our website www.mssocietyindia.org.

- **SOCIAL MEDIA** –Social media played an active role in the increase of our numbers. Facebook, WhatsApp, Insta, Twitter every avenue was used to showcase our activities and spread news about us far and wide. Our regular posts on these sites along with our frequent Broadcast announcements, Webinars, Zoom programmes & info-mails which in turn get shared on these platforms played a big role in creating awareness. We have been part of the national campaign **" Numbers Matter"** to get counted in the national registry. We have also been actively encouraging all our MS members to get their **UDID cards** and and disability cards , with guidance on all the benefits of these cards. MSSI Delhi is now helping our members with the enrolment process . Contact us for help.

- Our **Facebook page** traffic has increased substantially & has been having a cascade effect on all platforms. Our social media pages are being managed by a team of 5 people, 3 of whom are our young MSps!

- **ANNUAL HANDBOOK**– Even though our much awaited & loved Annual publication got delayed due to Covid issues, the 17th edition finally got printed last summer. We shared soft copies individually & posted hard copies to over 750 MSP's, Doctors, donors, supporters and advertisers as well as our other 9 MSSI Chapters. Since our Souvenir & Handbook has a long shelf life with interesting & useful information, the last 2 issues are now available in PDF format on our website as well. This Handbook has been appreciated by Doctors as a great information tool over the years. We are grateful to our senior Neurophysicians Dr Meena Gupta, Dr.P.K.Sethi , Dr. Mahajan and others for their personal notes of appreciation.

- **CONNECT GROUPS –**One of our recent initiatives is our effort to tell all our members *"you are not alone!"* We have formed 12 localised WhatsApp CONNECT GROUPS across North India in 8 key states where are members are located. Delhi is divided into 4 regional

Zones, North, South, East & West. Each zone is led by a core team of young MS persons, under the guidance of a senior Executive Member. This initiative was not an instant success as there was some hesitation to mingle (even online) with 'strangers' but has grown steadily & surely over the last year. Most of these groups are now a vibrant throbbing bunch of people chatting, sharing, discussing and supporting each other. Like all groups, there are some silent ones, but slowly many of them are emerging to join the main stream. Thousands of messages are exchanged all day long consisting of MS news, scientific discoveries in MS treatments, sharing of personal experiences, moral support for each other and of course all kinds of festive wishes, jokes, and forwards to liven up the day. This project was started following the **World MS Day theme #MSConnections.**

- **YMSG– Our Youth MS Group** was started in the year 2008 for the under 40 age group of MS members. This idea was an instant success, and in no time the young MSps were connecting with others not only within India, but also in different countries. They chat, they share their thoughts, feelings, ideas & emotions, as they connect with others. Many strong bonds of friendship have developed over the years, and they are the modern 'family of friends'. Delhi has **376 youth MS members**.

- **VOLUNTEERS**– We are enrolling young volunteers from within the MS family as well as those who want to help make a difference to the lives of others less fortunate than themselves. In time we hope these young MS volunteers will be leading MSSI to expand its scope & achieve much greater strength to help others. MSSI Delhi has several young and enthusiastic MS members who keep our social media buzzing, help organise webinars and special events like India MS Day-IMSD/World MS Day , and are always just a phone call away to help in times of need.

However, we need many more committed volunteers! Join us, be a part of any of these projects. You can work from home; you can help us complete the projects or start new ones. **Come-be a part of the team and use your skills to make a difference in the life of others .**

Volunteering provides many benefits to both mental and physical health.

- Volunteering helps counteract the effects of stress, anger, and anxiety.
- Volunteering combats depression.
- Volunteering makes you happy.
- Volunteering increases self-confidence.
- Volunteering provides a sense of purpose.

YOU ARE NOT ALONE

Right from the time of diagnosis, living with multiple sclerosis is a learning experience and with the unpredictability of symptoms and related issues, it's often a case of learning as you go.

Living with multiple sclerosis can impact all kinds of practical, everyday things. We're here to help you gather information from others who are facing the same problems & challenges as you – when you join hands, you learn through practical advice & find your way around faster.

Support Groups & Local Connect Groups are a great way to have a one-on-one conversation with somebody who understands, no matter where you live and who you are. Many people have said it's a great way to build a relationship and give and receive advice.

You can choose if you want to speak to another person living with multiple sclerosis, a caregiver or a family member. This project was started by MSSI Delhi following the **World MS Day theme #MS Connections.**

MSSI Support Groups

Living with multiple sclerosis or caring for someone with the condition can be challenging- especially people who are newly diagnosed can feel particularly helpless. One way we've addressed this is through our local Support groups program, whereby people living with multiple sclerosis or their family members or care givers can support one another either in a one-on-one or group setting, typically over the phone or online. Giving and receiving practical and emotional support can help you understand a recent diagnosis, manage your symptoms and live well with multiple sclerosis. This is a great way for people living with multiple sclerosis, caregivers, family and friends to connect with and support each other. It's also a great way to make new friends who understand you! We offer MS Support through a variety of channels, and it's completely your choice to participate.

Where are our Connect & Support groups?

We had planned that our face-to-face MS Support groups would meet each other personally at various locations across the city, but always at a location close to *your* home or Zone. However, Covid came in the way, and we modified it to "virtual meetings" or Face Time on the phone.

We have formed 12 localised WhatsApp Connect Groups across North India in 8 key states where our members are located – Delhi, UP, Haryana, Rajasthan, Punjab, J&K, Uttarakhand & Himachal Pradesh

Delhi is divided into 4 regional Zones, North, South, East & West . Each zone is led by a core team of young MS persons, under the guidance of a senior Executive Committee member.

This initiative was not an instant success as there was some hesitation to mingle (even online) with 'strangers' but it has grown steadily & surely over the last year.

Most of these groups are now a vibrant, throbbing bunch of people chatting, sharing, discussing and supporting each other. Like all groups, there are some silent ones, but slowly some of them are also emerging one by one to join the main stream.

Thousands of messages are exchanged all day long consisting of MS news, scientific discoveries in MS treatments, sharing of personal experiences, moral support for each other and of course all kinds of festive wishes, jokes, and forwards to liven up the day.

MSSI Delhi first meets its members over a video call on the phone, and then we connect you to your local Support group. We hope that in a post Covid world, we can finally get you to meet your local group members in get-togethers and outings for a casual coffee, or some discussion groups around specific multiple sclerosis issues or just an enjoyable group activity such as singing or exercise – you can find a friend with similar interests- there really is something for everybody!

Self Help groups

In addition to MS volunteer-led support groups, Self Help groups are led by people who are not MSps , but are family members or volunteers who work diligently and thoughtfully for their local communities.

MSSI one to one Support via phone

Telegroups

Our MS Support Telegroups enable people with similar interests or experience to connect by telephone as an alternative to face to face groups.

Some groups have a particular focus, such as young caregivers or parents or children's study groups , while others are a mixed bunch of ages and roles.

Caregiver Support Groups

Online MS Peer Support is a great way to make connections from the comfort of your own home, or on the go, no matter where you live. Online support leads to better self-care and a stronger sense of wellness. Plus, it's a great way to make a new group of friends outside of your usual networks!

We have connected a number of individuals who wish to talk in smaller more private groups, or one on one. Our role is purely to connect you after taking your permission by giving a short introduction of each other. We try to make sure that we put you in touch with like minded people. We do however remain in touch and are always available to assist you.

Our online communities are built on mutual respect and emotional support-they are not designed for medical advice. We suggest you check with your Doctor or health care professional before starting any therapy recommended by a person in your group, even though it may have been given with the best intentions.

Become an MS Peer Support volunteer

We need members of the MS community to provide emotional and practical support and a listening ear for other people affected by multiple sclerosis. MS volunteers with lived experience of MS are encouraged to become Support volunteers & group leaders

Call us today if you…

- Have been living with multiple sclerosis for more than two years-either as a PwMS or as a caregiver
- Have a positive approach to living with multiple sclerosis
- Become a positive ambassador for MSSI

MS Peer Support volunteers are informally 'interviewed' for suitability, provided with full information and support. There are a number of ways to get involved, including being a group facilitator, providing one-on-one telephone support and moderating our online support channels.

MSSI is here to help

If you can't find a group in your area, call MSSI Delhi to register your interest in joining a Connect Group near you

GETTING HELP FOR BOWEL INCONTINENCE WITH MS

One huge barrier to people with MS getting effective help for bowel problems is that most doctors don't ask about these issues Doctors don't always bring this up, and a lot of times patients aren't sure how to talk about it.

Patients are also sometimes not aware that this could be related to their MS, or what their neurologist would do about it.

So the first step in getting help for bowel problems is telling your neurologist or primary care doctor what's been happening. Getting an accurate picture of symptoms is really important. Doctors have to base a lot of their management advice on what patients self-report.

Your doctor may ask you to keep a diary record of your bowel symptoms, along with what you're eating and drinking, and other potentially relevant behaviors. Patterns related to what you eat or drink may emerge, and your doctor will also get a picture of your overall diet.

How Diet and Medication Can Contribute to Bowel Problems

"I don't think people realize that the food we eat and what we drink can really make a difference in bowel symptoms", says Rachael Stacom, an adult nurse practitioner and at Independence Care System in New York City.

Not consuming enough fiber or fluids can contribute to constipation, while consuming spicy foods, dairy products, caffeine, and artificial sweeteners can all lead to problems with bowel urgency.

In more difficult cases, it may help to follow a very restricted diet to see what foods might be problematic, she says. Then, "we'll have people slowly introduce foods to see if that aggravates or upsets your stomach."

Another potential contributor to both constipation and urgency is what kinds of medication you take. Some may have a stimulant effect or bother your stomach, leading to bowel contractions. Others may slow down your digestion, leading to constipation-and possibly a higher risk of incontinence.

Adjusting medication doses may be difficult, especially if they're working to relieve some other symptoms. But sometimes there are some easy things we can do, such as adjusting diet and a bathroom schedule to respond to the effects of the medication.

Medical Interventions for Bowel Incontinence in MS.

Certain drugs can be helpful to manage constipation and bowel incontinence, often in combination with a bowel training routine. "Sometimes the key is to get your bowels on a regular schedule," says Kaplan.

One technique involves taking a laxative powder or syrup at the same time each day. If someone can establish having a bowel movement routinely after breakfast, then that means for the rest of the day they might be free of the fear that they might have an accident.

There are many other drugs to as stool softeners and stimulants like bisacodyl and senna. But many of them should be used very carefully, since they can have side effects and their effectiveness may decrease as you develop a tolerance to them.

Another useful option for many people with bowel incontinence is glycerin suppositories-which you insert into your rectum to induce a bowel movement, usually within 10 minutes. "They essentially help soften the stool that's in the rectal area, and they're not chemically absorbed," she explains. "You can't overdose on them."

If you know you'll be going someplace-from a long car ride to a social function-where you don't want to risk a bowel accident, you can use a suppository beforehand. "I've had so many patients tell me that this was so liberating to them, because they could time their own bowel movement and do it at their convenience," says Kaplan.

Pelvic Floor PT and Other Solutions to Bowel Incontinence

Many patients benefit from pelvic floor physical therapy, which may help strengthen both your pelvic floor muscles and your anal sphincter-potentially addressing both bowel and bladder problems. Some people need only one or two sessions with a therapist and can then do the exercises at home. When lifestyle measures and medication aren't enough to control constipation or incontinence, transanal irrigation/ enema -using a device to flush out your rectum with water-may be an option, and has been shown to help relieve symptoms in people with MS, according to a study published in April 2016 in the journal Neurogastroenterology & Motility.

And if you still need protection from bowel accidents, wearing adult diapers can be helpful for many people with MS. Just remember that they're "not all created equal" in terms of absorption. You should also apply a skin barrier, such as petroleum jelly or pure Vaseline , to any area that may come into contact with your stool or urine especially if you spend most of the day sitting in a wheelchair or have reduced sensation in the area.

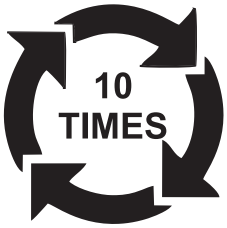
"Extreme constipation can lead to stool backup" in the colon, Kaplan says-making it much harder to control bowel movements when the inner anal sphincter finally opens and the pelvic floor relaxes to allow the muscles in the rectum to push the stool out.

But some people with MS experience bowel incontinence without constipation, or without knowing they're constipated-especially if the outer anal sphincter isn't functioning well.

Bowel problems often go hand-in-hand with bladder problems, and not just because they're both caused by a disruption in nerve signaling affecting the same region of your body. Often when someone has an overactive bladder, they try to self-treat by limiting their fluid intake. That can, in turn, worsen constipation and, in some cases, lead to incontinence or urine leaks.

LONG SQUEEZES

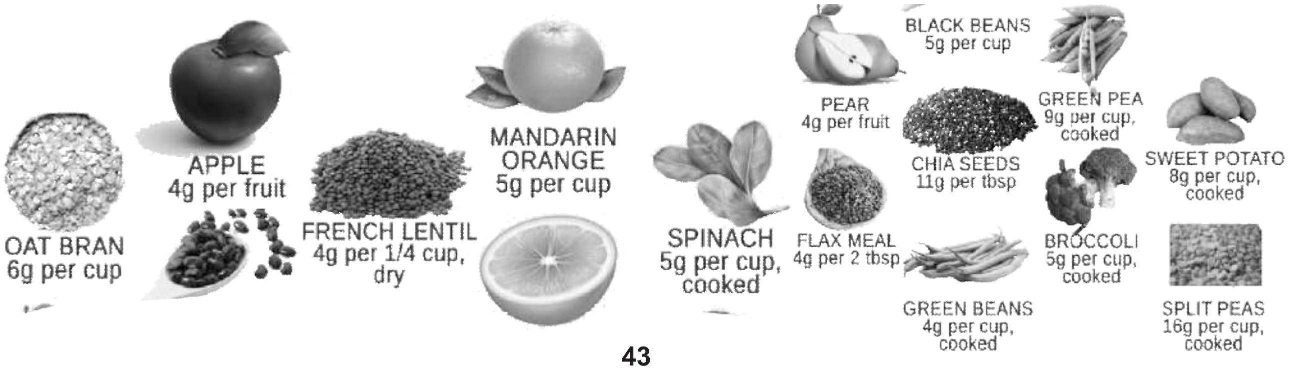
1. Lie, stand or sit with your knees slightly apart
2. Slowly tighten the pelvic muscles around your rectum and vagina
3. Squeeze both areas as hard as you can
4. Hold for 10 seconds and relax



HEALTHY EATING HABITS FOR MS

Making adjustments to your eating habits may help you better manage MS.
Let's face it-following a healthy diet is important to your overall wellness. And many people with multiple sclerosis (MS) say that making the right food choices helps them live better with the disease, too.
In fact, on Tippi MS, a social tool for sharing your go-to tips for living with MS, food is one of the most popular topics that people are talking about.
While an exact MS diet doesn't exist, choosing nutritious foods and cutting back on highly processed foods can provide benefits like improving your energy level and reducing the impact of other symptoms. According to the National Multiple Sclerosis Society (NMSS), diet could even play a role in disease progression.

Tip No. 1: Start With Good Nutrition
Because there's no specific diet for MS, navigating diet advice might seem confusing. But quite simply, the best diet for MS may be to follow the same healthy eating guidelines as everyone else. The NMSS recommends eating a low-fat, high-fiber diet that focuses on real food (like vegetables, fruits, whole grains, and lean protein) as opposed to processed foods that are high in salt, sugar, and other additives Follow a healthy diet. No specific diet has been shown (yet) to reduce MS progression. You will hear about all kinds of 'MS diets,' but the truth is that basic guidelines for a healthy diet also apply to those of us with MS. Mostly plant-based is best for us (and our environment)! Aim for at least 5 servings of fruits and veggies a day (the more, the better) , and also avoid red meat, saturated fat, highly processed food, and limit alcohol.
Don't get caught up in the diet game! Eat plenty of (organic) fruits and vegetables and limited low-fat meats. Above all, try to maintain a consistent routine and eat around the same time every day. Eating at regular times keeps my energy steady.
Tip No. 2: Reduce Processed Foods and Sugars
Which foods are off-limits for MS? None, really, although some people who have MS say that avoiding certain foods or even whole food groups improves their symptoms. Still, what works for them may not work for you.
If you suspect that a particular food group, such as dairy products, or a component of some foods, such as gluten, is negatively affecting your health, speak to your doctor about it. In some cases, your doctor may be able to administer tests to determine whether you have an intolerance or allergy to a food or food group.
In other cases, your doctor may suggest trying an elimination diet, ideally under the supervision of a registered dietitian. The idea behind an elimination diet is to stop eating foods that may be triggering an adverse reaction in your body for two or more weeks, then slowly reintroduce them, one by one, to identify how each food makes you feel.



You will have to modify your dietary habits and make sure to include at least five portions of fruit and vegetables every day and plenty of fibre This can help you to achieve regular bowel movements. These foods may help relieve mild constipation:

Also include the following:
whole-grain cereals (including porridge, bran flakes or muesli)
fruit (including dried fruit)
vegetables (lentils, peas and beans-including baked beans-are especially high in fibre) nuts including linseeds - also called flaxseeds or 'alsi'
Increase your fibre by switching from white bread, regular pasta and white rice, to wholemeal bread, whole-wheat pasta and brown rice. Do not remove the 'husk' from the atta before preparing your rotis.

Tip No. 3: Simplify It With MS-Approved Food Ideas

Now that you know what to eat, sometimes the trickier question can be how to stick with it - especially when you're dealing with fatigue and other MS symptoms.

1. Eat more fiber

According to the American Heart Association (AHA)Trusted Source, a high-fiber diet can help resolve constipation. It can also reduce your risk for a number of other conditions, including heart disease and diabetes. Women should get at least 25 grams of fiber each day and men 38 grams a day.
The AHA recommends getting fiber from food as opposed to supplements whenever possible. Whole grains, such as whole wheat, oats, and brown rice, are a great place to start. Other good sources of fiber include:

- Fresh fruit, such as apples, mangoes, and bananas
- Legumes, such as split peas, lentils, and beans (rajma, lobhia)
- Nuts, such as walnuts and almonds
- Vegetables, such as green leaves and broccoli

2. Try bulking agents

Maybe you're not a fan of vegetables or you feel like you don't have the time to cook whole grains. If that's the case, keep trying new foods until you find the high-fiber diet that works for you. In the meantime, bulking agents can also help.
Bulking agents, also known as fiber supplements, can increase the volume of your stool. That can make it easier to pass the stool. They include: herbal remedies like isabgol

When you add more fibre to your diet, go slowly. Too much too soon will cause bloating and wind. Fibre soaks up water in your bowel, so you'll need to drink more, otherwise your stool will become hard and your constipation won't get better.
For some people more fibre can make constipation worse. If this happens to you, get advice from a doctor or dietician.

If MS symptoms such as fatigue or reduced mobility mean you're less active than you used to be, this can add to problems with constipation.
Being active doesn't have to mean going out and playing a sport-it's about finding the right activity to suit you and your abilities.
Try to schedule a regular time to go to the toilet. Around 20 to 30 minutes after breakfast is often the best time. Or you might schedule a regular time after coffee or a hot meal.

A toilet also needs to be fitted out so you can feel comfortable and stable. As it's most natural for humans to squat to pass a stool, you may find it helps to have something to rest your feet on, so your knees are above hip level. When going to the loo, try to relax and breathe normally. If you hold your breath and strain, you'll tense up your anus – whereas you should be aiming to relax your anus to allow the stools to pass. Take your time (and have privacy), but try not to spend endless time in the toilet straining. If your bowels do not open, try again at the same time next day.

- Some types of drugs commonly taken in MS are can cause constipation, including: drugs used to treat over-active bladder in MS such as oxybutynin or tolterodine , anti-spasticity drugs, like baclofen which is used to treat muscle stiffness and spasms anti-depression drugs some painkillers like pregabalin and gabapentin.
- Treatments for constipation include laxatives that can be taken as tablets, capsules, a powder you add water to, or in a suppository (a capsule that you put up your back passage). Stool softeners can be used as a gel that you put inside your bottom using a micro or mini-enema.

Abdominal massage helps some people poo by stimulating the bowel to squeeze poo faster through it. You might use this as well as using laxatives or anal irrigation. A trained person needs to show you how to do this massage safely. You can use a finger (digital stimulation) or hand (manual evacuation) to help you to poo. A specially trained nurse needs to teach you manual evacuation.

If you have MS-related bladder problems, you may have limited your fluid intake. In this case, you will need to treat these as well.

You may be tempted to drink less if you have a bladder problem, or your MS makes getting to the toilet difficult. However, this can make constipation worse.

The generally recommended fluid intake is around 6 to 8 cups or glasses a day (more if the weather's hot or you're exercising). A good fluid intake can help treat and prevent constipation. Apart from your first pee of the day (which is often darker), wee should be pale yellow. Darker urine or strong bad smell means 'drink more'.

Here are diet tips from other MS members :

I live alone, so I ensure that I have a couple healthy snacks for myself that are grab-and-go, for days when I don't have the energy to go make a more elaborate breakfast or lunch. I love a quick fruit shake, yogurt, energy (dry fruit) bar, or fruit to help keep my energy up without worrying about if making it will sap too much time. My water bottle is always in my bag!
-Prashant, studying software Engineering , Age 23, living with RRMS

I try to avoid foods that are considered inflammatory (like sugar). I drink lots of water. Fatigue from dehydration is worse for me. I drink at least 1 liter a day. Drinking coffee and sugar makes me feel good for a short while, but doesn't help n the long run.
-Jaya, a media professional , Age 39, living with RRMS

I try to eat healthy and cut out the sugar, flour (maida), and artificial sweeteners. I do feel better when I eat well. It's not that it brings symptoms on, but I do feel better.
- Anand, age 48, living with RRMS

I take so many different medications, and each one has its own side effects, so I'm finding by having a healthy diet-eliminating fatty foods, consuming mostly fruits and vegetables with lots of fiber-I feel much better. I've also learned popcorn is helpful for staying 'regular.'
- Anaya, age 21, living with RRMS

I've tried. Best to stick with healthy foods with low sugars, but with some carbs for energy. But cutting back on fast foods, sweets, and foods high in saturated fats doesn't require following an elimination diet. It generally just means choosing healthful items from the grocery store and preparing more of your meals at home.
-Maloy, age 28, living with RRMS

HOW OUR SCHOLARSHIP PROJECT CHANGES LIVES.

Our late member Hamir Singh Dagar was a young MS Person who never missed the MSSI Delhi Quality of Life " Day Care" programme. Those were his only outings and he loved them, meeting other members, being treated to a little tea party and being fussed over by one and all.

Being unable to walk, his friend would literally hoist Hamir on his shoulder in a ' fireman's lift' , and bring him to the programme in an auto rickshaw. We provided him a wheelchair and arranged for home pick up & drop courtesy our sponsors Tata Power.
That did make life easier for him, and soon his shy wife also started attending the programmes. However, over the years he deteriorated to a point where these outings became rare.
Our MS nurse looked after him at home, we provided the best care and aids that were possible, but unfortunately we lost him due to complications brought on by his condition.
He left behind two little daughters Ankita & Tina and a barely literate loving wife Rajesh. His parents were 'safai karamcharis' and had hardly enough money for survival!
MSSI Delhi assessed the situation & tried to help in whichever way possible to support them and try to make them self sufficient.
We supported his wife Rajesh in getting a job as an angan wadi worker, while ensuring his daughters got the best possible education, and we have been supporting their education throughout these 14 years, long after Hamir Singh was gone.

The older daughter Ankita completed her schooling with scholarships from MSSI, and went on to graduate in Special Education learning sign language.
She is now working and supporting the family. The younger daughter Tina was admitted to a reputed Convent school under the EWS category with the help of our dear Mrs Diana Khambatta and is now a class 12 student. She is a bright student getting good grades.
MSSI is proud of their achievements, and it is a matter of great satisfaction to see the change we have been able to bring to their lives, as they grow up into confident & independent young ladies!
We thank all our supporters and donors-mostly individuals who stood by MSSI Delhi to make Hamir Singh's dream a reality.
MSSI Delhi does not forget it's members and like the famous line from the Insurance company , stands by its members during their lifetime, and after their passing as well.

If you wish to support the education of a child of an MS parent, contact our office today.

I WILL LIVE

"A new tactic to cheat and claim,
And climb the quick ladder to fame?"

He pointed to the watery trail,
On the patchy floor of the examination hall.
I thought the examiner was venting his spleen,
Amused and somewhat flummoxed,
I scribbled on, vigorously, on the sheets.
It was then the foursome gathered there,
My hand was clasped, the pen retrieved.
I was the culprit, I was told, who had dared to try,
A never before, heard of stunt, to cause a furore,
In the examination hall.
The trail was that of urine.
Not mine, I screamed !
In shock, I wondered at the scene.
That day was the beginning for me,
An introduction, of what life would be.
Of scenes of being wheeled for tests,
Of my legs giving way, as it gripped me thus.
I was a patient of M.S.
M.S.?
Then onwards, the training began.
The simple family, with financial constraints,
Was introduced to this auto immune disease.
Thanks to me.
The player in me, crumbled and died,
Ah yes.
Till at every conceivable step, the toilet door included,
Was I helped.

I fell but I was made to rise.
Yes, rise again, by my family and my young friends.
With those at MSSI.
I'd never stand, nay, not on the ground,
I did learn to wheel my self around.
And wheel I did, with the catheter by my side.
I played my game, they call me the Wheelchair Tennis champ.
I've been around!
I've been around where no ramps were seen,
My chair was lifted, I was carried like a trophy,
My friends were the champs, not me.
The crutches imbalanced my spine it seemed.
And this, hence, is my life, between the courts and at work.
Yes, I fought to be a wheelchair therapist,
For the streaming lines of those in distress.
Some days I'm unable to leave the bed.
The gloom, it often prevails upon me.
For my kidneys fight to do their best.
Yet now on dialysis they'll be.
The hospital visits are now weekly.
My skin it turns a blackish blue,
Sometimes I wonder if I'm in a dream.
I'll fight it out, each day you'll see.
I'm determined to live, for *they* have hope in me.

I dedicate this true story of an MS patient to all the other warriors.

I witness my sister fighting a daily battle with MS. Let us join hands to spread awareness about MS

Divya M.

चेयर पर बैठे बैठे योग

प्रस्तावना

कसरत करनी है, मतलब करनी है !

शरीर मुड़े या न मुड़े, अपनी दिनचर्या में हर दिन सरल सामान्य व्यायाम का समावेश अवश्य करें। ज्यादा नहीं तो शुरुआती तौर पर हर कसरत को एक-एक दो-दो बार ही सही, पर करें ज़रूर। ज्यों-ज्यों असर दिखाई देने लगेगा, व्यायाम में आपकी रुचि बढ़ती जाएगी। विश्वास करें आपको खुद से प्रेम होने लगेगा।

प्रारंभ में भले ही १०-१५ मिनट के लिए छोटी-छोटी आसान कसरतें करें, फिर धीरे-धीरे, खुद ब खुद, जैसे- जैसे कसरत के काउंट (गणना) बढ़ेंगे, कसरत का समय अपने आप बढ़ेगा।

प्रात:काल - सायंकाल २० मिनट के लिए भ्रमण भी ज़रूर करें। दिनचर्या के अन्य महत्वपूर्ण कार्यों की तरह कसरत को भी स्थान देना अत्यावश्यक है। जिस तरह जीवन मे खाना- पीना, सोना-जागना, काम पर जाना जैसे आवश्यक कार्य किए जाते हैं उसी प्रकार कसरत को भी एक आवश्यक अंग बना लें। बाकी सभी कार्य सुचारु रूप से तभी हो पाएँगे जब शरीर स्वस्थ अवं सुडौल होगा।

कसरत और आहार

कसरत कर ली और अब खाने की पूरी छूट हैश यह धारणा गलत है, निराधार है। अपने डॉक्टर की सलाह अनुसार, सब कुछ खा सकते हैं, पर एक ही दिन में या एक ही समय में नहीं अधिक मात्रा में न खाएँ। जो भी खाएँ, उसकी मात्रा केवल इतनी ही हो कि आपको बस ये लगे कि चलो थोड़ा स्वाद भी लिया और सेहत के साथ खिलवाड़ भी नहीं हुआ। ष खा लेते हैं, थोड़ी कसरत ज्यादा कर लेंगेषयह सोच भी गलत है।

कसरत के लिए संकल्प

यदि एक बार स्वास्थ्य अच्छा रखने का मन बना लेंगे तो मानसिक दृढ़ता स्वयं आ जाएगी। ऐसे में आप किसी ऐसे दोस्त या पार्टनर का चयन करें, जो आप ही की तरह सोच रखता हो-आप ही की तरह अपने स्वास्थ्य के प्रति सजग हो, अच्छे स्वास्थ्य के प्रतिदृढ निश्चयी हो। मन से इस सोच को दूर न होने दें कि कितने दिन मैंने केवल बस खाया ही खाया, शरीर को बढ़ने के लिए खुला छोड़ दिया, व्यायाम के लिए तो समय ही नहीं निकाला। यदि ऐसा है तो इस बात पर पश्चाताप का अनुभव होना चाहिए।

कसरत और अनुशासन

कसरत करने के भी कुछ नियम होतें हैं और उसे करने पद्धति का भी ख़ास ख्याल रखना आवश्यक है, क्योंकि गलत कसरत तथा गलत पद्धति के कारण अनेक समस्याएँ उत्पन्न हो सकती हैं। शरीर के अलग-अलग अंगों के लिए भिन्नभिन्न प्रकार की कसरतों का किया जाना आवश्यक है। एक ही कसरत को ज्यादा बार करने से लाभ नहीं होगा।

एक बार किसी विशेषज्ञ के संपर्क में रहकर हर आसन-कसरत नियमानुसार सीख लेना अनिवार्य है। जान लें कि आपके शरीर के अनुसार कौन-कौन सी कसरत की जा सकती हैं कौन सी नहीं। जो भी करसत करे उसे निपुणता से करना ज़रूर सीख लें। हर व्यायाम को करते समय कुछ बातों का ध्यान रखना आवश्यक होता है। धीरे-धीरे आप उसे उसी प्रकार करने के अभ्यस्त हो जाते हैं। अच्छे स्वास्थ्य के लिए कुछ समय एवं पैसा व्यय करना पड़े तो वह बीमार रहकर शारीरिक कष्ट सहने से तो कही बेहतर है। तो क्यों न हम इसके प्रति आज से ही बल्कि अभी से सजग हो जाएँ।कसरत नहाकर करें या बिना नहाए,

प्रात: करें या सायंकाल
पर करें खाली पेट, करें मन लगा कर,
नियमित रूप से, नियमानुसार करें
मजबूरी नहीं, इसे आनंद का विषय मानकर करें,
अपनी क्षमता के अनुसार करें
उम्र कोई भी हो, समय निर्धारित करते हुए
आज से ही व्यायाम प्रारंभ कर दें
व्यायाम को अपने जीवन का महत्त्वपूर्ण अंग बनाएँ।

यह आवश्यक नहीं कि आप सभी आसनों में माहिर हो जाएँ, परन्तु अहम बात यह है कि अपनी जीवनशैली के अनुसार कसरत का स्वरूप पहचान कर एक निश्चित रुपरेखा एवं क्रम तैयार कर लें। इन्हें नियमित रूप से करते हुए खुद में गर्व महसूस करें। हाँ, अपने आप को शाबाशी देना कभी न भूलें। दर्पण के समक्ष खड़े होकर आत्माविश्वास के साथ खुद को निहारें और मुस्कुराएँ।

जैसा कि ऊपर बताया गया है, प्रतिदिन २०-३० मिनट (अपनी क्षमता के अनुसार) पैदल भी अवश्य चलें। ध्यान रहे यह प्रक्रिया आहार से २० मिनट पूर्व की जानी चाहिए अथवा आहार के कम-से-कम ३ घंटे बाद करनी चाहिए।

चाल की तीव्रता सुनिश्चित करने का अंदाजा कुछ ऐसे लगाएँ कि जब आप भ्रमण कर रहे हैं और उस दौरान बात करने का प्रयास करते हैं तो आपके द्वारा उच्चारित शब्दों का प्रवाह टूटना नहीं चाहिए (फ्लुएंसी बनी रहे) परंतु सहजता से गीत गा सकना संभव न हो - चलने की वही गति सही मानी जाएगी (वाक एंड टॉक)।

भ्रमण की बात करते हुए हम यहाँ कुछ सरल चेयर योग (कुसी पर योग) का भी उल्लेख कर रहें हैं। ये उन वरिष्ठ नागरिकों के

के लिए उपयोगी हैं, जो ज़मीन पर नीचे बैठ कर व्यायाम करने में खुद को असमर्थ पाते हैं।

आराम देह वस्त्र पहनकर, एक स्वच्छ एवं शांत वातावरण में निम्नलिखित सामान्य कसरतों का अभ्यास करें तो आप निश्चित रूप से खुद में परिवर्तन महसूस करेंगे। ध्यान रहे इन कसरतों का अधिकतम लाभ प्राप्त करने के लिए, इन्हें वॉक के बाद, नीचे दर्शायी गई पद्धति के अनुसार ही करें। कसरत शुरू करने के लिए सर्वप्रथम एक बिना हत्थे (Arms) की, टेक और गद्दी वाली (backrest and cushioned) मजबूत कुर्सी लें। कुर्सी को किसी मेट पर रखें ताकि फिसलने का भय न रहे। कमर को कुर्सी की कमर-टेक के साथ सटा कर तटस्थ बैठ जाएँ। अपनी क्षमतानुसार पूरे अभ्यास के दौरान अपनी रीढ़ की हड्डी को बिलकुल सीधा रखें। पैरों को जमीन पर टिका लें। अगर पैर टिक न रहे हों तो एक पतली चौंकी (Stool) रखी जा सकती है।

श्वास निरीक्षण

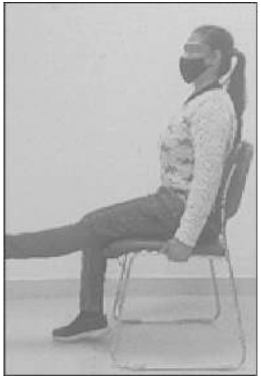
सबसे पहले गहरी साँस लेने की क्रिया से शुरुआत करेंगे। कुर्सी पर अच्छी तरह टेक लगाकर सीधे शांत मुद्रा में बैठ जाएँ। अपनी रीढ़ की हड्डी को बिलकुल सीधा रखें।

- आँखें हल्के से बंद करें और भीतर ही भीतर आत्मावलोकन करते हुए अपने शरीर की स्थिति पर गौर करें।
- एक गहरी लम्बी साँस लें और फिर धीरे-धीरे साँस छोड़ें
- कोई भी विचार आए तो आने दें
- अपना पूरा ध्यान साँसों पर केंद्रित करने का प्रयास करें।
- जब आप साँस लेते हैं तब आपको अपनी पसलियाँ फूलती हुई महसूस होगीं।
- साँस छोड़ने पर पसलियाँ भी सामान्य स्थिति में आ जाएँगी।

(शरीर की आरामदेह स्थिति)

घुटनों की कसरत

- कुर्सी पर अपने कूल्हे पीछे तक टिकाते हुए कमर से टेक ले कर या सीधे बैठ जाएँ



- कमर सीधी रखते हुए अपने हाथों को दोनों ओर आराम से रखें कंधे आरामदेह सामान्य स्थिति में हों
- अपनी दायाँ पाँव सीधा सामाने की ओर ले जाएँ, ऐसे में घुटने को कुर्सी पर दबान की स्थिति में बनाए रखें (घुटना ऊपर उठना नहीं चाहिए) (चित्र न०१)
- पैर के पंजे को आहिस्ता से अपनी ओर खींचे। इस स्थिति को एक गहरी साँस लेने तक बनाए रखें और फिर पैर प्रारंभिक स्थिति में ले आएँ। ऐसा ८ बार करें या अपनी क्षमता के अनुसार
- ठीक इसी प्रकार बाएँ पैर से कसरत करें।
- कसरत के दौरान सामान्य रूप से निरंतर श्वास निश्वास की प्रक्रिया चलती रहनी चाहिए। कसरत के दौरान कमर सीधी रखें।

प्रारंभिक स्थिति (Starting Position)

अब आप कुर्सी की गद्दी के आगे के आधे भाग का इस्तेमाल करते हुए (कुर्सी की गद्दी के आधे अग्र भाग पर) कूल्हे टिका कर बैठ जाएँ। पैरों को ज़रा आगे की ओर ले जाएँ और उन्हें पूरी तरह नीचे ज़मीन पर टिका कर रखें. दोनों पैरों के बीच का फाँसला आपके कूल्हे की चौड़ाई के जितना होना चाहिए। निश्चित करें कि कुर्सी का संतुलन ठीक है। कमर सीधी रहे, हाथ अपनी दोनों साइडों पर आराम की स्थिति में रखें। पैर ज़मीन पर टिकाए रखें। अब हम कुर्सी के अग्र भा पर बैठकर कुछ अभ्यास इस स्थिति में ही करेंगे।

छाती और कंधे का नियंत्रित स्ट्रेच

- प्रारंभिक स्थिति ले लें

- हाथ से कुर्सी की कमर टेक के निचले भाग को पकड़ें (अँगूठा सामने परंतु नीचे की ओर रहे)
- कोहनियों को सीधा रखते हुए छाती आगे की ओर तानकर रखें, झुकना नहीं है (चित्र न० २)
- कंधों को ऊपर की ओर न उचकने दें, सामान्य ही रखें। अधिक खिंचाव बनाने के लिएरू हाथों को धीरे-धीरे कुर्सी की कमर टेक के दोनो तरफ से पकड़े-पकडे, हथेलियों को ऊपर की ओर खिसकाने का प्रयास करें (चित्र न० ३)

- १० सेकंड के लिए (या अपनी क्षमता के अनुसार) इस स्थिति में बने रहें, इस दौरान अपनी साँस सामान्य बनाए रखें

पूर्व स्थिति में आ जाएँ, ऐसा केवल तीन बार करें।

शरीर/ धड़ की दाईं ओर का नियंत्रित स्ट्रेच (Stretch)

- प्रारंभिक स्थिति ले लें
- अपने बाएँ हाथ को कुर्सी की साइड पर टिका दें।
- श्वास भरते हुए, अपना दायाँ हाथ सीधा रखते हुए आगे की ओर से ऊपर ले जाए तथा बाँह को कान से सटाए रखें। अब हाथ नीचे

लाते हुए, बाँह को कोहनी से मोड़कर हथेली सिर के पीछे रख दें।

- अब साँस छोड़ते हुए धड़ को बाईं ओर मोड़ते हुए, दाईं तरफ कमर की साइड पर खिंचाव महसूस करें
- अब साँस भरते हुए धीरे धीरे, शरीर एवं पेट की दाईं ओर की पेशियों का इस्तेमाल करते हुए, वापस सीधे बैठ जाएँ। एक गहरा सांस लें और छोड़ें।

- इसी प्रकार बाईं ओर की भी कसरत करें।
- मुड़ते समय गरदन पर बहुत अधिक खिंचाव न बनाएँ। गर्दन को शरीर के साथ समरूप में बनाए रखें। ऐसा करते हुए कंधे को सामान्य स्तर पर रखें, उचकाएँ नहीं। ऐसा करीब, तीन-तीन बार (अपनी क्षमता के अनुसार करें। साँस लेने एवं छोड़ने की प्रक्रिया पर विशेष ध्यान दें।

स्क्वाट (Squat)(चित्र न० ५)

- प्रारंभिक स्थिति ले लें
- हाथों पर वज़न लेते हुए, आगे की ओर हल्का सा झुकत हुए, कूल्हों को गद्दी से ज़रा सा उठाएँ। एक गहरी साँस भरने तथा छोड़ने तक इस स्थिति में बने रहें (अपनी क्षमतानुसार)
- धीरे-धीरे इस कसरत को इसी तरह ३ बार की साँस लेने व छोड़ने की प्रक्रिया के जितने समय के लिए करें।

धड़ का दाईं ओर का घुमावप्रद नियंत्रित

- प्रारंभिक स्थिति ले लें
- श्वास भरते हुए, अपना दायाँ हाथ सामने से बाईं ओर ले जाएँ, और अपने घुटने के बाहरी सिरे पर टिका दें।
- बायाँ हाथ और बाँह का अगला भाग कुर्सी की कमर-टेक के ऊपरी सिरे पर टिका दें (चित्र न० ६.१ और ६.२-side view)
- अब कमर से धुमाव बनाते हुए छाती को बाईं ओर ले जाएँ। (ऐसे करते हुए कंधे सामान्य स्तर पर बनाए रखें, उचकाएँ नहीं)
- ध्यान रहे आपका धड़ और गर्दन एक ही सीध में हों इस मुद्रा में २-३ गहरे श्वास लें (अपनी क्षमता के अनुसार)

- श्वास छोड़ते हुए सामान्य मुद्रा में आ जाएँ
- ऐसा केवल तीन बार करें
- इसी प्रकार दूसरी तरफ का व्यायाम भी करें।

नितंब का नियंत्रित स्ट्रेच

- प्रारंभिक स्थिति ले लें
- अपनी दाईं टाँग को आराम से उठाएँ और बाएँ घुटने के ऊपर रख दें।
- इस स्थिति को ३ गहरे श्वासों जितने समय तक बनाए रखें (अपनी क्षमता के अनुसार)
- अधिक खिंचाव बनाने के लिए, इसी दौरान आप आगे की ओर झुकने का प्रयास कर सकते हैं।
- धीरे से अपने दाईं टाँग को घुटने से हटाकर सामान्य मुद्रा में ले आएँ
- अब यही कसरत बाई टाँग से भी दोहराएँ
- ऐसा केवल तीन-तीन बार करें।

कमर के निचले हिस्से का नियंत्रित स्ट्रेच

- कुर्सी पर अपने कूल्हे पीछे तक टिकाते हुए कमर से टेक ले कर या सीधे बैठ जाएँ
- कमर सीधी रखते हुए अपने हाथों को दोनों ओर आराम से रखें कंधे आरामदेह सामान्य स्थिति में हों
- अपने पैरों की ओर झुक जाएँ। खुद को ढीला छोड़ दें। तीन चार गहरे साँस लेने-छोड़ने जितने समय के लिए इस मुद्रा में रहें
- बहुत धीरे-धीरे आराम से, श्वाश भरते हुए, ऊपर आते हुए वापस अपनी सामान्य स्थिति में आ जाएँ।

श्रीमती अनीता गुप्ता
डॉ ऋचा हीरेन्द्र राय

OUR STARS SHINE BRIGHT !

Very few people realise the tremendous role played by the back-office staff of any organisation. This is even more true at MSSI Delhi. Though all of you remember just a couple of names because they have been there for many years , the truth is nothing works without teamwork. MSSI Delhi's not-so-visible, members are the strong silent pillars of the workforce, and the backbone of our team.

All our MSp's who have attended our events or have called up the office for any queries or assistance are familiar with the names of Shashi, Rajkumar and of course Puja!

Today, let's tell you something about all of them.

SHASHI VERMA:

She has been with us since 2008 and is one of our dependable trio at the office in Shahpur Jat. She is an amazing asset to our team. She recognises almost all of the members and knows their personal details so that when they call for help she knows what to do. Often it is just to lend a patient ear to their anxieties, although she has loads of work to do.

Shashi arranges Physiotherapy appointments and keeps track of all the schedules and payments.. that is a lot of work when there are 12-14 physiotherapists visiting 45 MSps adding up to almost 500 calls a month! She also prepares all the data charts for the Scholarship project as well as that of the Home Attendant ! Phew!

Shashi's strength lies in her ability to interact with all the MSP's who call up the office and come to the events held by us. She responds smilingly and with patience and makes sure that all queries are followed up and dealt with in time for our monthly reviews.

Shashi lives very close to the office in Shahpur Jat, and starts her day at 8 am – She works till the afternoon, so that she can be home in time to look after her young son (who is now in Class 12) , her home & ageing father in law before her husband returns from his office in the suburbs. It's not easy being a working woman !

We really appreciate her quiet dedication & smiling countenance.

RAJKUMAR:

Raj Kumar is not only a Jack of all trades, he is indeed a master of many talents as well ! Enthusiastic and self driven, he has been with MSSI Delhi since 2009. There is nothing that he cannot do–making payments, handling the utility billing, chasing the bank; sitting with our accountant to cross tally the bank entries, handle all the post & courier, arrange packing & shipping of the medicinal supplements; make sure that all the courier receipts have come back, supervise office repairs & maintenance,

, do the backend work during our events, filing, copying and collating all reports when we have our monthly EC Meetings at the office – and all this with a smile on his face!

His family- his wife and two sons (Class 8 and Class 5) live close by in Chirag Dilli. His ever-faithful bike is his steed and he has traversed throughout the Delhi and NCR region on it to complete all our outdoor jobs.

Most members are familiar with Puja, she has been a regular at all our functions, always smiling, always cheerful, she is now a key part of our Office team and is doing an amazing job there. She was diagnosed with MS in 2006 and has been a member of MSSI Delhi since 2007. An active member, she was and is always ready to help whenever we asked her . However in 2020 we requested her to join the office formally, as we realised that she would be an asset to our team. Puja has studied Hotel Management and went on to complete a degree in Law, so she brings many skills to her role.

Her upbringing as an "Army brat " ensured she is game for any kind of work-with discipline, punctuality & dedication! As she happily says–"she can do anything and everything".

Being a self starter, she began by looking after the social media but soon became an asset in Office Management. The systems and data were taken over by her to be updated and updated & updated! We now have all our MIS streamlined & are able to access almost all of it in real time.

She is mother to Purab, her 18 year old , and an absolutely delightful young lady Chahat who is now 10. Her favourite pastime is spending time with them, reading, playing games & instilling in them all the right values.

Ably supporting this key team are 2 others.

SHAGUFTA FATIMA: Our home care attendant who criss-crosses Delhi, Gurgaon & Noida to provide support services to caregivers regardless of burning hot sun, pouring rain or freezing winds!

And last but not the least-

GOPAL CHAKRABORTY: our Accountant, who works hard to keep our books clean transparent & up to date.

As you can see, our MSSI stars shine bright and are our strength and the true power behind our success. Without them we would be stranded, and we are using this opportunity to say thank you very much to all of them.

We are proud of the fact that you are a part of us and are always there for MSSI, making MSSI Delhi a truly 5 Star Office !

MSSI DELHI
wishes to thank you all

*Kotak Mahindra Bank Ltd

* Fena Foundation

* Swarn Lata Motherson Trust

Arvind Mohan Deshraj
Binoy Jacob
Castle Arts Pvt. Ltd.
D.H. Katrak
Deepak Joshi
Divya Anmol & Sons
Hemant Kumar
Jasmine Bindra
KSN Impex P Ltd
Neeraj Gupta
Netarwala & Aibara Interior Architects
Pran K Murgai
Dr Rana Patir
Satish & Madhu Jindal
SK Gupta
Span Foundation

Our deep gratitude to the Faculty of the Neuro Sciences Centre at AIIMS Delhi.

Our sincere thanks to all Hospitals and Doctors of Delhi NCR for their patience, cooperation & dedicated service.

All our silent volunteers, donors & supporters, thank you. We could not have done it without you.

MSSI is registered under Societies Registration Act of 1860 No: F1072
Donations are exempt under Section 80G of the IT Act 1961
FCRA No: 083780439, PAN: AAATM0133E


Best Western
Vib
PREMIER BEST WESTERN
Sadie BEST WESTERN
BW SIGNATURE COLLECTION by BEST WESTERN
Executive Residency
Best Western PLUS
Aiden by BEST WESTERN
BW Premier COLLECTION
GLō
SureStay HOTEL by BEST WESTERN
SureStay PLUS HOTEL by BEST WESTERN
SureStay COLLECTION by BEST WESTERN

MSSI®
Delhi

is Deeply grateful to

FENA FOUNDATION
for their generous support

MSSI®
Delhi

Thank you

DR. SUHAS SHAH
Mumbai

Actual Site Photo

Building
the Graphic Arts
Community
Since 1979

Our Magazines

Packaging South Asia
A decade old monthly magazine covering the packaging industry in the South Asian region. Consistently offering vital insights and industry intelligence a cross the supply chain.

Indian Printer and Publisher
A monthly magazine with a track record of 44 years of comprehensive and high quality coverage of the printing and publishing industry in the South Asian region and beyond.

IndiFoodBev
Three years old quarterly magazine covering all food and beverage sectors, procurement, sorting, storage, processing, packaging, logistics, retailing, food safety, automation ext,

Other activity

IPPStar
Services Training & Research
Where print business comes to life

A research-driven consulting enterprise dedicated to harnessing the best that the printing and packaging industry can offer to chart feasible roadmaps for its future growth.

N10, Sector XI, Noida, UP 201301. Telephone +91-120-4326053, 4546988
Advertisement: ads5@ippgroup.in I ads6@ippgroup.in Subscription: subscription@ippgroup.in

With Best Compliments
From:

KEGGFARMS GROUP

❖Keggfarms❖Indovax❖Avitech❖
❖Immunetics❖VSK Baithak❖

8th Floor, Eros Apartments, 56- Nehru Place, New Delhi-110019
Tel.: 8010948573, 0124-4567909, 4567900-03
Email: keggfarm@ndf.vsnl.net.in❖ chairman@indovax.com