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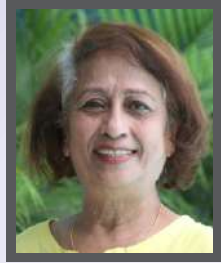
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MULTIPLE SCLEROSIS SOCIETY OF INDIA

MEET YOUR MSSI DELHI MANAGING COMMITTEE



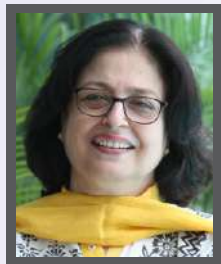
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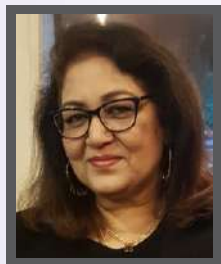
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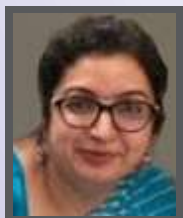


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Affiliated to Multiple Sclerosis International Federation (MSIF)
www.msif.org



Hello friends ,

The continued love, trust and deep faith that has been showered on the MSSI Delhi team by PwMS and their family members has been overwhelming. This love & trust has only resulted in strengthening our resolve and dedication towards this cause.

MSSI Delhi is now 34 years old, and an integral part of the 36 year old all India organisation. We are proud that almost all of our volunteers in the Managing Committee have been working selflessly for a large part of this period, with key members having spent over 20 years each !

Our cover picture is a memory of the MSIF International Conference of 2011

The Delhi Chapter with 800 plus registered PwMS has been serving all the MS persons & families across more than six states of North India, not to mention many others who seek information & assistance from different parts of India and Nepal. Ours is a non profit, voluntary charitable organisation and our supporters enjoy the benefits of 80G and FCRA.

We are deeply grateful & obliged to our donors, supporters & the medical community for their patience, continued support encouragement. Special gratitude to Kotak Bank, Nariman Trust Fena Foundation & SLMT for enabling us to help those less fortunate.

With our informative & well researched handbook we reach out and guide our members with a glimpse into MSSI ,the challenges of living with MS and progress in the MS world.

We look forward to your sharing of your own MS experiences and we welcome any suggestions that could help us in improving the quality of life of those living with MS. Your valuable presence in all our awareness programmes and active participation in our social media campaigns is always highly appreciated.

With warm wishes
Bipasha Gupta

Acknowledgments: We are pleased to share with you a "Walk Down Memory Lane"- Pictures from our archives of events and personalities who have made MSSI Delhi what it is today.

We acknowledge the following prime sources and their articles for the information in this Edition. Time Magazine, www.msif.org, MS Focus past issues, MS Society Australia, NMSS among other online sources.

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.

Editorial Team:

Meenakshi Bhujwala, Mridula Murgai

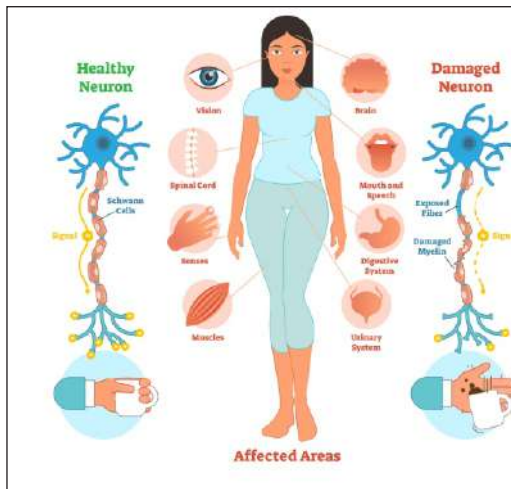
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ARE YOU SURE IT'S MS ?

Damage to the myelin coating around the nerve fibers in the central nervous system (CNS) and to the nerve fibers themselves interferes with the transmission of nerve signals between the brain, spinal cord and the rest of the body. Disrupted nerve signals cause the symptoms of MS, which vary from one person to another and over time for any given individual, depending on where and when the damage occurs.

The diagnosis of MS requires evidence of at least two areas of damage in the CNS, which have occurred at different times.

Overview

Perhaps you've read descriptions of MS on the internet that sounded like symptoms you are experiencing. You're probably worrying that you or someone you care about may have MS. Maybe someone else in your family has MS and you're worried about your own chances of developing it. Or, perhaps you've been told by your doctor that you might have MS because you have experienced a single episode of MS-like symptoms.

Is there someone I can talk to about my situation?

Absolutely. If you have questions about MS- what it is, how it's diagnosed, how it's treated, what might happen or any other issues that are of concern to you, call MSSSI Delhi on 011-26490087 and request a session with one of our friendly & knowledgeable counselors.

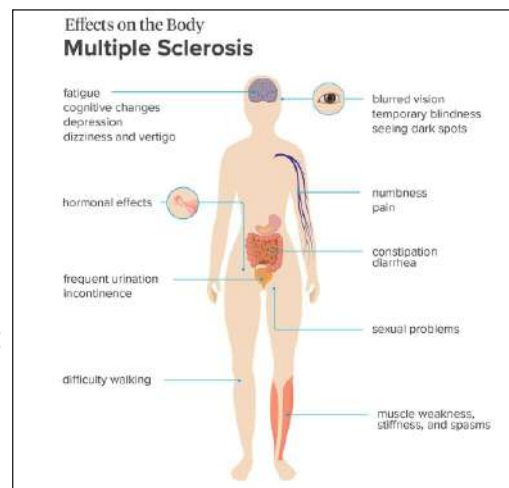
Why can't the doctor tell me what's wrong with me?

While diagnostic criteria exist to help make an accurate diagnosis of MS, it is not an easy disease to diagnose. There is no single test for multiple sclerosis. Second, the diagnosis cannot be made until the healthcare provider finds evidence of two episodes of disease activity in different locations in the central nervous system that have occurred at different points in time. And third, most MS symptoms, particularly early in the disease, can be caused by other conditions, which means that your healthcare provider needs to rule out all other possible explanations.

Very often, when a central nervous system problem, such as MS, is suspected, a number of tests will need to be done before the diagnosis is confirmed. One of those tests, MRI, is an important test that helps with the diagnosis as it can reveal areas of damage that are typical of MS.

Are there any treatments available to help me in the meantime?

- If your healthcare provider believes-based on your medical history, physical exam, and test results-that you have clinically isolated syndrome and are at high risk of developing MS, there are medications that have been shown to delay the development of clinically-definite MS.
- If you're experiencing symptoms that are making you uncomfortable or interfering with your everyday activities, be sure to discuss them with your healthcare provider. Many symptoms can be successfully managed even without a confirmed diagnosis.



- If you're feeling overwhelmed or stressed out by your symptoms or the uncertainty of the diagnosis, consider talking with a counselor about it. The Society can refer you to a professional in your area for help in dealing with this difficult situation.

What is clinically isolated syndrome (CIS)?

In multiple sclerosis, the immune system attacks the brain, spinal cord and optic nerves. These make up the central nervous system, which controls everything we do. Damage from the attack disrupts signals to and from the brain and causes the symptoms of MS. Clinically isolated syndrome (CIS) is one of the 4 multiple sclerosis disease courses. CIS refers to a first episode of neurologic symptoms like those in MS. If you experience CIS, you may or may not go on to develop MS. To be considered CIS, the episode must:

- Last at least 24 hours
- Be caused by inflammation and demyelination (loss of the myelin that covers the nerve cells) in the central nervous system. An episode can include one or more than one symptom. It usually has no associated fever or infection and is followed by a complete or partial recovery.

CIS symptoms

In CIS, your symptoms are linked to where the damage to the myelin occurred in the central nervous system. You may have:

- Vision problems, including optic neuritis, blurred vision, poor contrast or color vision and pain on eye movement
- Numbness or tingling of the face, body or extremities (arms and legs)
- Walking difficulties
- Spasticity
- Fatigue
- Weakness
- Bladder and/or bowel problems
- Dizziness
- Sexual problems

Who gets CIS, and when?

Like MS, CIS is not directly inherited, and it is not contagious. CIS is 2 to 3 times more common in women than men. Seventy percent of people diagnosed with CIS are between the ages of 20 and 40 years (the average age is 30). But people can develop CIS at older or younger ages.

How is CIS different from MS?

Based upon clinical symptoms alone, CIS and MS may appear the same. In both, damage to the myelin sheath (demyelination) interferes with the way nerve impulses travel to and from the brain, resulting in neurologic symptoms.

- A person with CIS, by definition, is experiencing the first episode of symptoms caused by inflammation and demyelination in the central nervous system. A person with MS has experienced more than one episode.
- With CIS, an MRI may demonstrate damage only in the area responsible for the current symptoms. With MS, there may be multiple lesions on MRI in different areas of the brain and spinal cord.

CIS progression to MS

If you have experienced CIS, you may or may not go on to develop MS. Your healthcare provider will do their best to determine the likelihood of this happening. Here are the criteria they use to make that determination:

- **High risk of developing MS:** If a provider sees brain lesions similar to those in MS on magnetic resonance imaging (MRI), they predict that you have a 60% to 80% chance of a second neurologic event and diagnosis of MS within several years.

- **Low risk of developing MS:** If CIS is not accompanied by MRI-detected brain lesions, you have about a 20% chance of developing MS over the same period of time.
- **Diagnosis of MS:** If CIS is accompanied by MRI findings of old lesions or scars that confirm an earlier episode of damage in a different location in the central nervous system, then an MS diagnosis is confirmed. The presence of oligoclonal bands in a person's cerebrospinal fluid can also help make the diagnosis.

As MRI technology becomes more advanced, it is likely that the diagnosis of MS will be made more quickly and there will be fewer people diagnosed with CIS. A quicker diagnosis also allows people to get treatment earlier and to slow their disease course.

For those whose CIS does turn into MS, how long does it take?

Not everyone who has an episode of CIS goes on to receive an MS diagnosis. Only 63% of those who experience an episode of CIS go on to receive an MS diagnosis. It is impossible to predict who will and in what period of time. Many factors contribute to this — including some that have not been identified yet.

In addition, many people with CIS are using disease-modifying therapies to delay (and in some cases prevent) MS. If you have had an episode of CIS and are not using a DMT, talk to your healthcare provider about treatment.

What factors influence whether or not CIS turns into MS?

Researchers have recognized multiple variables and risk factors that play a role in the potential for CIS to convert to MS. These include:

- Younger age of disease onset
- Male gender
- The number of MRI lesions
- Oligoclonal bands in cerebrospinal fluid

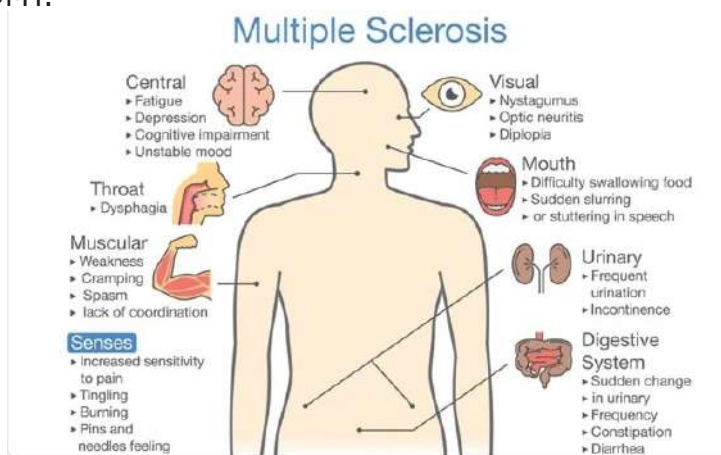
This list is not exhaustive. Also, the items in this list do not always apply to each person with CIS. For instance, all men with CIS are not guaranteed to get MS. Finally, there are also a number of risk factors associated with MS, like vitamin D deficiency and smoking, that you can control.

Treatment for clinically isolated syndrome

Treatment with a disease-modifying therapy (DMT) may delay or prevent a second neurologic episode and, therefore, the onset of MS. In addition, early treatment may minimize future disability caused by further inflammation and damage to nerve cells, which can sometimes occur without any noticeable symptoms. If you have CIS, discuss starting a DMT with your healthcare provider if both things are true:

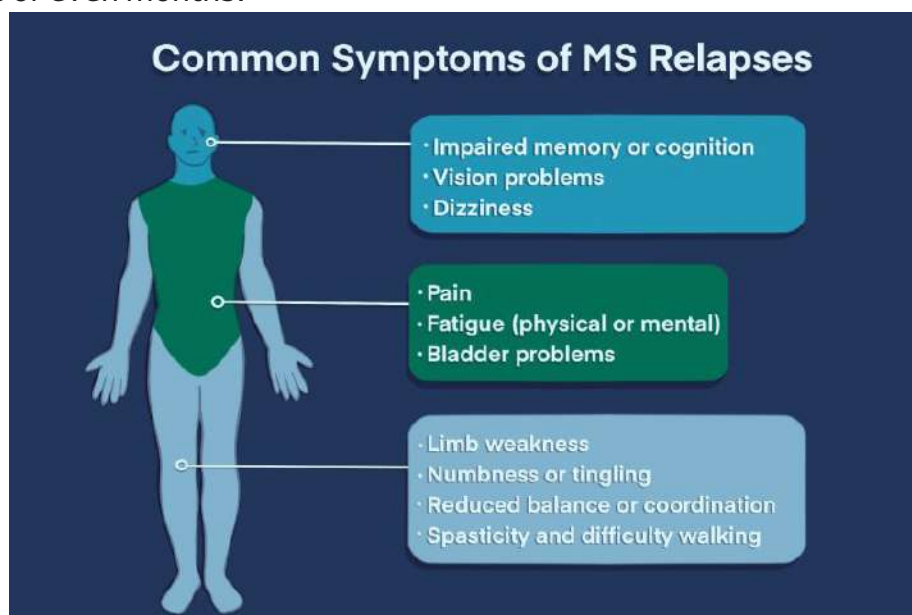
1. You have had one event of MS-like symptoms
2. You have two or more brain lesions on an MRI scan

You and your healthcare provider can take into account your specific risks and benefits and decide whether or not you should start a DMT.



MANAGING RELAPSES

An exacerbation of MS (also known as a relapse, attack or flare-up) is the occurrence of new symptoms or the worsening of old symptoms. It can be very mild, or severe enough to interfere with a person's ability to function. No two exacerbations are alike. Symptoms vary from person to person and from one exacerbation to another. For example, the exacerbation might be an episode of optic neuritis (caused by inflammation of the optic nerve that impairs vision), or problems with balance or severe fatigue. Some relapses produce only one symptom (related to inflammation in a single area of the central nervous system). Other relapses cause two or more symptoms at the same time (related to inflammation in more than one area of the central nervous system). To be a true exacerbation, the attack must last at least 24 hours and be separated from the previous attack by at least 30 days. It must also occur in the absence of infection, or other cause. Most exacerbations last from a few days to several weeks or even months.



What causes exacerbations?

Exacerbations (relapses) are caused by inflammation in the central nervous system (CNS). The inflammation damages the myelin, slowing or disrupting the transmission of nerve impulses and causing the symptoms of MS. In the most common disease course in MS-called relapsing-remitting MS-clearly defined acute exacerbations are followed by remissions as the inflammatory process gradually comes to an end. Going into remission doesn't necessarily mean that the symptoms disappear totally-some people will return to feeling exactly as they did before the exacerbation began, while others may find themselves left with some ongoing symptoms.

Treating exacerbations

The good news is that not all exacerbations require treatment. Mild sensory changes (numbness, pins-and-needle sensations) or bursts of fatigue that don't significantly impact a person's activities can generally be left to get better on their own.

For severe exacerbations (involving loss of vision, severe weakness or poor balance, for example) which interfere with a person's mobility, safety or overall ability to function, most neurologists recommend a short course of high-dose corticosteroids to reduce the inflammation and bring the relapse to an end more quickly. The most common treatment regimen is a three or five-day course of intravenous (Solu-Medrol-methylprednisolone) or oral (Deltasone-prednisone) corticosteroids. Corticosteroids are not believed to have any long-term benefit on the disease.

MSSI DELHI- KEEPING UP WITH THE TIMES

The world changed in March 2020, when each person on this planet learnt about a new illness: COVID 19. It turned our world upside down, it has made us look at our values differently and it has made us realise more than ever before the importance of staying in touch with those whom we love & cherish. It taught us even though we are locked up in our homes that distancing need not isolate us or make us feel isolated.

Social Media, in all its varied forms, came to our rescue and very soon we were all chatting, Zooming, WhatsApp -ing, video calling each other and spending a lot more time communicating with all those who are a part of the MS World far & wide. It actually turned the world into one big family as we started making contacts with people like us from all parts of the globe.

VIRTUAL HOME VISITS:

Our Home visits were always among our most popular programmes. Our MSPs always looked forward to the visit from our volunteers and welcomed them into their homes.. We looked forward to getting a first-hand glimpse of their home situations and towards getting a chance to talk to them personally on a one-to-one basis. However, in the last 3 years it has become a common activity, with everyone " meeting" on line. At MSSI Delhi we have slowly restarted our personal home visit since last summer, and now have both Virtual and in -person Home Visits taking place on a regular basis.

Would you like us to visit your home? Video call us, and let us know; introduce us to your family and we would love to chat with all of you! Our wonderful friendly volunteer Shalini Monga is a real treasure ! She tries not to miss a single birthday of our MS members, calling each one on their special day just to wish them.



SOME OF OUR MILESTONES : 2022-2023

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 Doctors sessions were a combination of Online & in person meetings These covered subjects like Medical Seminars, Doctor's lectures, sessions on Rights of Persons with Disability, Yoga, Mental Health, Physiotherapy, Alternate medicine and Diet & Nutrition Programmes along with social & entertainment programmes like the Picnics in the Park

- **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

● **HOME VISIT-** All of us at MSSSI Delhi really enjoy meeting you all in your homes- unfortunately that was not entirely possible this year either, so we ramped up our Video calling and found ourselves making many online visits & chats 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, even Bihar &

● **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 MS person. This year we supplied 6 wheelchairs, 2 walkers, 2 toilet chairs, 2 walking sticks and 1 Air bed.

● **BIRTHDAY CARDS-** Each year we send specially designed birthday cards to over 800 members by post.

Mostly Shalini makes video calls and talks to the birthday boy/girl and their family members, enjoying the virtual birthday sweets & cakes! Our EC Member Meera Hora has 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!

● **SCHOLARSHIPS TO CHILDREN OF MS FAMILIES:** We provide financial support to several families by subsidising or completely sponsoring the education of school children & young undergraduates to ensure that they become self reliant responsible individuals, and no family has to stop the education of their children for lack of resources. This is a noble task and many individuals have come forward to sponsor a student.

We are proud that in the last academic session we had many top scorers from all classes, with 5 shining stars who scored between 85% and 95% in the Class 12 Board exams. MSSSI Delhi is currently supporting 45 children , and our prime donor to this project is SLMT (Swarnlata Motherson Trust)

● **MEDICINES & NUTRITIONAL SUPPLEMENTS:** Supplements and protein powders, vitamins as recommended by the Doctor are regularly sent to those under privileged members who are going through nutritional deficiencies due to poor diet or poor health caused by being bed bound.

- Cod Liver Capsules· Vitamin D3 and Calcium
- Vitamin C with Zinc· Vitamin A to Z· Protein Shakes etc

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 senior MC members as deserving beneficiaries facing poor health due to lack of a balanced diet. This supplement project is essentially for MSPs who are in the low or no income group , with the family income from all sources being under Rs. 20,000/- pm . Under this scheme we also provide essential MS medicines , along with financial assistance for wheelchairs, hospital beds, air mattresses & other aids.

● **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.

We are grateful to **Justice Rohinton F Nariman** for his generous grant that ensures some dignity and a better quality of life to those living with MS.

● HOSPITAL ADMISSIONS AND APPOINTMENTS WITH LEADING NEURO DOCTORS:

Priority based emergency hospital admissions are organised with the help of senior consultants at AIIMS and RML Hospital. 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.

TOTAL REHABILITATION & CARE

● **HOME CARE ATTENDANT**-Shagufta, our home care attendant for home bound women MSPs 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 nail paint ! She makes them look and feel better, and this allows their caregivers some time off as well. She visits each lady MS member for 2-3 sessions per week, averaging over 50 visits a month.

● **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 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 MS Persons out for a walk occasionally or with the cooperation of their 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. The time which she gives to MSSSI Delhi so generously is deeply appreciated. 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 other cities as well in the near future.

We are grateful to **Kotak Mahindra Bank** for their continued generous support of this essential project.

HOW CLOSE ARE WE TO A CURE FOR MULTIPLE SCLEROSIS?

New disease-modifying therapies for multiple sclerosis can help slow disease progression. Some experimental therapies may show promise in treating the disease. There's currently no cure for multiple sclerosis (MS), but treatment can help manage it. In recent years, new medications have become available to help slow the progression of the disease and relieve symptoms.

Researchers continue to develop new treatments and learn more about the causes and risk factors of this disease. Read on to learn about some of the latest treatment breakthroughs and promising avenues of research.

New disease-modifying therapies

Disease-modifying therapies (DMTs) are the main group of medications used to treat MS. To date, the Food and Drug Administration of USA (FDA) has approved more than a dozen DMTs for different types of MS.

Most recently, the FDA has approved:

- **Ocrelizumab (Ocrevus)** It treats relapsing forms of MS and primary progressive MS (PPMS). It's the first DMT Trusted Source to be approved to treat PPMS and the only one approved for all four types of MS.
- **Fingolimod (Gilenya)** It treats pediatric MS. It was already approved for adults. In 2018, it became the first DMT to be approved for children Trusted Source.
- **Cladribine (Mavenclad)** It's approved to treat relapsing-remitting MS (RRMS) & active secondary progressive MS (SPMS).
- **Siponimod (Mayzent)** It's approved to treat RRMS, active SPMS, and clinically isolated syndrome (CIS). In a phase 3 clinical trial, siponimod effectively reduced the rate of relapse in people with active SPMS. Compared with a placebo, it cut the relapse rate in half.
- **Diroximel fumarate (Vumerity)** This drug is approved to treat RRMS, active SPMS, and CIS. It's similar to dimethyl fumarate (Tecfidera), an older DMT. However, it causes fewer gastrointestinal side effects.
- **Ozanimod (Zeposia)** This drug is approved to treat CIS, RRMS, and active SPMS. It's the newest DMT to be added to the market and was FDA approved in March 2020.
- **Ponesimod (Ponvory)** The FDA approved this drug in March 2021. Ponvory has been shown to reduce annual relapses for relapsing types of MS by 30.5 percent when compared with teriflunomide (Aubagio).

While new treatments have been approved, another medication has been removed from pharmacy shelves. In March 2018, daclizumab (Zinbryta) was withdrawn from markets around the world. This drug is no longer available to treat MS.

Experimental therapies

Several other medications are working their way through the research pipeline. In recent studies, some of these medications have shown promise for treating MS.

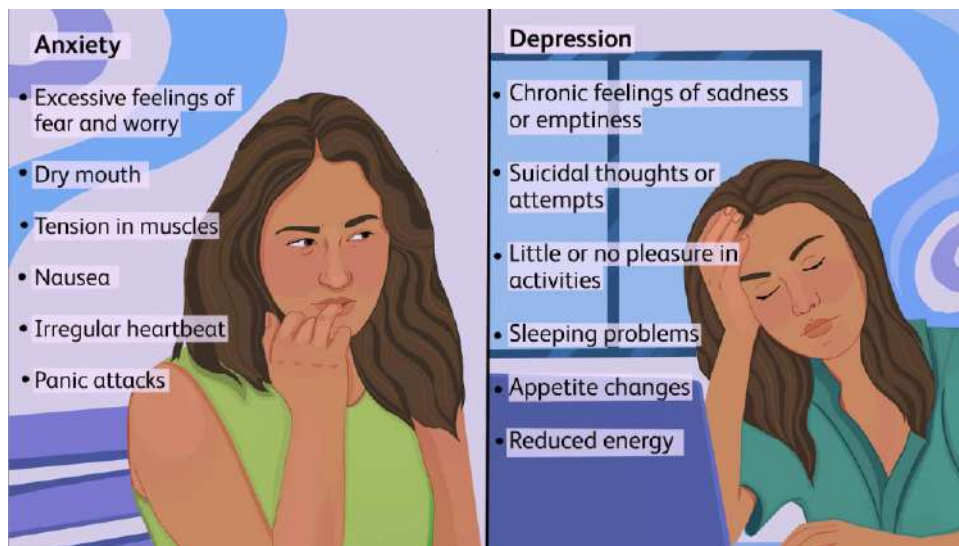
For example:

- The results of a phase 2 clinical trial suggest that ibudilast might help reduce the progression of disability in people with MS. To learn more about this medication, the manufacturer plans to conduct a phase 3 clinical trial.
- The findings of a small 2017 study suggest that clemastine fumarate might help restore the protective coating around nerves in people with relapsing forms of MS. This oral antihistamine is currently available over the counter, but not in the dose used in the clinical trial. More research is needed to study its potential benefits and risks for treating MS.

Other treatment options:

- H.P. Acthar Gel is a highly-purified preparation of adrenocorticotrophic hormone (ACTH) in a gel that is designed to provide extended release of the ACTH following injection. It is FDA-approved for the treatment of MS relapses in adults. Its use is limited due to high cost and access issues. It is often considered when someone cannot tolerate glucocorticoids.
- Plasmapheresis (plasma exchange) may be considered for severe exacerbations that do not respond adequately to the standard steroid treatment.

For more information about these medications, including usage, side effects and precautions, go to the Managing Relapses section of the Medications page.



Rehabilitation

The goal of a rehabilitation program is to restore or maintain functions essential to daily living. Rehabilitation can be especially useful soon after an exacerbation to help you get back on track. The members of the rehab team—including physical therapists, occupational therapists, speech/language pathologists and cognitive remediation specialists—address problems with mobility, dressing and personal care, role performance at home and work, and overall fitness. They also provide evaluation and treatment of speech and swallowing difficulties and problems with thinking and memory that may have appeared or worsened during the exacerbation.



MSSI DELHI MEMBERS ATTENDING NEURO CONFERENCE-2022



Treatment Options for Multiple Sclerosis

Although there is no cure yet, people with MS currently have a range of available therapies to help manage the disease and its symptoms.

Check out the guide below to find out more.



Disease-modifying therapies: medications that can alter the course of the disease by suppressing or modulating the immune system and reducing inflammation.

Relapse management therapies: treatments that help to manage relapses, or flare-ups, in which new symptoms arise or existing symptoms worsen.

Symptomatic treatments: therapies that help to manage MS symptoms, including spasticity, fatigue, nerve pain, and visual problems, among others.

Complementary therapies: non-pharmacological interventions, such as physical therapy, diet, and exercise, which may be used in addition to medication to help manage MS and its symptoms.

- Hematopoietic stem cell transplantation (HSCT) therapy is a promising new treatment for MS that's currently being studied. It's not currently approved, but interest is growing in the field, and it's being evaluated in clinical trials.

These are only a few of the treatments currently being studied. A lot is happening in the MS world , and we remain optimistic about an early positive breakthrough.

Data-driven strategies to target treatments

Thanks to the development of new medications for MS, people have a growing number of treatment options to choose from.

To help guide their decisions, scientists are using large databases and statistical analyses to try to pinpoint the best treatment options for different people.

Eventually, this research might help patients and doctors learn which treatments are most likely to work for them.

Progress in gene research

To understand the causes and risk factors of MS, geneticists and other scientists are combing the human genome for clues.

These are only a few of the treatments currently being studied. A lot is happening in the MS world , and we remain optimistic about an early positive breakthrough.

Thanks to the development of new medications for MS, people have a growing number of treatment options to choose from.

To help guide their decisions, scientists are using large databases and statistical analyses to try to pinpoint the best treatment options for different people.

Members of the International MS Genetics Consortium have identified more than 200 genetic variants associated with MS. For example, a 2018 study identified four new genes linked to the condition. Eventually, findings like this might help scientists develop new strategies and tools to predict, prevent, and treat MS.

Studies of the gut microbiome

Scientists have also studied the role that bacteria and other microbes in our gut (intestine and digestive tract) might play in the development and progression of MS. This community of bacteria is known as our gut microbiome. Not all bacteria are harmful. In fact, many “friendly” bacteria live in our bodies and help regulate our immune system. When the balance of bacteria in our bodies is off, it can lead to inflammation. This might contribute to the development of autoimmune diseases, including MS. Research into the gut microbiome might help scientists understand why and how people develop MS. It could also pave the way for new treatment approaches, including dietary interventions and other therapies.

In conclusion :

Scientists continue to gain new insight into the risk factors and causes of MS as well as potential treatment strategies. New medications have been approved recently, and some have shown promise in clinical trials. These advancements are helping improve the health and well-being of the many people who live with this condition while providing hope for a potential cure

Awareness is the first step in healing



MS IS DIFFERENT FOR EVERYONE- ALMOST LIKE YOUR FINGERPRINT

Each person's

MS journey
is as *unique* as
a fingerprint or a snowflake.

~ Earl Grollman



1. MS is different for everyone - almost like your fingerprint

2. For that reason, your doctor and MSSI are the best people to guide you. MSSI can answer stuff or expand on stuff that doctors fail to. MSSI organises programmes for us with experts in their fields. Without examining you and your case no one should, in all seriousness, tell you what to do.

3. Being our angels and guardians, MSSI has a lot of literature on what works and what doesn't work.

- basically, nutrition, exercise, rest and being stress free are highly recommended. For nutrition along with MSSI recommendations you could also find and read "What your doctor doesn't know about nutrition could be killing you!" there is a vitamin cure for everything For exercise - one

should be active for at least 2.5 hours in a 16 hour day. And restful sleep of 8 hours . Gentle exercise is the key. We don't want to aggravate our already aggravated nerves. Think of your nerves like the wiring of your home. Would you want to add load to an area of your home where the wiring was faulty!? Myelin impacts th nerves, nerves impact muscles and so on. Every muscle, including your brain, needs exercise to remain functional as time goes on. Physiotherapy is conducted by trained professionals. For yoga find a professional to help you. Check their credentials - talk to others - Beware -there are a lot of frauds out there. For rest - one should rest every two to three hours during the day no matter what. Being stress free comes from ones attitude - acceptance, faith, trust... The habits you inculcate now will benefit you for th rest of your life.

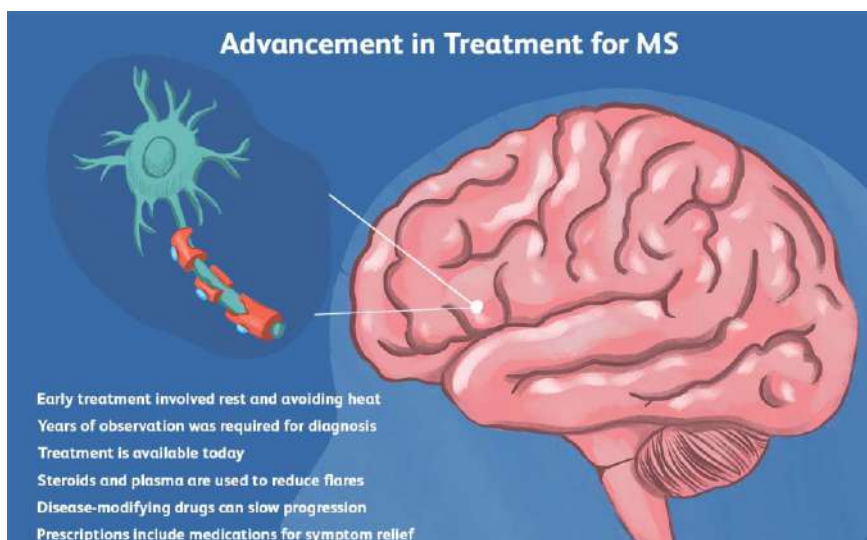
4. Vitamins : Methylcobalamine has been proven to regenerate myelin. There is a connection with vitamin D deficiency and MS. AIIMS suggests that we should monitor our vitamin D and B12 levels.

5. MSSI recommends that at least 6 people benefit from a particular treatment before it is shared with other MSPs .. again - beware of smooth talkers !

6. MSSI recommends AIIMS for all treatment especially those therapies that are still in the research phase like stemcell therapy.

- We do have contacts with many Drs all over .. talk to us to find one nearest you

- Most importantly: Stay in touch !



MS : Same Same But Different !

MS symptoms are variable and unpredictable. No two people have exactly the same symptoms, and each person's symptoms can change or fluctuate over time. One person might experience only one or two of the possible symptoms while another person experiences many more. Explore the list below to find more information about the symptoms you or someone you care about may experience. Most of these symptoms can be managed very effectively with medication, rehabilitation and other management strategies. Effective symptom management by an interdisciplinary team of healthcare professionals is one of the key components of comprehensive MS care.

More common symptoms

- **Fatigue**

Occurs in about 80% of people, can significantly interfere with the ability to function at home and work, and may be the most prominent symptom in a person who otherwise has minimal activity limitations.

- **MS Hug (Dysesthesia)**

Often a first symptom of MS or a relapse, an MS hug is a squeezing sensation around the torso that feels like a blood pressure cuff when it tightens.

- **Walking (Gait) Difficulties**

Related to several factors including weakness, spasticity, loss of balance, sensory deficit and fatigue, and can be helped by physical therapy, assistive therapy and medications.

- **Numbness or Tingling**

Numbness of the face, body, or extremities (arms and legs) is often the first symptom experienced by those eventually diagnosed as having MS.

- **Spasticity**

Refers to feelings of stiffness and a wide range of involuntary muscle spasms; can occur in any limb, but it is much more common in the legs.

- **Weakness**

Weakness in MS, which results from deconditioning of unused muscles or damage to nerves that stimulate muscles, can be managed with rehabilitation strategies and the use of mobility aids and other assistive devices.

- **Vision Problems**

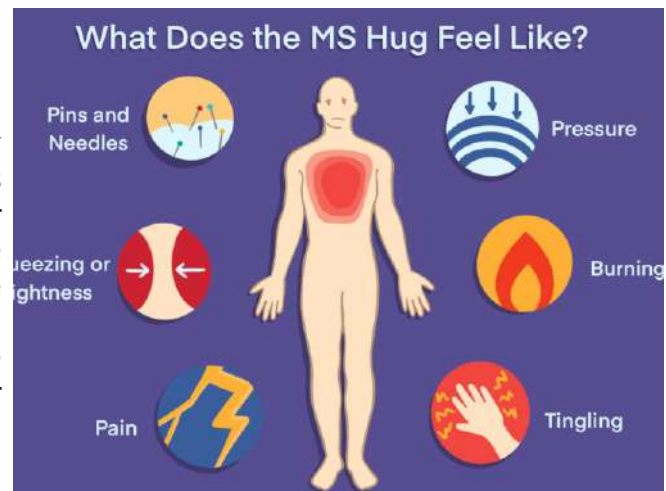
The first symptom of MS for many people. Optic neuritis, neuromyelitis optica, blurred vision, poor contrast or color vision, and pain on eye movement can be frightening-and should be evaluated promptly.

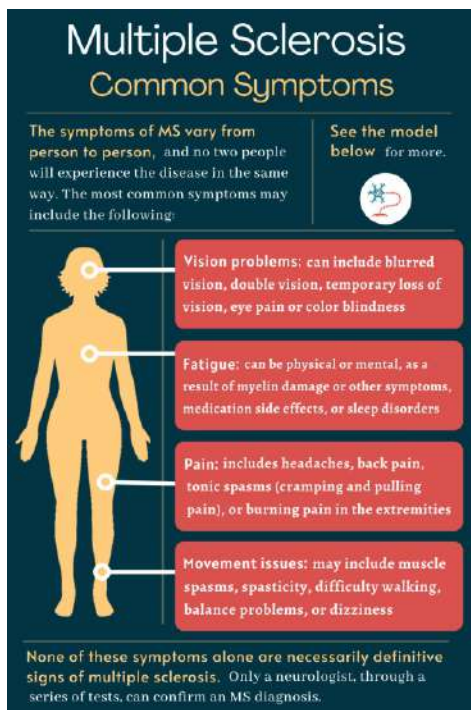
- **Vertigo and Dizziness**

People with MS may feel off balance or lightheaded, or-much less often- have the sensation that they or their surroundings are spinning (vertigo).

- **Bladder Problems**

Bladder dysfunction, which occurs in at least 80% of people with MS, can usually be managed quite successfully with medications, fluid management, and intermittent self-catheterization.





● **Sexual Problems**

Very common in the general population including people with MS. Sexual responses can be affected by damage in the central nervous system, as well by symptoms such as fatigue and spasticity, and by psychological factors.

● **Bowel Problems**

Constipation is a particular concern among people with MS, as is loss of control of the bowels. Bowel issues can typically be managed through diet, adequate fluid intake, physical activity and medication.

● **Pain & Itching**

Pain syndromes are common in MS. In one study, 55% of people with MS had "clinically significant pain" at some time, and almost half had chronic pain.

● **Cognitive Changes**

Changes in cognitive function are common in MS. Find out about different learning and memory exercises to help improve your cognitive health.

● **Emotional Changes**

Can be a reaction to the stresses of living with MS as well as the result of neurologic and immune changes. Anxiety,

mood swings, irritability, and episodes of uncontrollable laughing and crying pose significant challenges for people with MS and their families.

● **Depression**

Depression is a common symptom of MS. Take a free, confidential screening for depression and learn more about establishing good emotional health and wellness.

Less common symptoms

● **Speech Problems**

Speech problems, including slurring (dysarthria) and loss of volume (dysphonia) occur in approximately 25-40% of people with MS, particularly later in the disease course and during periods of extreme fatigue. Stuttering is occasionally reported as well.

● **Loss of Taste**

One quarter of people diagnosed with MS experience diminished taste.

● **Swallowing Problems**

Swallowing problems-referred to as dysphagia-result from damage to the nerves controlling the many small muscles in the mouth and throat.

● **Tremor**

Tremor, or uncontrollable shaking, can occur in various parts of the body because of damaged areas along the complex nerve pathways that are responsible for coordination of movements.

● **Seizures**

Seizures-which are the result of abnormal electrical discharges in an injured or scarred area of the brain-have been estimated to occur in 2-5% people with MS, compared to the estimated 3% of the general population.

● **Breathing Problems**

Respiration problems occur in people whose chest muscles have been severely weakened by damage to the nerves that control those muscles.

● **Hearing Loss**

About 6% of people who have MS complain of impaired hearing. In very rare cases, hearing loss has been reported as the first symptom of the disease.

#MyMSstory: Shruti Kaushik

My First DMT (Disease Modifying Therapy) Infusion of Rituximab



After refusing to take any DMTs for years, the decision to finally take a medication was taken in 2022. After discussing with doctors and cross checking with the neurologists at a Neurology seminar, the final go ahead was taken by us. The efficacy of the drug Rituximab was reconfirmed and it got a green signal from all quarters.

A conscious decision to get the infusion seemed like a crucial decision of my life. As important as choosing subjects for college, finalising a deal, an assignment or to one extreme, selecting a life partner. It was an important step which I took along with my husband.

Years ago, we didn't think much of any disease modifiers as they were only targeting the length of time between two relapses with no guarantee of a cure. Experiments and trials were on. At that stage, with our children growing up, important decisions had to be made regarding their future. Another significant factor was the cost of the therapy. Medicines were exorbitant. Few pharmaceutical companies were making DMTs in those days. These were meant to be taken over a longer period.

This by no means discredits or undermines the impact of this disease in other people. I do understand and appreciate how many of us are dependent on external

factors to run our lives. Few attacks over the years, depending on the situation, I carried on taking steroids medication as and when required and most importantly once prescribed by the treating Neurologist. We never take any injections or steroids, intravenous or oral by ourselves.

I dealt with it as well as manage the other responsibilities of my life. What led me to not attempt a DMT was primarily the question of whether it would be effective. We were told that it was not a cure but might slow the progression, if at all. This was both mentally and physically straining situation, adding to the challenges to my overall day to day life and responsibilities. So, the decision was made. We would wait. I am not disrespecting research or telling the others not to take a DMT. It was our point of view at that time when the certainty of them helping me effectively was a question mark.

At least that is what I thought of them, then. Now over the years, we did make an informed decision and are happy with it. After a serious attack, according to my MRI in 2017 and later with my growing disability while walking, I took the seasoned and veteran expert's advice. You see, a lot of research is ongoing at a much larger scale than it was 15 years ago. The decision to take the infusion was made after checking the efficacy of the proposed drug and its positive response.

I must mention the role of Ms Bipasha Gupta at the MSSSI Delhi to push me towards deciding on a DMT. This led me further to Dr Padma at AIIMS. A little chiding from her on delaying my treatment, each time I met her at the MSSSI seminars, made me firm up the decision to eventually take the DMT. Once a senior and a seasoned doctor like Dr Padma guides you to a medication, one has to take it seriously.



The level of support, care and help extended by the society is phenomenal. I often think of how my life changed after becoming a member of MSSSI DELHI in 2003. I was lucky to be an executive committee member for many years. One never leaves the Delhi Chapter; the work carries on. The dedication and commitment of each member at MSSSI is praiseworthy too. My journey there has been full of learning. It is indeed noteworthy and commendable to see the involvement and expertise of Dr Padma in her diagnosis, treatment and guidance on how to tackle the ailment.

Six days post the infusion, I seem to be doing fine, the regular issues of impaired bowel and bladder movements prop up, fatigue and other issues normally associated with a drug can occur. Each symptom different for each MSP. Overall, I am doing well. I say so as I am able to carry on my regular routine without any major hindrance. Of course, the most importance responsibility which each one of us has to undertake is to keep away from infections. Adhere to the habit of wearing masks when in the presence of other people.

I would like to take this opportunity to encourage all my fellow MSPs to start on the DMTs as soon as the disease is diagnosed. Reputed Neurophysians can be consulted and the DMT can be started as advised and prescribed by that doctor. One such hospital is AIIMS. The MS Society fixes appointments for their registered MSPs at AIIMS for the Tuesday MS Clinic in the Neurology OPD and with other MS experts of other Government and Private hospitals. If one has taken a resolve to get better then we owe it to ourselves to follow a safety regimen. It's for us to protect ourselves from infections. Yes, each one of us has a different environment and issues and most need outside help of caregivers in our daily life. We can help by following a healthy life style, in whichever way we can. The onus lies on us.

The more one does and sees and feels , the more one is able to do and the more genuine maybe one's appreciation of fundamental things like home, and love, and understanding companionship.

Goodwill Message Sponsored by: Kunal Seth...

MSSI DELHI:

Multiple Sclerosis Society of India, MSSI-Delhi was established on 25th October, 1989 and was started in Northern India for the benefit of young persons affected by multiple sclerosis, which is a potentially disabling disease of the brain and spinal cord (central nervous system). The Society networks all over India through its 9 chapters across India. It works with guidance of a Governing Council which comprises members & representatives from all its Chapters MSSI Support groups bring people together to share and learn from common life experiences for support and mutual aid.

Our members benefit greatly from these interactions, and feel confident and secure in the knowledge that they are not alone.

Benefits of participating in a support group programmes include:

- Learning new information and strategies for confronting problems.
- Finding support from others.
- The opportunity to help others.
- Feeling empowered and more self-confident in coping with challenges.

Multiple Sclerosis support groups focus on advocacy, education, wellness and programmes that encourage socialisation. MSSI-Delhi concentrates on specific needs of MS persons, such as young adults, care partners or care givers; they also focus on particular fields, such as physical exercises through Home Physiotherapy, education grants, free Home Care services through a trained nurse & attendant. And of course Free Home Counselling which also provides solace, support and information for wellness.

If you or someone close to you has recently been diagnosed with Multiple Sclerosis (MS), you probably have a lot of questions and concerns. Or, you may be feeling so overwhelmed by the diagnosis that you aren't even sure what kind of questions to ask.

TAKING THE FIRST STEPS

Learn more about MS: Get the facts about MS: What it is, who gets it and why, what symptoms it can cause. Understanding treatment options: Strategies available to modify the disease course, treat relapses, manage symptoms, and improve function and quality of life. Deciding to disclose... or not: Telling your employer about your MS may be the first thing you want to do-or the last. Protecting your employment options: Read about the ways MS can affect employment and learn some strategies for maintaining your place in the workforce.

Knowledge is Power: A programme series for people newly diagnosed with MS or those who have a loved one recently diagnosed.

People come together at MSSI-Delhi regular gatherings to lift each other's spirits by exchanging stories of overcoming personal struggles and encourage each other to try new things, living each day to its full potential. People affected by MS can live their best lives as MSSI tries to stop MS in its tracks, restore what has been lost and end MS forever.

CONTACT:

Contact members of MS Society of India at the following numbers for support or go to MSSI website: www.mssocietyindia.org for further information. MSSI-Delhi on Facebook /Instagram

MSSI HELP LINES:

Bengaluru: 91-8022992626 **Chennai:** +91-4466240358 **Hyderabad:** +919390055598
Delhi/NCR: +91 11-26490087/+ 91-9312210645/+91-9811012334
Indore:+91-7134043596 **Kolkata:** +91-3322627498 **Mumbai:** +91-2224037390
Pune: +91-2026614779 **Trivandrum:** +91-9809382262

HEAT & TEMPERATURE : MS

Many people with MS experience a temporary worsening of their symptoms when the weather is very hot or humid, or when they run a fever. These temporary changes can result from even a slight elevation in core body temperature (one-quarter to one-half of a degree). An elevated temperature further impairs the ability of a demyelinated nerve to conduct electrical impulses. Activities including sunbathing, exercise, and taking very hot showers or baths can have the same effect. For example, some people notice their vision becomes blurred when they get overheated—a phenomenon known as Uhthoff's sign. In fact, many years ago the "hot bath" test was used to diagnose multiple sclerosis. A person suspected of having MS was immersed in a hot tub of water, and the appearance of or worsening neurologic symptoms was taken as evidence the person had MS.

Heat-related symptoms are temporary

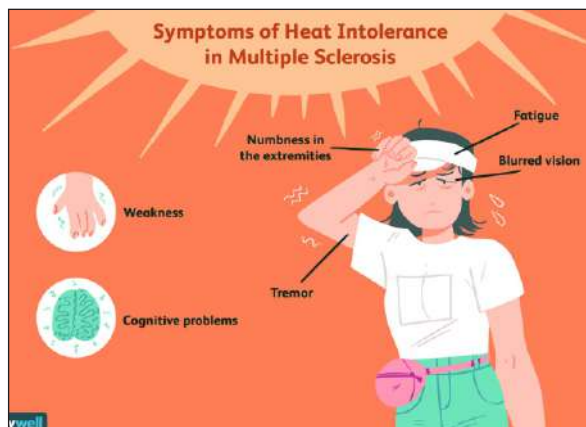
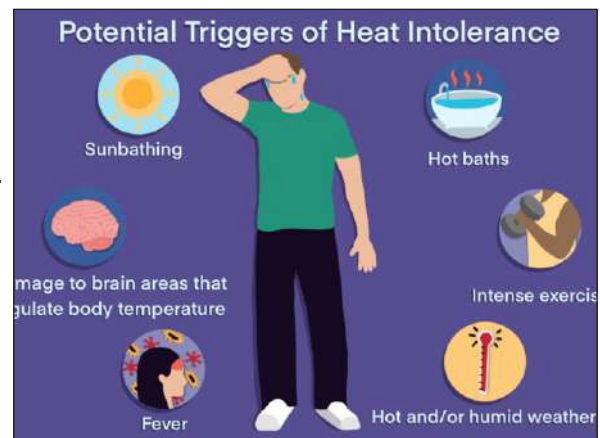
Heat generally produces only temporary worsening of symptoms. It does not cause more disease activity (demyelination or damage to the nerves themselves). The symptoms improve after you cool down.

Strategies for easing the effects of heat

- Stay in an air-conditioned environment during periods of extreme heat and humidity. If an air conditioner is needed to help minimize symptoms, the cost of this equipment may be tax deductible if your healthcare provider has written a prescription for it.
- Use cooling products such as vests, neck wraps, and bandana during exercise or outdoor activity.
- Wear lightweight, loose, breathable clothing.
- Drink cold fluids and cold fruits or frozen ice candy - like orange bar ice cream.
- Exercise in a cool pool (<30 C degrees) or a cool environment. If you are exercising outside, pick cooler times of the day, usually early morning or evening.
- Try pre- and post-cooling to decrease the heating effects of exercise. Start your bath with tepid water (gunguna paani) and continue adding cooler water slowly. A cool bath or shower can also help reduce core body temperature following activity or exposure to a hot environment.
- Avoid very hot water baths even in winter.
- Do not step into a very hot car which has been parked in the sun. Wait, get help to open the windows and let the excess heat out. Then put on the AC before you step in.

Cold can also be a problem

Some people with MS notice that symptoms, particularly spasticity, become worse in cold weather. It is generally recommended that people with MS who are sensitive to temperature try to avoid extremes of either hot or cold.



Moving for optimal climate

If you are considering a move to a "better" climate town you may want to investigate to see if this improves your symptoms first. Visit it, stay for a few days and get used to the environment.

Additional resources

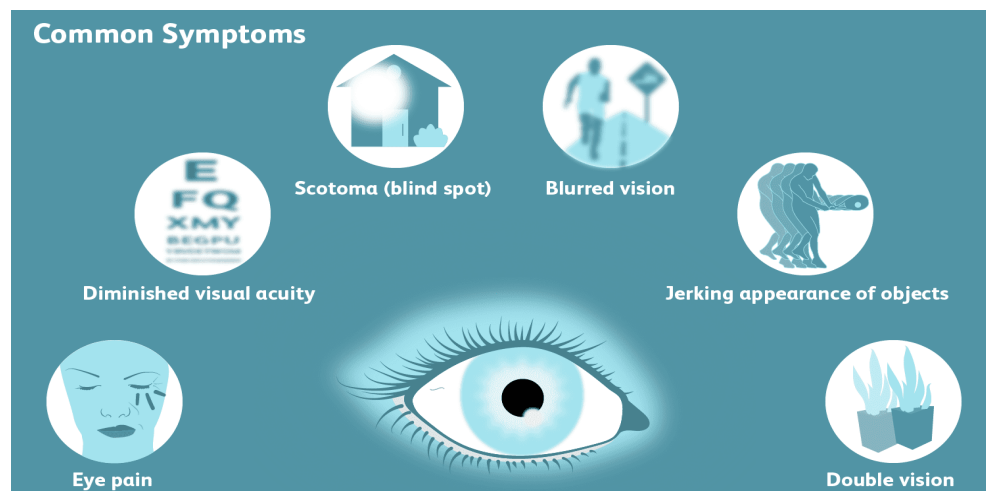
- Explore cooling equipment options and read product reviews - there are many options now available online - like cooling jackets.
- Stay indoors & use the cooler or AC
- Keep a cold ice pack or wet towel near you while exercising. Dip, squeeze & wipe your face, neck, arms & underarms. Dry off with a dry towel.

VISION ISSUES

Problems with vision are often one of the first symptoms noticed by people with MS. After lunch, Jia puts on make up. It is difficult for her to go out, but she insists on making up before she goes out. Her positive attitude is more than just the make up. A problem with vision is one of the most common symptoms of MS, and often one of the first that people with MS notice. The symptoms can include blurred vision, double vision (diplopia), optic neuritis, involuntary rapid eye movement and occasionally, a total loss of sight.

Problems with vision can result from damage to the optic nerve or from a lack of coordination in the eye muscles. The optic nerve connects the eye to the brain. Inflammation or demyelination in the optic nerve causes optic neuritis, which is experienced as a temporary loss or disturbance in vision and possibly pain behind the affected eye.

Typically, vision returns partially or fully within a few weeks. While it is quite rare for a person with MS to become totally blind, it is not at all uncommon for an individual to have recurrent episodes of optic neuritis over the course of the disease, usually in one eye at a time. Damage to the optic nerve can result in a blurring of vision, which may or may not totally resolve over time. Colour vision requires a great many nerve fibres from the eye for accurate transmission and is particularly susceptible to changes from demyelination.



Jerkiness

Optic neuritis can cause a large, noticeable "blind spot" in the centre of the visual field, and the person experiences a visual image with a dark, blank area in the middle. This is called a central scotoma and is not correctable with either eyeglasses or medication, although steroids may be helpful in the early, acute phase.

Diplopia (double vision), the experience of seeing two of everything, is caused by weakening or in coordination of eye muscles. This symptom is typically treated with a short course of steroids. Patching one eye while trying to drive or read will stop the double image; however, permanent patching of the eye will slow the brain's remarkable ability to accommodate to the weakness and produce a single image in spite of the weakened muscles. Some physicians are prescribing eyeglasses with special prisms that help to minimise double vision.

Upon examination, the physician may detect a rhythmic jerkiness or bounce in one or both eyes. This relatively common visual finding in MS is nystagmus. Nystagmus does not always cause symptoms of which the person is aware. In the event that it does become troublesome, please ask your doctor to suggest the appropriate medicine which can be effective in reducing this annoying but painless problem.

BRAIN HEALTH

Multiple sclerosis (MS) can impair the flow of nerve signals in the central nervous system. The brain, spinal cord, and optic nerves are all part of the central nervous system, and MS tends to affect all of these areas. There's currently no cure for MS, but medications have been developed to slow the progression of the condition. Leading an overall healthy lifestyle may also help protect your brain. For example, research suggests that exercise may improve certain aspects of brain health and cognitive functioning.

Read on to learn about some of the strategies you can use to promote good brain health.

Ask the Expert: What Do I Need to Know About How Multiple Sclerosis Affects the Brain?

- Lesions
- The brain
- Brain atrophy
- Cognitive symptoms
- Cognitive symptoms and the brain
- Screening tools
- Treatment
- Lifestyle changes



1. How does multiple sclerosis (MS) affect the central nervous system? What are some of the issues MS causes with brain health?

Multiple sclerosis is a condition of the central nervous system (CNS), which includes the brain, spinal cord, and optic nerve.

Nerves communicate with each other and with the rest of the body by sending electrical and chemical signals.

To understand how your nerves work, think about how they're similar to electrical cables. Nerves consist of a "wire," which we call the axon. The axon is covered by an insulating material called myelin.

MS damages the myelin so that the nerve's ability to conduct electrical signals is slowed and uncoordinated. If the axon is also damaged, the electrical signal may be blocked entirely. When this happens, the nerve can't send appropriate information. This produces symptoms.

For example:

- If a muscle doesn't receive sufficient nerve input, there's weakness.
- If the part of the brain that's responsible for coordination is damaged, this can cause tremors or loss of balance.
- Lesions, or areas of nerve damage, in the optic nerve may result in vision loss.
- Spinal cord damage is usually associated with decreased mobility, impaired or abnormal sensations, and impaired genitourinary (genital and urinary) function.

When it comes to the brain, changes due to MS can contribute to fatigue and other symptoms. Brain lesions can produce difficulty with thinking and memory. MS brain changes may also contribute to mood disorders such as depression.

2. MS causes lesions in certain areas of the body. Why do these lesions occur? What's the best way to reduce, limit, or prevent them?

MS is widely believed to be an autoimmune process. In other words, the immune system, which normally protects your body, goes "rogue" and begins to attack parts of your body. In MS, the immune system attacks nerves in the CNS. The Food and Drug Administration (FDA) has approved more than 20 different medications- known as disease-modifying therapies (DMTs)-that can limit the number of new lesions due to MS. The most important strategies that have been documented for reducing future nerve damage are early diagnosis and timely treatment with these medications. Lifestyle habits such as exercising regularly, not smoking, and maintaining a moderate body weight are also important.

3. Does MS affect different parts of the brain in different ways? What do we know about how MS affects the brain's white matter and gray matter?

MS produces damage in the more heavily myelinated regions of the brain, known as white matter. MS has also been shown to affect the less myelinated regions closer to the surface of the brain, known as cortical gray matter. Damage to both white matter and gray matter structures are linked to cognitive impairment. Damage to specific brain regions can produce difficulty with specific cognitive skills.

4. Why is it normal to experience brain atrophy or loss of brain volume as we age? Is there anything that can be done to slow the rate of brain atrophy in people with MS?

The rate of brain atrophy, or shrinkage, in people with MS has been shown to be several times Source than the rate of brain atrophy in people of similar ages who don't have MS. This is because MS causes the destruction of axons as well as damage to the brain's white and gray matter. People with MS who smoke tobacco have been reported Trusted Source to have more brain atrophy than nonsmokers. Some studies have reported Trusted Source that certain DMTs may reduce the rate of brain atrophy. There are also reports that people with MS who are more physically active have less atrophy than people who are less physically active.

5. What are some of the cognitive symptoms of MS?

The cognitive difficulties that are most common in people with MS tend to be related to memory and speed of information processing.

There may also be problems with:

- multitasking
- sustained memory and concentration
- prioritizing
- decision making
- organization

Additionally, difficulty with verbal fluency, especially word finding-the feeling that "the word is on the tip of my tongue" - is common.

Cognitive difficulties may be a direct result of lesions. Cognition may also be impaired by one or more of these contributing factors:

- fatigue
- poor sleep
- depression
- the effects of medication

Some cognitive functions are more likely than others to remain healthy. General intelligence and information, and understanding of words, tend to be preserved.

6. What's the connection between the cognitive symptoms of MS and where MS affects the brain?

Different cognitive functions tend to be associated with different parts of the brain, although there's a lot of overlap.

So-called "executive functions"- such as multitasking, prioritizing, and decision making- are most associated with the frontal lobes of the brain.

Many memory functions occur in a gray matter structure called the hippocampus. Its name comes from the Greek word for seahorse.

Damage to the corpus callosum, a very heavily myelinated bundle of nerves that connects the two hemispheres of the brain, is also associated with cognitive impairment.

MS commonly affects all of these areas.

7. What screening tools are used to look for cognitive symptoms in people living with MS? How often should people with MS be screened for signs of cognitive change?

There are short tests of specific cognitive functions that can be easily and quickly administered in a doctor's office. These can help screen for evidence of cognitive impairment. For example, one such test is called the Symbol Digit Modalities Test (SDMT).

If a screening test suggests cognitive problems, your doctor may recommend a more in-depth assessment. This would usually be formally done with tests that are collectively referred to as neuropsychological testing. It's recommended that people with MS be assessed for cognitive function at least once per year.

8. How are cognitive symptoms of MS treated?

When addressing cognitive impairment in people with MS, it's important to identify any contributing factors, such as fatigue or depression, that may worsen cognitive problems. People living with MS may have untreated sleep disorders such as sleep apnea. This can also affect cognition. When these secondary factors are treated, cognitive function often improves.

Research has shown that targeted cognitive rehabilitation strategies are beneficial. These strategies address specific domains-such as attention, multitasking, processing speed, or memory- using techniques such as computer training.

9. Are there any lifestyle approaches, such as diet and exercise, that may help people living with MS to reduce or limit cognitive changes?

A growing body of literature suggests that regular physical exercise may improve cognitive function in people with MS.

While no diet has been shown to affect cognition in people with MS per se, a heart-healthy diet may reduce the risk of comorbidities (other diseases) that can contribute to cognitive impairment.

A heart-healthy diet is generally one that primarily contains lots of fruits and vegetables, lean proteins, and "good" fats such as olive oil. The diet should also limit saturated fats and refined sugars.

Following this type of eating plan may limit comorbidities such as vascular disease, type 2 diabetes, or high blood pressure. All of these conditions can contribute to cognitive impairment and disability in people with MS.

Smoking is a risk factor for brain atrophy, so quitting smoking may help to limit further atrophy.

It's also important to stay mentally active and socially connected.

Barbara S. Giesser, MD received her medical degree from the University of Texas Health Science Center at San Antonio, and completed neurology residency training and MS fellowship at the Montefiore Medical Center (NY) and Albert Einstein College of Medicine. She's specialized in the care of persons with MS since 1982. She's currently Professor of Clinical Neurology at the David Geffen UCLA School of Medicine and Clinical Director of the UCLA MS program.

Dr. Giesser has conducted peer-reviewed research into the effects of exercise in persons with MS. She's also created educational curricula for national organizations such as the National MS Society and the American Academy of Neurology. She's active in advocacy efforts to promote access to care and medications for persons with MS and other neurologic diseases.

#MyMSstory: Tapasya Gulati

My journey with multiple sclerosis started at a tender age, 16 years, in 1995. That year, a young girl who is enjoying life and suddenly has blurred vision in her left eye, and is not able to explain her pain to her parents, or the doctor. The doctors say that there's nothing wrong with her eyes, she has perfect vision. Going to the doctors in a small city like Ghaziabad was a problem because no one could understand her pain. Then one of our family friends told my parents to go to a doctor in Delhi. In Delhi he took two days to understand that what was wrong with the eye. Once again, the diagnosis was swelling in the nerves of the eye, not multiple sclerosis. Steroids were given for 28 days and finally, I was back to normal with a clear vision and a weight gain of 2-3 kgs, cute and plump. I did my fashion designing from a reputed college and was the winner of "the most innovative collection" by the end of the year -1999. Once again, I had an anxiety attack while preparing for the final fashion show. The doctor gave me anxiety pills but no diagnosis of multiple sclerosis. Next year, in 2000, my left ankle twisted while going for a swimming pool party at a farmhouse. In the evening we went to an orthopaedic and was diagnosed of hair line ankle fracture. I was tied up with a crepe bandage and was told to rest of 15 days, but once again no clue of multiple sclerosis. Ankle twisting continued for months, every 15 days. The doctors said it was genetic, flat foot fatigue. But no diagnosis of multiple sclerosis. Regular physiotherapy was started on the doctor's prescription with vigorous exercises, and weight training.



I got married in 2005 with good health, but slight limping of left leg. My son was born in 2006. The diagnosis of multiple sclerosis in 2006 came as a shock to everyone in my family. I was not able to walk properly, I could not maintain my balance while standing, I would eat with shivering hands, and I was not able to pick up a bottle to feed my child. Those years I was not taking any allopathic medicine.

I was being treated with alternative medicine such as Homeopathy and Acupressure and Yoga. Any new therapy was suggested, and I would be game for it.

My husband and in-laws were taking care of my little baby, but I was missing my baby every second. In 2011, had an attack on my bladder where I lost urine control. The doctors told me to learn how to use a catheter myself.

However, I did get better with homeopathic medicines. Learning to use a catheter, dealing with the other issues of MS made me feel very depressed. Soon I realised that this mental depression was leading nowhere, hence I started focusing on my passion, baking. I began taking Allopathic medicine during this time.



I was injecting myself on my body parts on alternate days for two years. Then began treatment with the oral medicine Tecfidera and I took that for two years. After two years I was prescribed Difra tablets, but the side effects were intolerable. In 2015, I was shattered when I lost my mother to cancer.

In 2016, I decided to take control over myself.

I began by following Art of Living-happiness courses and advance courses. I began healing therapies myself, learnt to forgive myself and my loved ones. I enjoy swimming, and I began swimming for 1 hour every day during summers. Presently I am not taking any medication!

I'm 44 years old, I do strength training exercise every day, I do Pranayam - breathing exercises regularly.

Meditation and a healthy diet are an important part of my daily routine.

I am now enjoying life with my family. I am motivating other MS Persons via MSSSI Delhi. I am working with Delhi MS Society by doing voice-overs for their videos, taking active participation in their activities and projects, and am spreading awareness about Multiple Sclerosis.

My suggestions to all my fellow MS Persons:

Being active and not thinking about the disease is the key to MS management.

- Follow your passion
- Live your dreams
- I thank everyone who has been a part of my journey.

Love you always



One looks back with appreciation and gratitude to those who touch our human feelings. Warmth and empathy is a vital element for growth of the soul.

Goodwill Message Sponsored by: Parul Mathur

HEALTHY LIVING WITH MULTIPLE SCLEROSIS

Multiple sclerosis is a life-long neurological illness that creates variability and uncertainty in the day-to-day lives of those who have the disease. It is important to have a multi-faceted wellness programme in order to make the most of physical, emotional, social and spiritual health. Although there is no cure for MS, there is hope that one can renew and refresh along the way, and create a balance in life that promotes harmony.

Deciding to adhere to a healthy lifestyle or to maintain healthy habits is a choice for each person. This concept of choice is especially relevant for people with MS who often feel they have little control over the disease. Diet, exercise, stress management, travel, leisure activities and health promotion activities are all aspects of living well that are, to a certain extent, under the control of the individual.

Although there are no particular diets that have been shown to affect the disease process in MS, food fuels the body, and provides energy. A well balanced nutrition plan, low in fat, high in fibre, can help stabilise weight and improve bowel health. Adding dietary supplements such as multi-vitamins with minerals, calcium, and vitamin D should not replace proper food intake, but can be useful. People with MS should be encouraged to check with their doctor or nurse before taking vitamins, minerals, or herbal supplements to ensure safety and compatibility with the traditional medications already prescribed.

Regular exercise is important for several reasons, and should be part of everyone's routine. Exercise not only improves cardiovascular health, but also helps improve strength and endurance, and is a factor in stabilising mood. Exercise can help relieve MS-related fatigue and manage spasticity. Aquatics therapy (also known as hydrotherapy) can be very helpful in MS because it provides an aerobic workout while keeping the body temperature down. Other helpful exercise regimens include stretching, and low impact aerobic workouts, combined with strength training, using light weights. People with MS should discuss exercising with their doctor or nurse, and may need a consultation with a physiotherapist before beginning a programme.

Coping with stress can be difficult in these demanding times. Stress makes most people feel bad, but those with MS may actually experience the consequences of stress in ways that make their symptoms feel worse. Stress may raise body temperature. People with MS tend to feel more fatigued, or have temporary worsening of MS related symptoms when their body temperature is elevated. Relieving stress can be as easy as taking a few deep breaths, visualising a pleasant memory, or scene, or simply smiling.



More regimented strategies include practicing progressive relaxation techniques, yoga, meditation, tai chi, or prayer. Some people enjoy the relaxation found in nature, art, music or other sources. The important message is that people should incorporate whatever brings a calm and serene feeling into their daily routines.

Travelling is fun, but can be stressful when one has MS. There are many travel agencies that work with people with disabilities, and help to make the holiday a success. Some important points to think about when choosing a destination include the climate and average temperature (places that are hot or humid may not be ideal vacation spots), accessibility, proximity to a healthcare provider or healthcare facility, and whether there will be a refrigerator for storing medications for injection. Planning ahead is essential to enjoy any trip. Some people with MS take very good care of the MS, but forget about the other parts of the body that require attention.



Regular examinations by a primary care doctor may include a cardiogram, and monitoring of blood glucose, triglycerides, and cholesterol levels. Women should see a gynaecologist for a regular cervical smear test, breast examination, and bone density study. The last is especially important if there is a history of receiving multiple doses of steroid medication, or limited mobility related to MS. Individuals should consult their primary care doctor about what general health checkups are important and how often they should be done.

Feeling hopeful and optimistic can promote health, and aid in the healing process. When asked what they hope for, most people with MS say that they hope for a cure, or relief from the troublesome symptoms they are experiencing. These are promising times in the field of MS, but there is still no cure. However, there are interventions for MS that can reduce relapse rate, slow the disease progression, and help to alleviate related symptoms, such as pain and fatigue.

Accessing good care is of prime concern among those who have the disease, and it is important to find a place that provides the kind of comprehensive care one needs to stay healthy. Good care by healthcare providers, who view MS in a holistic way, can be the best way to sustain hope despite the ups and downs of living with this unpredictable illness.

MSSI DELHI FOUNDER MEMBERS



DELHI CHAPTER MANAGING COMMITTEE AT OUR 1ST DAY CARE PROGRAMME



REPRESENTING MSSI INDIA AT MSIF CONFERENCE IN BERLIN, GERMANY 2002



OUR HOME VISIT TEAM : THROUGH THE YEARS



OUR ANNUAL DIWALI GET TOGETHER-2022



INDIA MS DAY 2023 WALK AT SUNDER NURSERY PARK



IMSD 2023 IN LUCKNOW

ENCOURAGING WORDS ARE NOT SAID ENOUGH. STORY OF A MULTIPLE SCLEROSIS FIGHTER.

#MyMSstory: Abhishek Trivedi

God laughed when I told my plans to him. I know this personally because during very first year of engineering I was diagnosed with Multiple sclerosis (2005) since then nothing ever worked according to the plan.



Automobile industry was my preferred carrier choice but had to switch to IT sector (I'm mechanical engineer) where I worked at Infosys for 4 years. I met my extremely understanding and supportive soul partner Richa and I got married. Unfortunately my condition deteriorated further and I had to switch again to banking sector where I worked at State Bank of India for another 9 years. Ironically these switches were for easier situation but didn't work and now I'm on a wheelchair.

Beginning is always difficult. I **couldn't accept new reality**. I lived obliviously kind of ostrich way. Thank fully my sister registered me in MSSSI Delhi but I had acceptance issue and did not want the world to know about my condition for nearly 12 years. I realized, no one should have this stigma, as letting people know has its own benefits and support. And acceptance helps one to listen & learn from others to as how to manage MS and remain well with higher quality of life style. In the year 2022 a miracle happened. For the first time my wish came true. At the epitome of depression I caught COVID. Seeing blood stream flowing from my nose and lying on the bed completely immobilized a promise I made **"either I'll die now or if it couldn't kill me I'll live like free man."** I lived and made a Plan to travel across India giving ray of hope to everyone. This plan actually worked, I drove on my modified hand driven car from **Chandigarh to Kerala covering total 3635 kms. I started on 12th June22 and and my MS Awareness journey ended at Kochi on 28th June 22.** I personally drove the car throughout with several breaks for awareness. At every stop we met more than 100 MS patients, their care givers and other people who just came to meet us after reading news about our travel. We met and motivated over 1000 people personally during my drive, distributed MS leaflets in Hindi and English. We were also able to inspire lakhs of people through television news and print News.



More than **90 various local newspapers covered our story including the Times of India**. At Delhi **NDTV did a coverage creating awareness about MS through their channel**.

MSSI Delhi chapter was my North Star who gave me guidance and flag off and much needed encouragement. It's was Bipasha Gupta Mam's effort that we connected with Indore, Maharashtra, Hyderabad, Bangalore and Kerala Chapters of MSSI during the long, tiring but satisfying journey- **MS Awareness** trip. I was overwhelmed with the responses-greet, meet, accolades and cheers.

Also I learnt so much from the journey but one in particular I wish to share with you that's "**encouraging words are not said enough**". This

understanding gave me a purpose in life and in this pursuit Prestigious MSSI can help me. Especially now as we have taken this mission of creating MS awareness all over India, please enable me further to help so many others. And my **MS AWARENESS journey on road will continue and is continuing.....**

NOTE-Recommendation

MSP Abhshek Trvedi proved- not accepting one's own condition, actually is harmful for MS. Unless; one accepts one cannot manage MS.

Abhishek is an example of **NOTHING CAN STOP YOU FROM MOVING ON IN LIFE WITH MS**. His journey throughout was shared and followed by me closely; He started driving on **12th June'22 from his Home Chandigarh** and ended on **28th June'22** at Kochi- Kerala with halts to meet **Chapter representatives in Gwalior, Indore, Bhopal, Bangalore, Hyderabad and Kerala** . During this time North India heat is unbearable but that did not deter him. He achieved miles on the way. This was successful due to his own will power, sheer determination, positive attitude and surrounding support.

MSSI Delhi MS Person Abhishek Trivedi is an example for all the MS persons. His journey with MS awareness is note worthy and he in spite of his own problems thought of going beyond his physical capacity for the sake of other people with MS and drew overwhelming electronic and print Media attention as well as Disability Ministry sector attention creating massive awareness of MS.

His MS Awareness journey is being taken forward by other members on a road trip...



THE MOST EFFECTIVE WAYS DOCTORS CAN TREAT PERSONS WITH MS

By Elizabeth Millard

Because multiple sclerosis involves nerve damage that can occur throughout the body, including brain connections, symptoms can vary widely and be progressive. That makes each patient's journey unique, and can prompt challenges on both sides of the exam table.

Here's what eight patients with the disease wish doctors knew when it comes to helping them manage the condition more effectively.

Diagnosis Should Be Its Own Appointment

Although Dr. Claire Warren—a 70-year-old Stonington, N.Y.-based physician—has plenty of experience treating patients with all kinds of ailments, it wasn't until she was diagnosed with MS that she truly understood what it felt like to be diagnosed with a chronic condition. MS is a disease of the brain and spinal cord that can cause symptoms such as vision changes, balance problems, and weakness.

"Honestly, I was a hot mess," she says. "By the time I went, I had numerous symptoms, but I was in denial about the fatigue, numbness, and increasing mobility concerns. Then, even when I had an answer about what was going on, I refused to accept the devastation of it."

After her doctor said, "You have MS," Warren realized, she didn't hear anything that followed. That's true as well for Johnnah Rosano, a 39-year-old Boston resident who says it felt as if her brain shut off as soon as that diagnosis was made. Because this is a life-changing condition, being able to adjust to the news takes time—and it would be beneficial to have one appointment that's simply about getting the diagnosis and doesn't also include all the possible treatment options, Warren suggests.

"I think it's helpful for doctors to know that this is devastating," she says. "This disease will affect your whole life, and that means you have to adjust mentally, which takes time."

Take Time To Explain Tests And Imaging

With MS, there are so many tests that it can be dizzying to understand the purpose of each one, much less what those tests are supposed to convey, says Vickie Hadge, a 56-year-old Connecticut resident.

Although patients may have access to results in their patient portals, it can be confusing to navigate through terms like white matter hyperintensities and to understand why 10 vials of blood are needed.

"Even if you had a printout of what each test is supposed to show, that would help, because this disease often feels overwhelming," Hadge says. "Clarity and understanding can reduce that feeling, and that's a big advantage."

Make it a habit to tell people 'thank you'. To express your appreciation, sincerely and without the expectations of anything in return, truly appreciate those around you, and you will soon find many others around you. Truly appreciate life, and you will find you have more of it.

Goodwill Message Sponsored by: Anil Kumar Seth

Another aspect of care that would be useful, she adds, is simply conveying what different evaluations include and what to expect. For example, a functional evaluation often takes about three hours, and Hadge went into her first one with no idea why she was going, what would happen during the appointment, and how the results might affect her treatment. That lack of preparation can cause stress and anxiety, she says, potentially worsening MS symptoms and leaving patients feeling helpless.

Grief counseling is a helpful addition to treatment

Mental health is a major component of dealing with MS, and while seeing a therapist is often helpful, focusing on grief specifically makes a strong starting point, believes Brittany Quiroz, 33, who lives in Corona, Calif.

After all, MS diagnosis and progression can involve feeling loss, in terms of both physical function and potential future plans, as well as cognitive challenges. Being able to find peace within the condition would be hugely valuable for disease management, Quiroz suggests.

"Managing illness like this is a full-time job, and having emotional support should be part of treatment," she says. "If doctors could have those resources available in advance, so they could share them immediately, that would go a long way toward dealing with the stress of having MS."

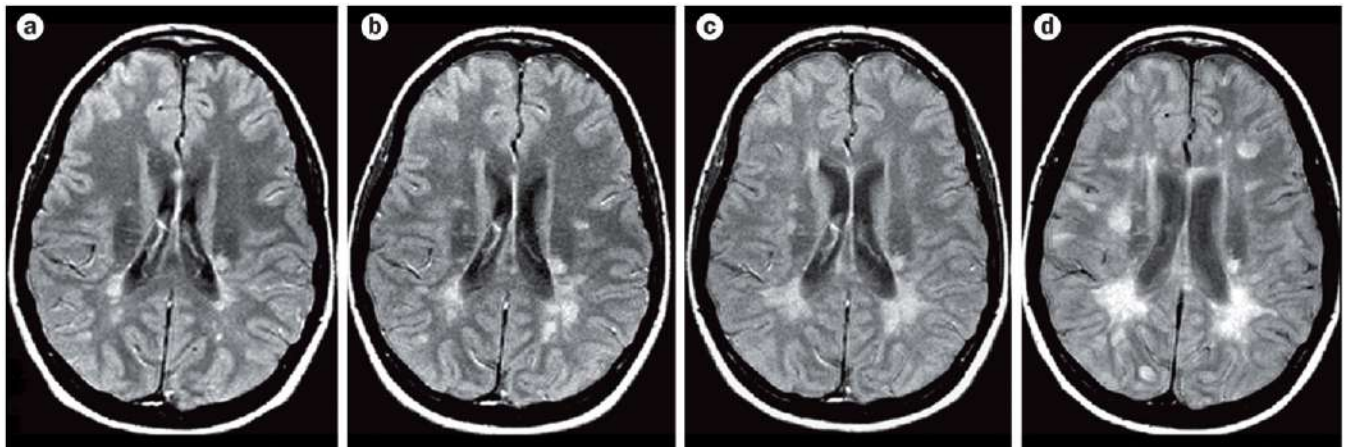
Understanding our frustrations helps us feel heard

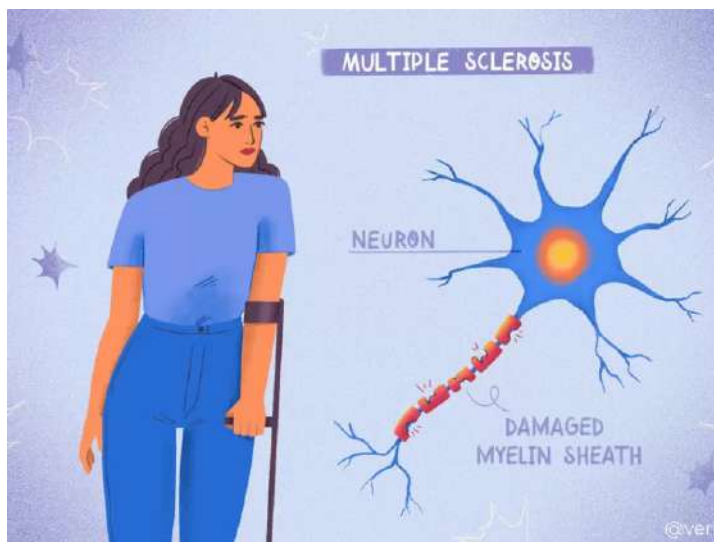
Much like a condition like lupus, MS can take years to diagnose after symptoms begin, and those symptoms can change over time-sometimes even from month to month. That's already stressful, but if you feel unheard at a doctor's appointment, it's so much worse, says Sonda Rossman, a 51-year-old Detroit resident.

"There are many symptoms that are invisible, like cognitive impairment, fatigue, and sensory issues," she says. "These don't show up on lab or imaging tests, so I believe doctors need to rely a little less on what the results say and a little more on what patients are saying. Don't tell me I'm OK because that's what the MRI says. I know my body, and I know when it's not OK."

Another frustration may be a lack of coordination among specialists, adds Rosano. For instance, she began experiencing high blood pressure, and her neurologist suggested anxiety medication because "people with MS don't have high blood pressure." But she didn't feel anxious, so she asked to see a cardiologist. He told her it's common to see blood-pressure issues in those with MS, and prescribed medication that addressed the problem.

"This is just one example of how we often have to talk to one doctor after another, because for many of us, there's no point person looking at the whole picture," Rosano says. "So on top of being sick with a disease that usually includes fatigue, we have to be our own health advocates. It's exhausting, and it can lead people to be reluctant to talk about their symptoms, which is obviously not ideal. "We want to discuss nutrition and other lifestyle changes Nutrition is notoriously understudied in medical schools, says Warren, who had to educate herself on the topic, both before her MS diagnosis and afterward. Her sister, who's an ER physician, began eating a plant-based diet as a way to reduce dementia risk and encouraged Warren to give it a





try for her MS symptoms. She's been eating that way for seven years now, and she's seen significant improvements in her "brain fog" and energy levels.

"Even though MS involves inflammation and is an autoimmune disease, not once did a doctor talk to me about what I was eating and whether that might be making symptoms worse," she says. "There's a connection between your gut health and your immune system, so it makes sense that improving your diet might help your MS. But I know it's challenging, because doctors don't get

paid to talk to people about nutrition; it's not considered a priority. But it really should be." Patients are eager to hear about the effects of other lifestyle changes as well, adds Jenna Green, 37, who lives in Mansfield, Mass. That includes sleep habits, exercise, stress management, and complementary therapies like mindfulness, acupuncture, and massage. In general, conversations like these acknowledge that MS affects every aspect of a patient's life, Green says.

"To live your best life with MS is to factor in everything from what you're eating to how you're moving to how you're managing stress," she says. "Even small changes can make a huge difference for us, so we want to talk about that. Help us put together a health team that includes not just specialists but also professionals like therapists and dietitians."

Another major lifestyle habit that's essential is connecting regularly with others who have MS, says Green. Doctors who do a little research up front on what those communities might be and how patients can tap in to them would be offering a valuable service, especially for those who are newly diagnosed and feel adrift, she adds.

"This can be a very disempowering diagnosis," Green says. "Connecting with others and having strategies that help us feel more in control of our health can give us back part of what we've lost when it comes to confidence in making our own health care decisions."

Many of us are incredibly well informed about our condition

What Rossman has found in the nearly three decades since she was first diagnosed is that the MS population tends to stay current on research, and connects often with one another about symptom management, potential therapies, and clinical trials.

"What many people do when they first get diagnosed these days is get online, and we are a very active community of patients—we're eager to share insights and information," she says. That means doctors and other health care professionals should consider patients as part of the disease-management team, she says. For example, talking about possible research directions in a field like personalized medicine doesn't give a false sense of hope; it loops patients into discussions that they want to have.

"We want to feel included in what's happening with MS on a larger scale, not just with our treatment specifically," says Rossman. "I think doctors sometimes underestimate the power of a patient community and how that drives advocacy and action for us."

"Please treat us kindly, and be transparent about our prognosis and all options available in our treatment," Ratcliff says. "Get to know us. We are real people dealing with the trauma of being diagnosed with an incurable illness."

5 TIPS FOR A HEALTHY LIFE

● Eat for optimal health.

Everyone can benefit from a good diet, but especially people with chronic diseases such as MS. The National Multiple Sclerosis Society notes that there's no special diet for MS, but that eating a diet low in fat and high in vitamins and fiber can help you feel better, while maximizing your energy and supporting healthy bladder and bowel function. A good diet supports caregivers too, with more energy, optimism and general health. A better diet may actually be therapeutic for MS patients, since it can help them avoid metabolic syndrome, the all-too-common constellation of high blood pressure, high blood sugar, high cholesterol, abdominal obesity and insulin resistance that puts patients at risk for developing diabetes, cardiovascular disease and other chronic conditions. an expert in MS at The Johns Hopkins Hospital, says, "Data around this point are hard to quantify, but our team is very interested in lifestyle modifications in patients with MS. "There is mounting evidence that metabolic syndrome compounding MS is particularly lethal. We're seeing that the so-called Western industrial lifestyle breeds autoimmune diseases like MS. It's hard to get biomarkers, but we're looking closely at the role of excessive sugar, animal fats and too much salt."

● Commit to regular exercise.

Research shows that people with MS who participate in an aerobic exercise program benefit from improved cardiovascular fitness, increased strength, better bladder and bowel function, and a more upbeat attitude. Yoga, adaptive tai chi and water exercise are also excellent workouts for people with MS and anyone else, including busy caregivers who can benefit from stress management.

● Address sleep issues.

MS can cause sleep problems, including insomnia, frequent nighttime urination, narcolepsy and leg spasms-over half of MS patients suffer with restless legs syndrome. Dr. Calabresi says, "Sleep is very much underestimated in brain function. We know there's a correlation between poor sleep and both Alzheimer's and MS. "It's hard to tell which comes first, since people with MS have disrupted sleep patterns. There can be early morning awakening caused by depression and nighttime awakenings due to overactive bladder. But we do know that poor sleep correlates with poor daytime cognitive ability, which can affect patients' ability to cope." Be proactive and ask your doctor for help, whether you're suffering with MS or caring for someone who has it. Chronic illness can be exhausting, and MS patients and their caregivers both need as much quality sleep as they can get.

● Customize your environment.

MS symptoms can strike suddenly and make it hard for patients to physically navigate their environment. Life is easier for people with MS when their homes and offices are arranged for maximum efficiency and minimum risk. Keep essentials within easy reach, install safety features in the bath and shower and cut down on clutter to reduce the risk of falls.

● Reach out and get involved.

Self-help and MS support groups can help you connect with other patients and caregivers and establish a valuable network for exchanging ideas, new research news and encouragement. Check your local hospitals or care centers, as well as MS organizations.

HOW TO APPLY FOR A UDID CARD

It is now compulsory, please get one for yourself today !

Henceforth, all persons desirous of applying for a Disability Certificate/UDID card are to apply online Person with Disability Registration | Unique Disability ID, Department of Empowerment of Persons with Disabilities, Ministry of Social

Justice & Empowerment, Government of India (swavlambancard.gov.in)

This procedure is applicable to all states. In the NCT of Delhi no offline applications will be entertained.

You can apply with or without a valid disability certificate. Please upload your disability certificate on the portal if you have been issued with one. In case not, you can still apply. Once your application is processed, you will be intimated on further action required. Please record and save the enrolment number generated once your application is successfully submitted.

Request all who have successfully registered to share their confirmation with the MSSSI society, under the following heads: -

1. Submitted and received UDID Card or
2. Submitted with date of submission/acknowledgement
3. State of residence

Why should you apply for an online UDID Card (Unique Disability Card) once you are diagnosed with MS:

Some important questions and their answers:

● **I am not disabled, why should I apply?**

It has now been made compulsory by the Govt of India - for all persons with MS or similar conditions/ progressive diseases to apply . UDID card is an identification proof launched under the Rare Diseases Policy of 2021 by the Central Govt for persons who have been diagnosed with MS and other recognised diseases under this Act, so that all of them get registered under one head.

● **I already have a Disability Certificate; do I still need to apply for UDID?**

Yes, this card is an identity card (like Aadhaar). It has a different purpose. You will require both for different things.

● **Why should I apply? Is there any benefit for me?**

Yes! There are many benefits that can help you & your family. Some of them are listed below:

UDID CARD BENEFITS

- A. Railway travel discounts - for you & an attendant/caregiver.
- B. Income Tax Exemptions - for you & the caregiver.
- C. Assistance at public places like banks, airports, railway stations, hospitals.
- D. The government is providing reservation in jobs, one can apply for the same using this card.
- E. The government is continually launching schemes like disability pension* and self-employment schemes.

(* As per State Rules & Conditions- to be applied at State level)



SO APPLY NOW - Visit: <https://www.swavlambancard.gov.in/>

It will help you, your family, the Society & also the Government to frame public policy based on large numbers!

THIS IS WHAT YOU NEED WHEN YOU APPLY: (Scans of the following docs.)

1. Passport Photo
2. Aadhar card both sides on one page
3. Thumb impression
4. Disability certificate -if you have one

If you have any difficulty or questions, write to MSSSI Delhi for help. Email us this information:



I need help to apply for my UDID Card. My information is given below:

My Name :

1. Father's Name
2. Mother's Name
3. Date of birth
4. Mobile no.
5. Spouse's Name
6. Guardian's Name and mobile no.
7. Marital status
8. E-mail ID
9. Category- General or OBC or SC
10. Education
11. Disability certificate: y/n If yes pls share photo
12. Visible Mark of identification
13. Blood group
14. Disability since which year.
15. Area affected
16. Treating hospital
17. Employed
18. If unemployed, since when
19. Present address
20. Permanent address



Enclosed are scans of my:

- Passport Photo
- Aadhar card both sides on one page
 - Thumb impression
- Disability certificate

NEUROGENIC PAIN IN MS

Claudio Solaro, MD, Department of Neurology, ASL 3 Hospitals, Genoa, Italy.

Introduction Pain is defined as an "unpleasant sensory experience associated with actual or potential tissue damage or described in terms of such damage". Although symptom management in MS represents a primary focus for health care professionals, data available in the literature on pain management is lacking. Neurogenic pain common in MS includes dysesthetic pain, trigeminal neuralgia, painful tonic spasms and Lhermitte's sign. Ethical issues regarding studies on pain make it difficult to identify the best treatment strategies based on comparisons of medication versus a placebo. Thus, for many of these symptoms treatment is based on anecdotal information and small, unblinded trials. Dysesthetic pain A number of studies have reported dysesthetic pain to be among the most common pain syndromes associated with MS.

Dysesthetic pain is described as a constant symmetric or asymmetric burning sensation, usually affecting a person's lower limbs, more frequently distally (meaning farther away from the body, such as in the feet and lower legs) than proximally (meaning closer to the body, such as in the upper part of the legs). A degree of sensory loss associated with dysesthetic pain can be detected during a neurological examination. First-line medications for the treatment of dysesthetic pain in MS are tricyclic antidepressants, including amitriptyline, nortriptyline and clomipramine.



Anticonvulsant medications such as carbamazepine, lamotrigine and gabapentin are also used in treating dysesthetic pain associated with MS. Carbamazepine appears to have a higher incidence of side effects, when compared to gabapentin and lamotrigine. Some people have difficulty tolerating this medication due to its side effects, and are not able to even reach the dose necessary for the medication to be effective. It is not uncommon for a person to try different medications before finding one that is effective and tolerable.

Open communication with the neurologist is very important throughout this process. In general, anticonvulsant medications, as well as tricyclic antidepressants, may be useful in some MS patients, although unfortunately there is not enough data available from studies with large numbers of participants, which is necessary for drawing conclusions as to the best choice of medication.

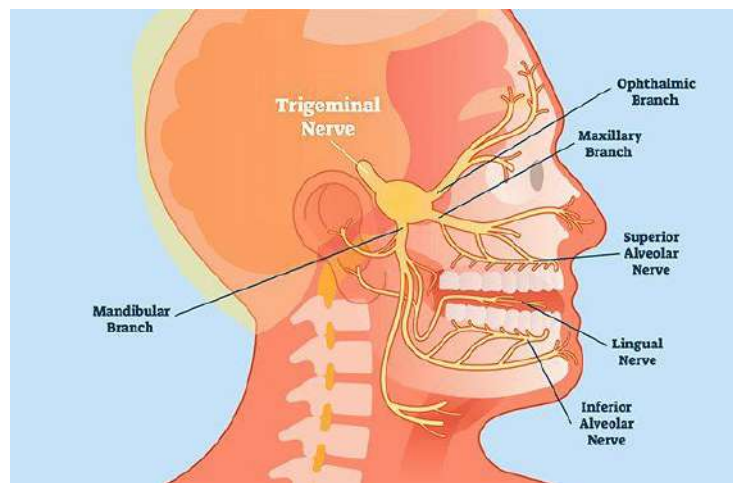
Trigeminal neuralgia:

Trigeminal neuralgia (TN) is probably the most widely recognised neurogenic pain syndrome in MS. It affects the trigeminal nerve, one of the largest nerves in the head (see above). The trigeminal nerve sends impulses of touch, pain, pressure and temperature to the brain from the face, jaw, gums, forehead and around the eyes. TN in people with MS has been widely studied, with prevalence ranging from 1.9 percent to 4.4 percent.

TN is characterised by paroxysmal (sudden), episodic facial pain which occurs in the area of the fifth cranial or trigeminus nerve, often triggered by touch, chewing, shaving or even a light breeze. TN in MS and essential TN (TN not related to MS) differ in that TN in MS is more often bilateral. The trigeminal nerve and its branches Trigeminal nerve (occurs on both sides of the face) and tends to occur at a younger age.

Essentially TN is most frequently caused by a blood vessel pressing on the nerve near the brain stem. Over time, changes in the blood vessels of the brain can result in a blood vessel rubbing against the trigeminal nerve root. The constant rubbing with each heartbeat wears away the insulating membrane of the nerve, resulting in nerve irritation. TN in MS is likely to be caused by a plaque at the TN nerve entry zone in the nerve fibres on the lower front surface of the brain.

However, magnetic resonance imaging (MRI) studies have demonstrated conflicting results, pointing to multiple causes of TN, even in the same person with MS. Treatment of TN primarily consists of anticonvulsant medications. Some antidepressant drugs can also be helpful in relieving this type of pain. Non-pharmacological interventions for trigeminal neuralgia



When medications are ineffective or if they produce undesirable side effects, neurosurgical procedures are available to relieve pressure on the nerve, to reduce nerve sensitivity or to interrupt the nerve pathway. These procedures have been reported as treatment for TN associated with MS, although with small numbers of people and limited follow-up. These techniques can cause nerve damage which may lead to increased sensitivity or numbness in the affected area, decreased corneal reflex, temporary difficulty chewing and hearing loss.

Painful tonic spasms:

Painful tonic spasms (PTS) are described as a cramping, pulling pain and can affect both the upper and lower limbs, although they are more common in the lower extremities. The spasms are triggered by movements or sensory stimuli, often occurring during the night. PTS are estimated to occur in approximately 11 percent of people with MS. PTS indirectly result from a lesion triggering the painful spasms in the central nervous system. Antispasticity medications, such as baclofen and benzodiazepines, gabapentin and tiagabine, are largely used for the treatment of PTS.



Lhermitte's Sign:

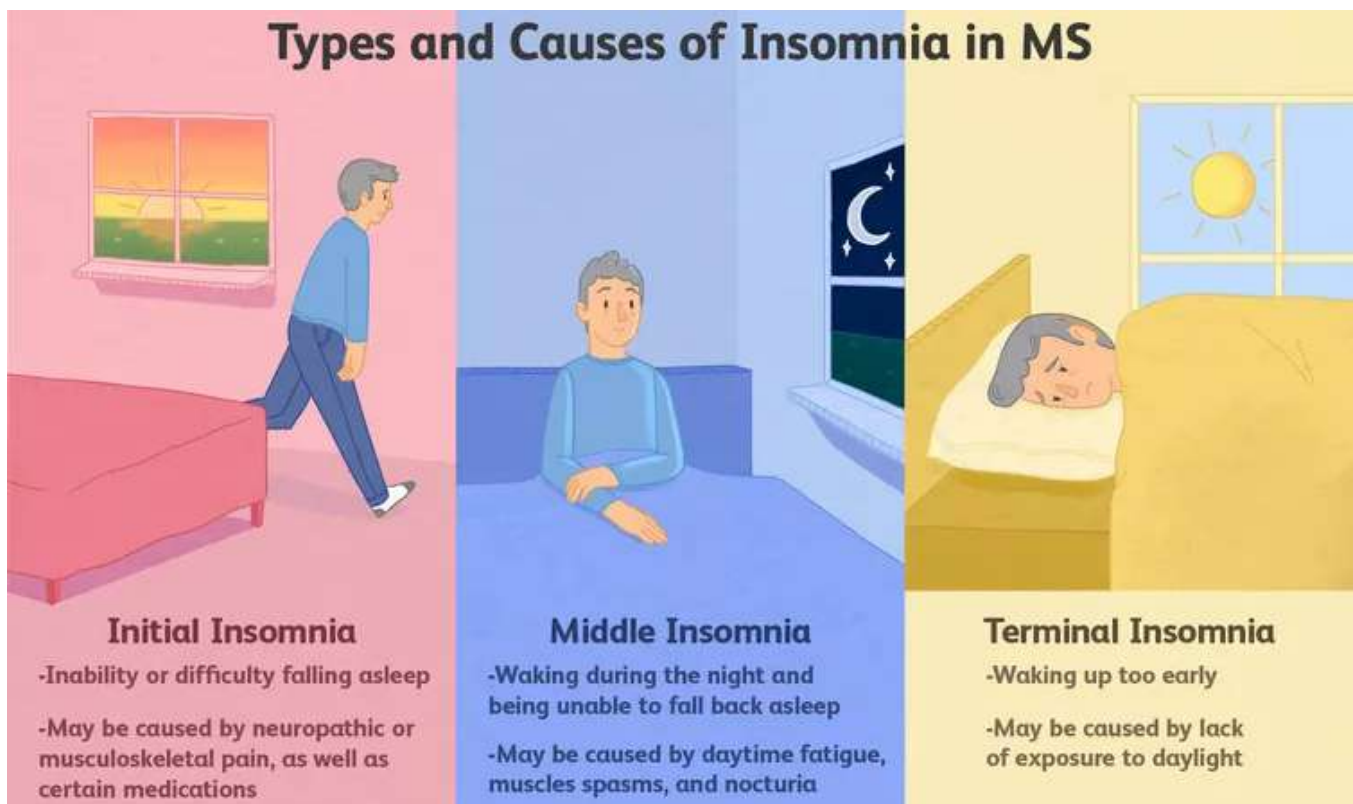
Lhermitte's sign, a short-lasting paroxysmal (sudden) pain radiating down the spine to the lower extremities triggered by flexing or extending the neck forward, is strongly linked to MS. It is experienced by approximately 40 percent of people with MS at some point throughout the disease course. If the phenomenon becomes persistent, small doses of carbamazepine have been recommended for reducing the frequency and severity. Often people with MS who experience this symptom do not require medication.

Conclusion Neurogenic pain in MS is variable with different treatment strategies. Often these painful symptoms can have a negative impact on a person's quality of life, and therefore require involvement of the neurologist and health care team in order to identify and treat them as effectively as possible. Achieving relief for neurogenic pain in MS may require trying different medications and dosages before identifying the most

effective solution. Since many types of pain common in MS are difficult to treat effectively with standard medications, clinicians should also be open to discussing non-standard strategies for improving pain relief.

THROWBACK : MSIF INTERNATIONAL CONFERENCE NEW DELHI 2011





INSOMNIA & MS

Sleep disorders are pervasive in patients with multiple sclerosis (MS) although clinically underrecognized by most physicians. The most common sleep disorders seen in patients with MS include insomnia, nocturnal movement disorders, sleep-disordered breathing, narcolepsy, and rapid eye movement sleep behavior disorder.

Quality sleep is important to maintaining overall health and wellness but sometimes it's hard to get. Lack of restful sleep can cause daytime drowsiness and make some MS symptoms feel worse. Sleep difficulties are actually more common in MS than in the general population.

Sleep disturbance is a general term for a wide range of sleep-related symptoms and disorders, and can include:

- Difficulty with initiating or maintaining sleep, also known as insomnia
- Difficulty with too much sleep, also known as hypersomnia or hypersomnolence
- Uncontrollable lapses into sleep, also known as narcolepsy
- Sleep related breathing difficulty, including sleep apnea
- Abnormal movements during sleep, including restless legs/body syndrome
- Abnormal behaviors during sleep including acting out dreams
- Excessive daytime sleepiness

Are you sleep-deprived?

If you answer yes to any of the following questions, you may not be getting enough good quality sleep.

- Do you feel sleepy, grumpy or "down" during much of the day?
- Do you fall asleep as soon as your head hits the pillow?
- Do you sleep fewer than 7 hours most nights?
- Do you still feel tired even after having 8 hours of sleep or more?

Causes of sleep disturbances in MS Sleep is impacted in a number of ways including:

- Deficiencies in Vitamin D and other nutrients that may help regulate sleep
- Side effects of MS medications including the disease-modifying therapies, corticosteroids, and stimulant medications for fatigue
- Increased napping during the day due to fatigue
- Reduced physical activity due to fatigue and MS-related disability
- Emotional changes including stress, anxiety or depression.
- Other MS symptoms including restless legs, pain, urinary or bowel symptoms, and temperature dysregulation

Strategies to get the sleep you need

- Tell your primary care or MS healthcare provider about your sleep problems
- Treat MS symptoms that may cause sleepiness
- Consider the side effects of medications
- Sleeping pills may be of some benefit, at least for a short time. However, many experts recommend taking them as only a last resort because they lose their effectiveness quickly and are potentially addictive.
- Cognitive Behavioral Therapy (CBT) can help with insomnia.

STEPS YOU CAN TAKE TO IMPROVE YOUR SLEEP QUALITY INCLUDE:

- Go to bed and get up at the same time every day-and no more than 1 hour later on weekends. Regularity helps set your biological clock.
- Clear your mind before bed. Do you rehash the day's problems or worry about tomorrow once you are in bed? It may help to write a list of today's worries and things to do tomorrow well before bedtime.
- Plan your exercise to occur about 4-6 hours before bedtime. Exercise is a stimulant, so don't exercise close to bedtime.
- Limit your caffeine use to the morning.
- Limit alcohol use, particularly within 6 hours of bedtime.
- Quit smoking or using other tobacco products. In the meantime limit nicotine use close to bedtime.
- Create a bedtime ritual to signal the body and mind to slow down. Change into pajamas, wash up and brush your teeth at least an hour before sleep. In that last hour, wind down by listening to calm music, reading or writing in a journal.
- Don't drink a lot of fluids just before bedtime. Urinate before going to bed.
- Make sure your bedroom is cool, quiet and dark.
- Try a relaxation technique that you like (breathing, imagery or muscle relaxation) once the lights are off.
- Use your bedroom for sleeping and sex only. Don't read, watch TV, use your mobile device or talk on the phone in bed.
- If you don't fall asleep within 15-20 minutes... get up. Don't stay in bed and watch the clock. Do something boring and relaxing (read something light or watch an old movie).
- Manage your mood. Talk to your healthcare provider if you've noticed any emotional changes.

Assessing your sleep is the first step to identifying sleep-related problems and/or clinically significant sleep disorders.

STUDY ON SLEEP DISORDER BY MUKUL VIJ

Dr. Mukul Vij (Occupational Therapist) who is on the panel of MSSSI Delhi for Home Physiotherapy and Occupational Therapy consultancy had done his Masters in Occupational Therapy in Neurology. His research topic result with the help of MSSSI Delhi was as follows -



"Relationship between Sensory Processing Patterns and Sleep Quality in Multiple Sclerosis, MS".

This study aimed to find the relationship between sensory processing patterns and sleep quality in persons with Multiple Sclerosis . **This was a cross sectional study design with the sample size of 50 persons with MS taken from Multiple Sclerosis Society of India ,Delhi Chapter** and Community in which inclusion criteria was persons with Multiple Sclerosis aged 18 and above and the subjects who could read and understand English language. Those MSps were excluded who had neurological conditions other than Multiple Sclerosis, severe cognitive decline and any psychiatric condition. Demographic details and informed consent were taken from the subjects followed by the administration of Pittsburgh sleep quality index and Adolescent/Adult sensory profile. The data was statistically analyzed.

As stated by the Pittsburgh sleep quality index, participants with scores equal to more than 5 are bad sleepers and the participants with scores less than 5 are good sleepers.

In our study, it came out that out of 50 participants, only 4(8%) participants were good sleepers and 46(92%) participants were bad sleepers.

It was concluded from the study that sensory processing difficulties are present in the patients with Multiple Sclerosis with the difficulties in low registration, sensory sensitivity and sensory avoidance.

It was also concluded that sleep difficulties are very common in patients with Multiple Sclerosis.

Finally the research concluded that with disturbed sensory stimuli, sleep was also disturbed and the patients who showed increasing sensory stimuli in the sensation seeking quadrant and other sensory stimuli in normal ranges, emerged to be good sleepers.

BEDTIME SNACKS TO HELP YOU SLEEP

When it comes to good health, factors like diet, physical activity, stress, and sleep are all connected.

That said, it's not surprising that what you eat can affect your nighttime rest. While the foods you eat throughout the day may have some impact on your sleep, your best chance to snack your way to better shuteye is just before you turn in.

Eating the right foods (or combination of foods) in the evening hours could mean the difference between fitful and restful sleep.

Find out why and how foods can help you sleep, plus 15 bedtime snacks that may help send you snoozing.

How foods can help you sleep

The link between foods and sleep comes down to what's in what you eat. According to research blood levels of micro nutrients like magnesium, iron, and zinc, for example, have been linked with longer sleep duration.

They also showed that fats like omega-3 fatty acids can reduce the time it takes to fall asleep.

According to this research higher-protein diets may also contribute to improved sleep quality.

For some people, a racing mind or feelings of anxiety are the cause of insomnia.

An older study noted that serotonin-rich foods may be especially helpful in that case, since serotonin may be involved in regulating an anxious mood.

If you've ever heard that turkey makes you sleepy, you're probably familiar with the effects of tryptophan. This amino acid converts to serotonin and melatonin, which both help the body relax.

Tryptophan can be found in:

- Cheese
- Chicken
- Egg whites
- Fish
- Milk
- Sunflower seeds
- Peanuts
- Pumpkin seeds



Milk ↗



Tart Cherry
Juice ↗



Hard Boiled
Egg ↗



Cheese Stick ↗



↗
1/2 Peanut Butter
& Jelly Sandwich



↗
Nut Butter
& Crackers
48



↗
Cottage Cheese
& Fruit

How foods can disrupt sleep

Just like some foods can promote sleep, others can disrupt it.

You probably know that foods like coffee and energy drinks aren't great nightcaps due to caffeine and common energizers like ginseng and yerba mate.

These aren't the only choices to avoid before bed.

Eating spicy or acidic foods shortly before bed may cause indigestion or acid reflux, which could keep you tossing and turning.

Another culprit is sugary foods. Research has proved that a high-glycemic index diet, or one high in sugar, is linked to a higher risk of insomnia.

Eating foods high in sugar right before bed could make you feel sleepy, making it easier to fall asleep, but will also increase the chances of a restless night's sleep.

This is due to a sharp rise in blood sugar that releases insulin and other hormones to help bring blood sugar back down. This hormonal activity can disrupt sleep.

Foods to eat before bedtime, plus quick prep tips

When hunger strikes at night, head to the kitchen for any of these pro-sleep snacks. Just note that eating too close to climbing into bed could backfire.

"Do your best to avoid eating close to bedtime," says Rebecca Robbins, PhD, sleep expert for Oura sleep tracking devices. Robbins recommends finishing a snack at least one hour before going to bed.

Tart cherry juice smoothie

Nutritionists in the west are recommending tart (sour) cherry juice for its antioxidant properties, however that is not easily available in India. It can be replaced with turmeric milk. The antioxidants in it can help with improved cognitive function, and it's even been found to improve memory and language skills in patients with dementia.

Pro tip: Sprinkle in some flax seeds for extra omega-3 fats.

Smoked salmon cream cheese rollups

Salmon contains the highest omega-3's of most fish in the sea. Since these healthy fats may improve sleep efficiency, it's a good idea to let them swim into your diet pre-bedtime.

Try spreading a layer of cream cheese on a chapati and topping with smoked salmon. Then roll it and slice it into bite-sized pieces.

Whole grain toast with peanut butter

Keep it simple at bedtime with a tablespoon of peanut butter on whole-grain toast.

"This magnesium-rich snack will help keep you full throughout the night without spiking your blood sugar," says Lorenz.

Blueberry-almond oatmeal

You might associate oatmeal with breakfast, but don't discount it as a nighttime snack! Lorenz recommends a bowl of oats with berries before bed. Mixed berries are now available in most grocery stores and are affordable. You can find a berry, flax seed & pumpkin seed mix which can be added to your bowl of curd, porridge or oats for a delicious crunch.

"Oats are a good source of tryptophan, which helps your body to produce melatonin to support a natural sleep cycle," she says. "Sweeten oatmeal with berries for a fiber-rich, sweet bedtime snack that will produce a gradual rise and fall in blood sugar while you snooze." It's also a good idea to add a handful of walnuts to boost your omega-3 fatty acids and protein, plus they can help prevent blood sugar levels from dropping too low.

Tuna cucumber bites

Canned tuna may be a humble snack, but it contains plenty of sleep-promoting omega-3s. It's also a source of vitamin B6, which assists in the production of melatonin. Mix some with a little mayo and spread it on cucumber slices for a light, crunchy snack.

Kiwi slices

Sweet dreams are made of... kiwi? It's possible! 24 subjects found that eating two kiwi fruits one hour before bed for four weeks helped subjects fall asleep faster and stay asleep longer.

Handful of pistachios

Pistachios contain more melatonin than any other nut. Try snacking on a handful an hour or so before bed. Like cashews and pistachios, almonds are another nut with bedtime benefits. They contain melatonin and magnesium to contribute to better rest.

Cashew trail mix

Like pistachios, cashews are rich in melatonin. Plus, they boast another bonus: They're a good source of magnesium. Create a trail mix with cashews, dried cranberries, almonds, or any of your favorite nuts and dried fruits. Go easy on the cashews though.. taken in excess they could be fattening !

Spinach egg bites

Spinach and eggs may be a powerful combo for better sleep. The magnesium in spinach promotes relaxation, while its vitamin B6 is a co-factor in converting tryptophan to serotonin. Eggs, meanwhile, are high in melatonin. To make a yummy egg bite, just beat an egg spread over a portion of creamed spinach, cover with a lid till it cooks. You could add a knob of cheese for a yummy flavour.

Chamomile tea with warm milk

"Drinking chamomile tea before bed is a great way to reduce anxiety symptoms and support a good night of sleep," says Lorenz. Chamomile is particularly rich in the antioxidant apigenin, which works like an antidepressant and antianxiety agent to inhibit monoamine oxidases (MAO's)." Chamomile tea bags are easily available in the market.

According to a 2022 study on animal models, inhibiting MAO increases the level of monoamines, like serotonin, in the brain, which is associated with a reduction in depressive symptoms.

Add a splash of warm milk to your steaming cup for a soothing, cream Nutsy texture and a bit of healthy fat.



The keys to patience are acceptance and faith. Accept things as they are ,and look realistically at the world around you. Have faith in yourself and in the direction you have chosen.

Goodwill Message Sponsored by: Brigesh Aiyar

MAKING NUTRITIONAL CHOICES

By Dr Anne Payne, Lecturer in Clinical Nutrition and Dietetics, Glasgow Caledonian University, Glasgow, United Kingdom

We know that our health and happiness are intricately bound up in our choice of food and drink. We also know we gain a sense of well-being from taking control of our diets. It's not surprising that people with MS so frequently ask:

"What type of food should I eat to stay healthy?"

The simple answer – "a low animal-fat diet" – is true of relapsing-remitting MS and is good advice. However, the real answer is actually quite complex as individual needs in MS are as varied and unpredictable as the symptoms of MS themselves. In the beginning When MS is first diagnosed, most people are able to eat a varied diet. This is a good time to encourage the principles of a healthy-eating regimen, outlined in Table 1, as most people with MS are motivated to make positive changes.

Those who have had MS for some time will be familiar with the concept of a healthy diet, low in animal fats such as butter and fatty meat, but rich in vegetable fats and oily fish. This type of diet has been advised by MS societies world-wide for many years. The evidence in support of this type of diet suggests that omega-3 oils found in oily fish such as mackerel, sardines, herring and tuna may have an anti-inflammatory role in many conditions, including MS. Linoleic acid, a type of omega-6 polyunsaturated fat found in some vegetable oils, has been described as a treatment which may help slow down the disabling effects of MS.

Health professionals are not unanimous about this, but there is no doubt that linoleic acid is a valuable part of a healthy diet. However, the daily recommended amount can be obtained through a balanced diet and there is no need for capsules if the diet is adequate. More than the recommended dose does not increase the potential benefits. As many people with MS are minimally active, with low energy needs, the lower amounts of linoleic acid they need are best taken from concentrated omega-6 oils, such as sunflower oil, safflower oil or soya oil. These oils are also a rich source of vitamin E. This is thought to protect myelin and other tissues from oxidative damage. Vitamin E is found in abundance in wholegrain cereals as well.



Using omega-6 oils Food oils can be easily consumed as a salad dressing, with added herbs for flavour, as a dip for bread, or sprinkled into sauces and soups. Heating them to a high temperature reduces their nutritional benefit, so they should not be used in frying, other than for a rapid stir-fry. In practice, people with MS should be encouraged to use a variety of omega-6 oils and spreads in moderation, to provide about 10 per cent of total energy intake.

As symptoms progress Diet is of particular benefit in the clinical management of MS when symptoms of disability develop. Constipation, weight gain, urinary tract infections (UTIs), swallowing difficulty, malnutrition, pressure sores and fatigue may all benefit from appropriate food, fluid and nutritional care. Early warning Change in body weight and nutritional well-being in MS usually occurs slowly and so the onset of debilitating weight gain or malnutrition is often ill defined and a pattern of poor eating habits has become well-established by the time any action is taken.

This can be prevented by ensuring that weight and height are recorded at diagnosis and that weight is recorded at each clinic visit thereafter to enable a nurse, nutritionist or dietician to monitor "body mass index" (BMI), a measure of weight for height.

Poor mobility Constipation, weight gain and UTIs often occur simultaneously in those with MS who use a wheelchair, due to limited mobility. Their diet should include a fair amount of bulky, low fat, high fibre foods, including soft fruits such as bananas, prunes and peaches, a good selection of vegetables, whole grain cereals, and a daily intake of two litres or more of sugar-free fluids. Cranberry juice is popular in the prevention of UTI. However, cranberry drinks contain a lot of sugar so they should be used with caution. Cranberry capsules are an alternative to juice.

Modify with care: At no time is choice of diet of greater importance in MS than when the ability to swallow food or fluid is affected. Dysphagia, as this is known, causes coughing and choking during meals and commonly results in poor intake. This can lead to severe weight loss, possible dehydration, and to pneumonia if food particles are aspirated during coughing or choking. The diet should be modified with care. To prepare soft but nourishing food, it may be necessary to finely mash chopped fish or meat into thick sauce or gravy with a fork. If a purée diet is advised by a health professional trained to assess swallowing ability, then a food blender may be needed. Sometimes drinks are taken more easily when thickened a little with a special food starch. Thickening can help prevent a trickle of fluid from entering the lungs. When malnutrition is a problem Other symptoms of MS can also contribute to malnutrition and should be identified early.

Severe tremor and postural difficulties may make eating physically difficult to accomplish. Tremor may also increase energy and nutrient needs. Many adaptive aids are available that can assist people who experience physical difficulties while eating or drinking. These include plates with rims and nonslip surfaces, special grip cutlery, weighted utensils, drinking cups with handles, special grip surfaces or weights and many others. Poor vision affects the ability to shop, prepare meals and to eat.

Online shopping using an adapted computer screen can be helpful for some people with visual difficulties. An occupational therapist can provide suggestions for adapting meal preparations and eating. Fatigue and poor appetite cause weight loss as small, less frequent meals are taken. Fatigue can be especially problematic for people with MS who have the responsibility for meal preparation in the home.



Some energy-conservation strategies that can be helpful during food preparation. Poor memory or depression can reduce the motivation to eat. People with these types of problems should be encouraged to discuss these issues with their healthcare professionals.

Finally, some drugs for MS symptoms may cause poor appetite or a dry mouth, which makes it difficult to chew and swallow. When malnutrition is a risk, the greatest nutritional need is for energy to help prevent loss of body weight and muscle strength. Food may need to be quite high in fat to provide concentrated nourishment. Full-fat dairy foods, such as milk, cream, cheese and butter should not be avoided as they can be stirred into sweet and savoury food to increase their energy content. Milk, cheese and yoghurt are also rich sources of calcium. This is essential for bone health, especially when mobility is poor or when taking steroids.

Choose wisely A multi-vitamin supplement can be reassuring, but if a good variety of high-energy food is available, expensive supplements (in pill form or drinks) should not be needed. Be wary of self-help books that suggest avoiding specific foods or taking expensive supplements. To date, there is no medical evidence to support any of these 'MS diet' or supplement claims, and while they may give people a temporary feeling of control and well-being, they may contribute to the onset of malnutrition and be expensive or even dangerous. So before following any special diet, people with MS should consult a qualified healthcare professional.



#MyMSstory: Shalini Monga

MSSI Delhi and myself go a long way back to 2003 ,I remember getting calls from Bipasha ma'am to get registered in MSSI Delhi but I was a typical working girl of 28 yrs that time with 6 attacks of ms behind me, did not know the seriousness of the problem except that I have to go through annual MS attacks and I had taken it as a part of life.

I joined MSSI in 2008 as a Youth MS Group Delhi after much convincing with a visit of Bipasha mam and 1 more MS boy. in fact, Delhi was the first place in the world to come up with this idea n it was Bipasha mam's idea, so together we worked for YMSG Delhi i.e Youth MS Group, Delhi. I remember the launch was attended by 4 young msp's on 13th Sep 2008, the day of

serial blasts in Delhi. But slowly our Youth MS group family started growing and I started enjoying talking to number of young MS members to encourage the youth and understand their complains and anxiety which they were unable to share with elders. This also helped me realise that though I was suffering since a longer time than all of them I was keeping much better than them. I had gone to the U.S for my treatment . There I had seen the difference in approach to MS and wanted to bring it back here also. But that was not possible, I had a talk with Bipasha mam n she made me the leader of ymsg Delhi. Being in North India always I knew the concept of family prevalent in North and how young MS person would need someone their age group to listen to them. It could be a relationship breakup or losing a job or siblings not or parents not understanding them and their mental condition. Every Saturday Bipasha mam n me would have a run through of the week's activities. Bipasha mam and Meenakshi mam would gather young MSPs at clubs or Coffee shops for interaction ,they would make us comfortable and disappear. They managed to make us independent by constant explanation to parents not to accompany their MS child.

In 2010 YMSG was taken up at a national level and we formed the first INDIA YMSG . I was appointed as the first YMSG INDIA leader. In 2011 there was a MSIF conference in Delhi where members from chapters all over the world had come. The idea of ymsg really clicked with them n many of them also started ymsg in their respective chapters.

That was a turning point in my life. I have a presentation on Youth MS Group during AGM in Delhi. In mean time I had visited Pune and strengthened YMSG group there.

I realised that bringing happiness into people's life gives one greater happiness than working in a MNC. With MSSI I can work at my own convenient times, MSSI understands my post insomnia n mood upswings n my pains(both mental n physical).

In 2018, I was one of the 3 speakers who had to speak impromptu on my journey with MS in front of 500 audiences at the LALIT CHARITY FUNDRAISER. It gave me a lot of confidence. This was again Ms. Bipasha Gupta's idea to put me in the limelight. A constant endeavour by all members of the Executive Committee - Mr. Prabal Malaker, Ms. Bipasha Gupta, Ms. Meenakshi Bhujwala, Ms. Nina Kochhar, Ms. Pinky Hora, Ms. Milly, Ms. Ragini Mathur and Ms. Puja Chaudhary to always increase my confidence by always handing me over a project to take over has always increased my confidence. I worked as a MSSI Delhi Executive Member also for a while. This year in 2023 I completed 15 yrs of my life with MSSI, I have evolved as a person compassionately n have become more strong with MSSI. For which I will always be thankful to the Society . I am very happy to be a part of MSSI DELHI and will always be offering them my services.

With the pandemic coming into our lives I was given the HAPPY BIRTHDAY project to handle. That project helped me realise how important it is to always be in touch with people.

It gave me such a lot of mental happiness to just hear a pleasantly surprised voice- "You remember my birthday!" Day by day my MS Family is growing, I started attending day cares regularly.

Since 2009, MSSSI also started getting stalls at OZ HAAT i.e the NGO mela at AUSTRALIAN HIGH COMMISSION and since last 3 of years in British High Commission, Tamanna mela. That was also handed over to me to take care of. I was very nervous in the beginning but Ms.Pinky Hora and others were there with me to support me. I sell home made pickles made by a MSp and help other MSP participants who is on a wheelchairs to sell their products through our 'SWAYAM ' project . With the passing of years and continuous support n help from MSSSI, the last time I managed to sell pickles worth Rs.8000/- in a span of 6 hrs. Not to forget, all the Executive members came there every year to volunteer and encourage me. This year, I was given the Certificate of Excellence for my services as a volunteer for MSSSI. This certificate was handed over by Ms. Bipasha Gupta (Hon Chairperson of MSSSI) and Ms. Meenakshi Bhujwala (Hon. Treasurer) I am short of words to express my gratitude to MSSSI Delhi and their love and everlasting support for me.

I would encourage all MS persons to join MSSSI and take up volunteering for MSSSI, it will surely improve their own life style and mental condition and they will be able to help MSSSI Delhi to grow further.

I would like to end by saying that MSSSI Delhi has given me a reason to live and laugh.

Shalini Monga

THROWBACK : MSIF INTERNATIONAL CONFERENCE NEW DELHI 2011

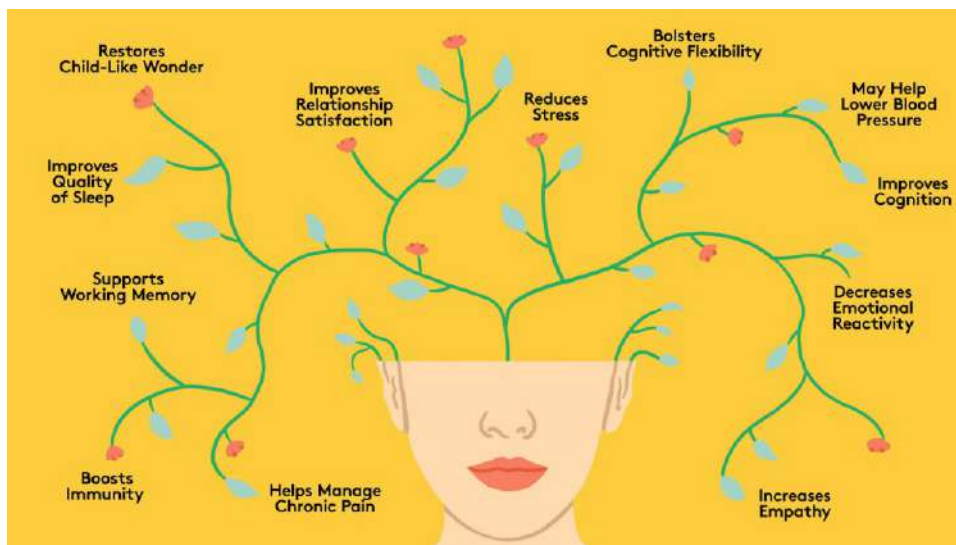


MINDFULNESS

6 Mindfulness Exercises You Can Try Today

In this busy world of ours, the mind is constantly pulled from pillar to post, scattering our thoughts and emotions and leaving us feeling stressed, highly-strung and at times quite anxious. Most of us don't have five minutes to sit down and relax, let alone 30 minutes or more for a meditation session. But it is essential for our wellbeing to take a few minutes each day to cultivate mental spaciousness and achieve a positive mind-body balance. So if you are a busy bee like me, you can use these simple mindfulness exercises to empty your mind and find some much-needed calm amidst the madness of your hectic day. I'm going to cover 6 exercises that take very little effort and can be done pretty much anywhere at anytime:

- Mindful breathing
- Mindful observation
- Mindful awareness
- Mindful listening
- Mindful immersion
- Mindful appreciation



1. Mindful Breathing

This exercise can be done standing up or sitting down, and pretty much anywhere at any time. If you can sit down in the meditation (lotus) position, that's great, if not, no worries. Either way, all you have to do is be still and focus on your breath for just one minute.

- Start by breathing in and out slowly. One breath cycle should last for approximately 6 seconds.
- Breathe in through your nose and out through your mouth, letting your breath flow effortlessly in and out of your body.
- Let go of your thoughts. Let go of things you have to do later today or pending projects that need your attention. Simply let thoughts rise and fall of their own accord and be at one with your breath.
- Purposefully watch your breath, focusing your sense of awareness on its pathway as it enters your body and fills you with life.
- Then watch with your awareness as it works work its way up and out of your mouth and its energy dissipates into the world.

If you are someone who thought they'd never be able to meditate, guess what? You are half way there already!

If you enjoyed one minute of this mind-calming exercise, why not try two or three?

2. Mindful Observation

This exercise is simple but incredibly powerful because it helps you notice and appreciate seemingly simple elements of your environment in a more profound way.

The exercise is designed to connect us with the beauty of the natural environment, something that is easily missed when we are rushing around in the car or hopping on and off trains on the way to work.

- Choose a natural object from within your immediate environment and focus on watching it for a minute or two. This could be a flower or an insect, or even the clouds or the moon.
- Don't do anything except notice the thing you are looking at. Simply relax into watching for as long as your concentration allows.
- Look at this object as if you are seeing it for the first time.
- Visually explore every aspect of its formation, and allow yourself to be consumed by its presence.
- Allow yourself to connect with its energy and its purpose within the natural world.

3. Mindful Awareness

This exercise is designed to cultivate a heightened awareness and appreciation of simple daily tasks and the results they achieve. Think of something that happens every day more than once; something you take for granted, like opening a door, for example. At the very moment you touch the doorknob to open the door, stop for a moment and be mindful of where you are, how you feel in that moment and where the door will lead you.

Similarly, the moment you open your computer to start work, take a moment to appreciate the hands that enable this process and the brain that facilitates your understanding of how to use the computer.

These 'touch point' cues don't have to be physical ones.

For example: Each time you think a negative thought, you might choose to take a moment to stop, label the thought as unhelpful and release the negativity. Or, perhaps each time you smell food, you take a moment to stop and appreciate how lucky you are to have good food to eat and share with your family and friends. Choose a touch point that resonates with you today and, instead of going through your daily motions on autopilot, take occasional moments to stop and cultivate purposeful awareness of what you are doing and the blessings these actions brings to your life.

4. Mindful Listening

This exercise is designed to open your ears to sound in a non-judgmental way, and indeed to train your mind to be less swayed by the influence of past experiences and preconception.

So much of what we "feel" is influenced by past experience. For example, we may dislike a song because it reminds us of a breakup or another period of life when things felt negative.

So the idea of this exercise is to listen to some music from a neutral standpoint, with a present awareness that is unhindered by preconception.

Select a piece of music you have never heard before. You may have something in your own collection that you have never listened to, or you might choose to turn the radio dial until something catches your ear.

- Close your eyes and put on your headphones.
- Try not to get drawn into judging the music by its genre, title or artist name before it has begun. Instead, ignore any labels and neutrally allow yourself to get lost in the journey of sound for the duration of the song.
- Allow yourself to explore every aspect of track. Even if the music isn't to your liking at first, let go of your dislike and give your awareness full permission to climb inside the track and dance among the sound waves.
- Explore the song by listening to the dynamics of each instrument. Separate each sound in your mind and analyze each one by one.
- Hone in on the vocals: the sound of the voice, its range and tones. If there is more than one voice, separate them out as you did in step 4.

The idea is to listen intently, to become fully entwined with the composition without preconception or judgment of the genre, artist, lyrics or instrumentation. Don't think, hear.

5. Mindful Immersion

The intention of this exercise is to cultivate contentment in the moment and escape the persistent striving we find ourselves caught up in on a daily basis. Rather than anxiously wanting to finish an everyday routine task in order to get on with doing something else, take that regular routine and fully experience it like never before. For example: if you are cleaning your house, pay attention to every detail of the activity. Rather than treat this as a regular chore, create an entirely new experience by noticing every aspect of your actions:

Feel and become the motion when sweeping the floor, sense the muscles you use when scrubbing the dishes, develop a more efficient way of wiping the windows clean. The idea is to get creative and discover new experiences within a familiar routine task. Instead of labouring through and constantly thinking about finishing the task, become aware of every step and fully immerse yourself in the progress. Take the activity beyond a routine by aligning yourself with it physically, mentally and spiritually.

Who knows, you might even enjoy the cleaning for once!

6. Mindful Appreciation

In this last exercise, all you have to do is notice 5 things in your day that usually go unappreciated. These things can be objects or people; it's up to you. Use a notepad to check off 5 by the end of the day. The point of this exercise is to simply give thanks and appreciate the seemingly insignificant things in life, the things that support our existence but rarely get a second thought amidst our desire for bigger and better things.

For example: electricity powers your kettle, the postman delivers your mail, your clothes provide you warmth, your nose lets you smell the flowers in the park, your ears let you hear the birds in the tree by the bus stop, but...

- Do you know how these things/processes came to exist, or how they really work?
- Have you ever properly acknowledged how these things benefit your life and the lives of others?
- Have you ever thought about what life might be like without these things?
- Have you ever stopped to notice their finer, more intricate details?
- Have you ever sat down and thought about the relationships between these things and how together they play an interconnected role in the functioning of the earth?

Once you have identified your 5 things, make it your duty to find out everything you can about their creation and purpose to truly appreciate the way in which they support your life.

Why Mindfulness Exercises?

The cultivation of moment-by-moment awareness of our surrounding environment is a practice that helps us better cope with the difficult thoughts and feelings that cause us stress and anxiety in everyday life.

With regular practice of mindfulness exercises, rather than being led on auto-pilot by emotions influenced by negative past experiences and fears of future occurrences, we harness the ability to root the mind in the present moment and deal with life's challenges in a clear-minded, calm, assertive way.

In turn, we develop a fully conscious mind-set that frees us from the imprisonment of unhelpful, self-limiting thought patterns, and enables us to be fully present to focus on positive emotions that increase compassion and understanding in ourselves and others.

CARING FOR YOU

A complex disease requires a comprehensive approach

Today multiple sclerosis (MS) is not a curable disease. Effective strategies can help modify or slow the disease course, treat relapses (also called attacks or exacerbations), manage symptoms, improve function and safety, and address emotional health.

The model of comprehensive MS care involves the expertise of many different healthcare professionals-each contributing in a unique way to the management of the disease and the symptoms it can cause. Sometimes this team works within a single center, offering you “one-stop shopping”. More often, you are referred by your MS physician to other specialists in the community. In either case, the goal is comprehensive, coordinated care to manage the disease and promote comfort, function, independence, health and wellness.

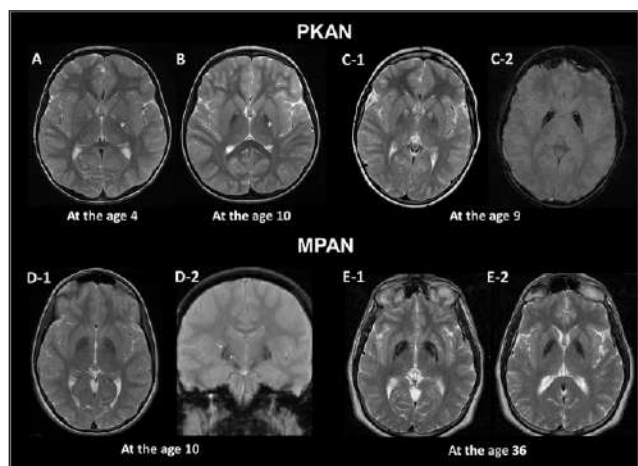
For most people with MS, the neurologist functions as the leader of the team. As a specialist in diseases of the nervous system, it is the neurologist’s job to make the MS diagnosis, identify treatment strategies and coordinate these treatment efforts with other members of the team.

MS is only part of overall health

Comprehensive MS care is part-but not all-of your overall health management strategies. Like the general population, you are subject to medical problems that have nothing to do with your MS. Regular visits with a primary care physician and age-appropriate screening tests are just as important for you as they are for everyone else. Routine dental care and taking care of dental issues is also important and can help prevent complications from infections. The same goes for family members- their health and well-being are also a priority. The parts that make up the whole

Modifying the disease course

More than a dozen disease-modifying medications have been approved to treat relapsing forms of MS. One has now been approved to treat both relapsing MS and primary-progressive MS with several others approved for secondary progressive MS and clinically isolated syndrome. These medications reduce the frequency and severity of relapses (also called attacks or exacerbations), reduce the accumulation of lesions in the brain and spinal cord as seen on magnetic resonance imaging (MRI) and may slow the accumulation of disability for many people with MS. Treating exacerbations (MRI) and may slow the accumulation of disability for many people with MS.





Treating exacerbations: An exacerbation (attack) of MS is caused by inflammation in the central nervous system (CNS) that causes damage to the myelin and slows or blocks the transmission of nerve impulses. To be a true exacerbation, the attack must last at least 24 hours and be separated from a previous exacerbation by at least 30 days. However, most exacerbations last from a few days to several weeks or even months. Exacerbations can be mild or severe enough to interfere with a person's ability to function at home and at work. Severe exacerbations are most commonly treated with high-dose corticosteroids to reduce the inflammation.

Managing symptoms: In MS, damage to the myelin and nerve fibers in the CNS (central nervous system) interferes with the transmission of nerve signals between the brain and spinal cord and other parts of the body. This disruption of nerve signals produces the symptoms of MS, which vary depending on where the damage has occurred.



Promoting function through rehabilitation: Rehabilitation programs focus on **function**—they are designed to help you improve or maintain your ability to perform effectively and safely at home and at work. Rehabilitation professionals focus on overall fitness and energy management, while addressing problems with accessibility and mobility, speech and swallowing, and memory and other cognitive functions. Rehabilitation is an important component of comprehensive, quality healthcare for people with MS at all stages of the disease.

Providing emotional support: Comprehensive care includes attention to emotional health as well as physical health. Mental health professionals and our counselors provide support and education, help you in diagnosing and treating the depression, anxiety and other mood changes that are so common in MS. Neuro-psychologists assess and treat cognitive problems.

The MSSSI Delhi Care program connects you to appropriate health care providers and medical facilities that have demonstrated exceptional care, knowledge and expertise in treating patients with MS. All partners, whether they are a neurologist or counsellor, physiotherapist or our Nurse or Home care attendant, have a strong relationship with the Society and connect their patients to the information, resources and support they need to live their best lives with MS.

MS WELLNESS TOOLKIT

MS and Wellness

Twenty years ago, there were no disease-modifying therapies for MS. Now, there are almost 15. It's up to each person and their healthcare team to determine which, if any, is right for them. To help from a wellness perspective, the MS Society reached out to those living with MS to determine common threads in managing – and thriving – with this disease. MS can be erratic, and a “one-size-fits-all” treatment does not exist.

A few wellness themes emerged:

1) Move Your Body

Exercise is key. For most people (with or without MS), eight hours a day in the gym is not realistic, but that doesn't mean you do nothing. Pilates and yoga are emerging as new ways to be active and can be tailored for people living with MS. Or a variety of other activities can be adapted to provide beneficial aerobic and strength training. Just do as much as you can, as often as you can.

2) Feed Your Health

While there is a vast amount of research about diet and wellness, the general rule of thumb is to eat healthy. For some that means cutting out dairy, gluten and sugar, for others it can simply mean increasing your whole foods intake. Find the personal balance that feeds your body and soul.

3) Look Beyond the Traditional

While having a traditional healthcare team is a must for most MS protocols, you don't have to stop there. Many people living with MS take a holistic approach to healing and incorporate nutritionists, naturopaths, massage therapists, or acupuncturists. Just ensure everyone involved in your healthcare is aware of all treatments.

4) Share

Most people living with MS find it helpful to talk about their experiences. While support groups are very popular, they are not for everyone. Some people living with MS choose other avenues like writing a blog; keeping a diary; confiding in a close friend; or attending therapy sessions.

5) Take it Easy

You are going to have bad days. Allow yourself to be down for a day, and then work to make tomorrow better. Just always know that you are not alone on this journey, and that help can be around the corner or a phone call away.





Priya is an outgoing, positive leader within the MS community. She gets involved. She is making a difference. When asked for her advice, she points to the analogy that she uses in her support group, "MS is a path. Sometimes there are bumps, sometimes it's hilly and sometimes it goes downhill, but it's part of the journey."

Priya has developed her own "PATH" to wellness:

P is for Passion: Continue with your passion, whatever that may be. (For Priya, it's her kids and her devotion to her family.)

A is for Attitude: Your attitude

determines so much of your outlook and your success. If you need to take a bad day, take it, but then coach yourself out of it, or find a support group that can help.

T is for Try: Try different things and determine what's best for you. There is so much uncertainty around this disease, when you hear a success story, investigate and try the new technique if you think it's right for you. If it works, great. If it doesn't, try something else.

H is for Help: Ask for help from family, friends, and the MS Society. You are not alone. And if you can, offer help to others as often as you can.

"I'm very fortunate," concludes Priya. "I still work full-time, I have a family I adore, and I'm still able to go about my daily life. I have found my own way to personalize my treatment and it's working for me."

Listen to what Hema has to say -

Hema believes that one of the worst things for you is anger, and she does not permit negativity in her home. When asked about her advice for others living with MS, she responds, "I don't give advice. My experience is different from what others are experiencing, but in our groups, we do share 'I statements' to discuss what has worked for each of us." Here are Hema's "I Statements":

- I try to live as stress-free as I can
- I find a daily routine that works for me
- I eat well (avoid the obvious- sweets, fried stuff, junk food)
- I move my body every day
- I stay connected with friends
- I try not to be angry

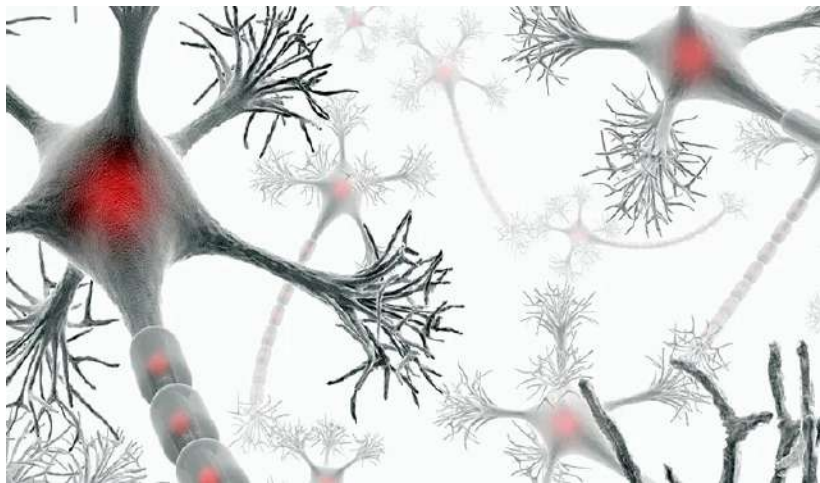
Hema's next project is to start a laughing group. "Everyone has to come with a funny story and we'll just laugh." Sounds like a great idea.



STEM CELL THERAPY AND MS

Multiple sclerosis is a rare but progressive autoimmune disorder that affects the central nervous system and is characterized by visual loss, mobility issues, and paralysis. The achievements of Stem Cell Treatment for Multiple sclerosis are as follows:

- Improved Balance.
- Heightened Vision.
- Enhanced Motor Functions.
- Significantly better sensitivity.
- Lesser occurrences of tremor.
- Lowered neuropathic pain.
- Diminished spasticity.
- Lesser tiredness.



Neural stem cell therapy is a type of treatment that has potential benefits for slowing down or even reversing the effects of MS. Neural stem cells are cells that can turn into many different types of nerve cell. The idea behind the therapy is that if these cells are infused into a person with MS, they can travel to areas of the brain and spinal cord, where they may help protect and repair damaged neurons.

Professor Gianvito Martino, from the San Raffaele Scientific Institute in Milan, Italy, has been researching this area for many years, most recently leading an early-stage (phase 1) clinical trial of neural stem cell therapy. The results of this trial – which involved 12 people with progressive MS – showed that the treatment is safe, and can be tolerated by people with MS. In addition, a reduction in the amount of brain atrophy (shrinkage) was seen in some people, particularly in those who received the largest number of neural stem cells. This innovative research was supported by our member organisation, the Italian MS Society. The Chairman of the Italian MS Foundation (FISM), Professor Mario Alberto Battaglia states:

“For over twenty years we have promoted and supported stem cell research, investing in basic research and human trials. Scientific research is a lengthy process, but it’s the only way to achieve results that can tangibly change people’s lives. This is the research we want and the research we fund. Over the past twenty years, a lot has changed in multiple sclerosis, and a lot is being done for the progressive forms. People with the most serious forms [of MS] have innovative answers to help them deal with symptoms and have a better quality of life, also thanks to rehabilitation. We will continue to develop this stem cell research as well as other innovative projects to continue towards a world without multiple sclerosis.”

In India it could cost from Rs 5 lakh to 15 lakhs.

Although these results are very promising, they need to be confirmed in a larger group of patients before this type of therapy could be used in routine clinical practice. The next step will be to develop new clinical trials that involve broader groups of patients. These trials will need to prove that the treatment can stop the progression of the disease as well as showing the ability of neural stem cells to regenerate damaged areas of the nervous system .

KEEPING HEALTHY

There is no cure for MS, but people can find their own way to live with the disease and to try to live in a healthy way

MS is a life-long neurological illness that can be variable and create uncertainty in the day-to-day lives of those who have the disease. It is important to have a positive outlook on living a healthy life in order to make the most of physical, emotional, social and spiritual aspects of health. Although there is no cure for MS at present, there is hope that people can find their own way to live with the disease and to try to live in a healthy way.

Deciding to adhere to a healthy lifestyle or to maintain healthy habits is a choice for each person. This concept of choice is especially relevant for people with MS who often feel they have little control over the disease. Diet, exercise, stress management, travel, leisure activities and health-promotion activities are all aspects of living well that are, to a certain extent, under the control of the individual.

Although there are no particular diets that have been shown to affect the disease process in MS, food fuels the body and provides energy. A well-balanced diet, low in fat and high in fibre, can help stabilise weight and improve bowel health.

Supplements

Dietary supplements such as multi-vitamins with minerals, calcium, and vitamin D should not replace proper food intake, but can be useful. People with MS should be encouraged to check with their doctor or nurse before taking vitamins, minerals or herbal supplements to ensure safety and compatibility with the traditional medications already prescribed.

Regular exercise for people with MS is important for several reasons. It improves cardiovascular health, helps improve strength and endurance, and is a factor in stabilising mood. Exercise can help relieve MS-related fatigue and manage spasticity.

Aquatics therapy (also known as hydrotherapy) can be very helpful in MS because it provides an aerobic workout while keeping the body temperature down. Other helpful exercise regimens include stretching, and low impact aerobic workouts, combined with strength training using light weights. People with MS should discuss exercising with their doctor or nurse, and may need a consultation with a physiotherapist before starting an exercise programme.

Coping with stress can be difficult. Stress makes most people feel bad, but those with MS may experience stress in ways that make their symptoms feel worse. Stress may raise body temperature. People with MS tend to feel more fatigued, or have temporary worsening of other symptoms, when their body temperature is elevated. Relieving stress can be as easy as taking a few deep breaths, visualising a pleasant memory, undertaking relaxation techniques or enjoying a favourite pastime or hobby.



SPIRITUALITY

Spirituality may be thought of as that which gives meaning and a feeling of vitality to one's life. When people connect with their spirituality, they feel centered, calm and energized. It should not be confused with religion & God - and definitely not faith healers. It is your own strength of mind and consciousness that form your spiritual being. Spirituality is a powerful aspect of the human experience that can help fuel one's efforts to achieve wellness in the face of life's challenges and obstacles, including a diagnosis of MS.

Religious beliefs may or may not be central to a person's spirituality. For some, religion is the driving force or organizing principle of their spirituality. For others, spirituality is reflected in their connection to nature, other people, art forms, or anything else that gives their lives particular meaning.



Many times in life people become aware of being on a spiritual journey, most often when confronted by a major shift or crisis. Did you know, the Chinese character for crisis consists of two characters, one being for danger and the other for opportunity. Each crisis brings fears about the uncertain future but also opportunities for growth, including:

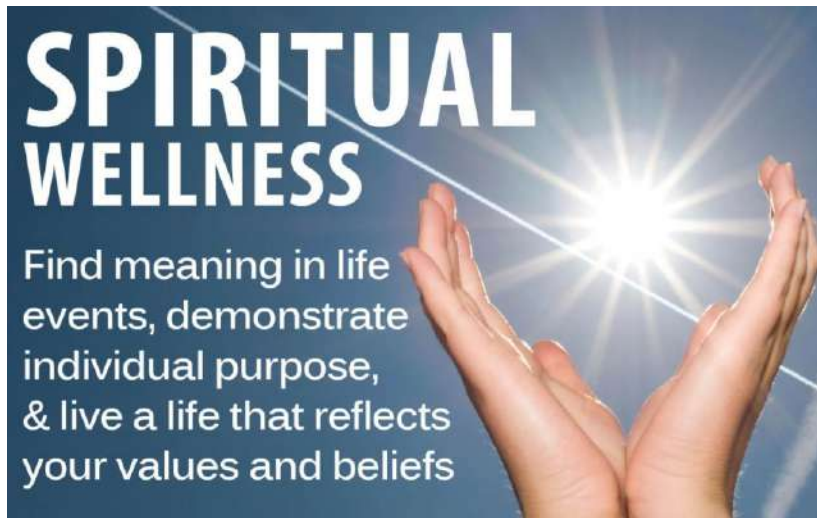
- Becoming more self-aware
- Discovering inner strengths and resources
- Finding meaning in the challenge
- Discovering greater balance, harmony and purpose
- Changing feelings of powerlessness into feelings of creative strength
- Finding opportunities for personal growth and increased resilience - or power to bounce back.
- Deepened, more meaningful relationships with others

If you imagine life as a path – and crises or challenges as detours along the way – the following resources can help you navigate the journey.

Recognizing the emotional impact Grief is a natural reaction to loss. Whether it's the loss of a loved one, a diagnosis of MS, (loss of health , or a " normal" life as you knew it), a change in one's ability function or any other disruption in one's life path, healthy grieving is the first step toward healing. The grieving process sets the stage for goal-setting, creative problem-solving and personal growth.

Identifying what drains you and sustains you

Dealing with changes and challenges takes energy. Given that fatigue is one of the most common and challenging MS symptoms, it is helpful to identify the things in your life that



drain you physically and emotionally, as well as the things in your life that stimulate, fuel and replenish you.

Getting your priorities in order
When energy is limited and life's challenges seem to create endless hurdles, it is helpful to prioritize the ways you spend your energy – both physical and emotional – and time. Focusing your energies on the things that are most important to you, and most in line with your goals and

personal values, is part of staying on your spiritual path.

Connecting with your true self

Part of a spiritual journey is connecting with one's true self – the self that recognizes and trust its own motives, emotions and ideas, recognizes its strengths and weaknesses, acts in ways that reflect personal values and needs, and allows true intimacy with others.

Building spirituality into your life

Daily life often feels too pressured to allow time for inner reflection, awareness of feelings – our own and others' – and personal growth. Finding and maintaining one's spiritual self

involves carving out time and space to explore, nurture and refuel one's inner self, to focus with intention on opportunities for change and growth and to remain open to new ideas, feelings and ways of interacting with the world.

Maintaining balance in your relationships

A person's life challenges, including the unpredictable symptoms of MS, also affect close family and friends – at times altering the roles and responsibilities in a relationship, impacting shared activities, challenging intimacy, requiring a redefinition of shared plans and goals. Working to maintain balance and connection in valued relationships is part of one's spiritual path.

THROWBACK: MSSI DELHI PARTICIPATING IN THE OZ HAAT MELA 2008



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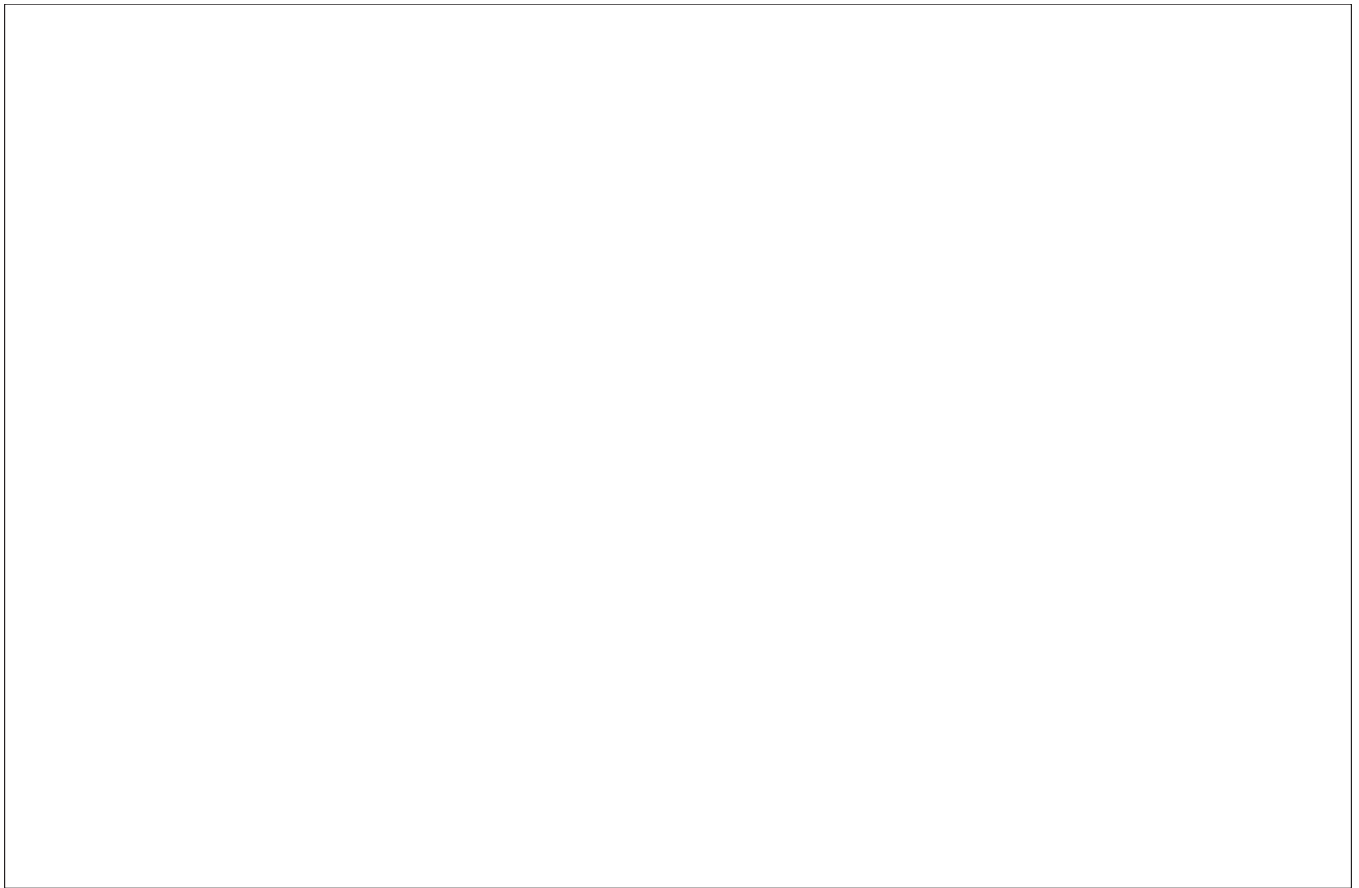
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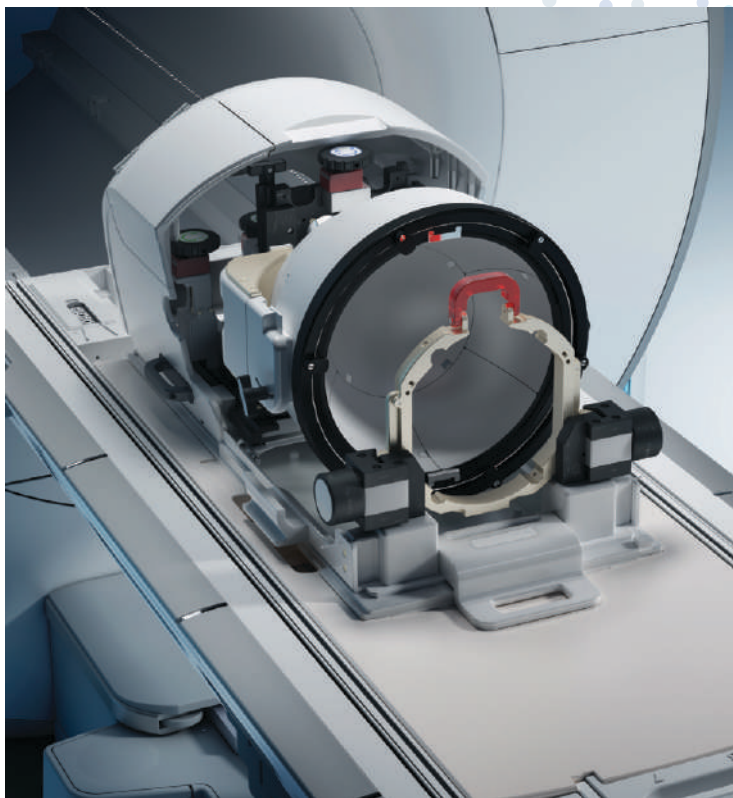
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