MSSI®

MULTIPLE SCLEROSIS SOCIETY OF INDIA
Delhi Chapter

FIGHT HARDER LIVE

STRONGER

40 YEARS

OF STELLAR SERVICE TO THE MS COMMUNITY 1985-2025

2024-2025

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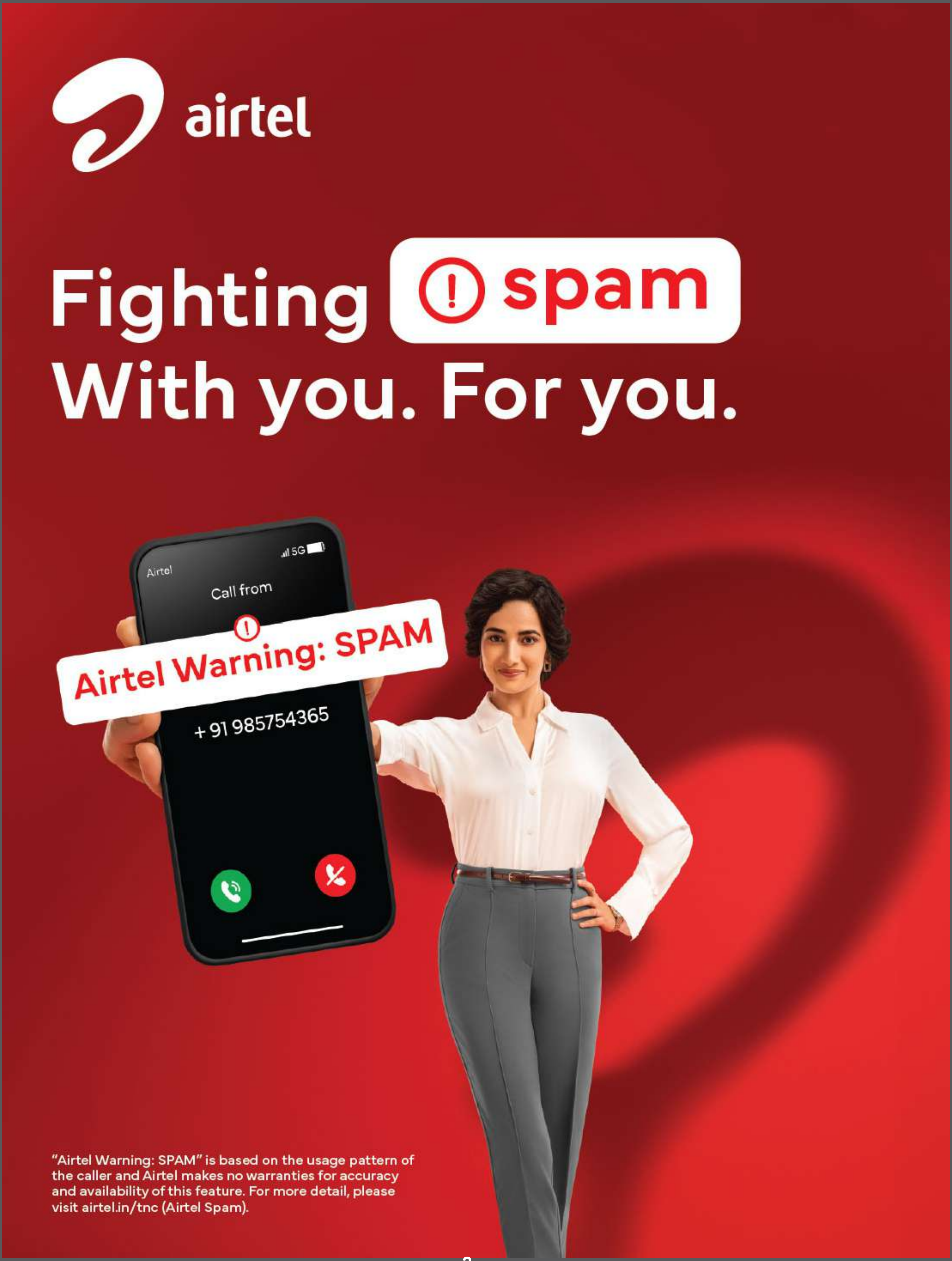
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MSSI®
Delhi Chapter

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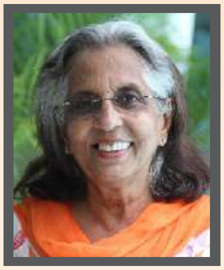
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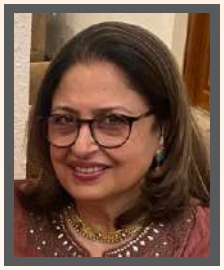
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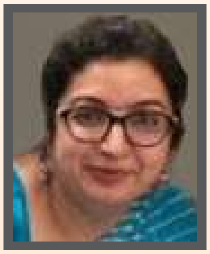
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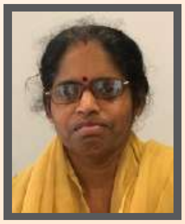
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Affiliated to Multiple Sclerosis International Federation (MSIF)
www.msif.org

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THE TEAM BEHIND IT ALL

MSSI has completed 40 years of dedicated and unstinting support & service to people affected by Multiple Sclerosis in India . On this occasion we proudly present our 22nd Annual MS Handbook 2025, reminding everyone of the profound impact that MS has on individuals, families, and communities worldwide. This chronic and often unpredictable condition can be overwhelming, but it is not insoluble.

The purpose of this handbook is to provide a comprehensive and accessible resource for those affected by MS. Our goal is to empower individuals with the knowledge, tools, and support needed to navigate the complexities of MS and to live fulfilling lives.

Within these pages, you will find expert insights, personal stories, and practical advice on managing symptoms, treatments, and lifestyle modifications specific to the Indian environment. We explore and bring to you the latest research and advancements in MS care, as well as the emotional and psychological aspects of living with the condition.

This handbook is not just a resource – it's a symbol of hope and resilience. It represents the collective efforts of healthcare professionals & individuals living with MS who are dedicated to improving lives and advancing our understanding of this complex condition.

As you read through this handbook, we encourage you to:
- Learn about the latest therapies
- Learn about our Legal Support
- Discover strategies for managing symptoms and improving quality of life
- Connect with others who share your experiences and challenges through Connect Groups
- Find inspiration in the stories of resilience and hope through our wide spread projects

Together, we have created an excellent team of members at MSSI Delhi that supports, educates, and empowers individuals affected by MS.

Thank you for joining us on this journey.

Bipasha Gupta
Hon.Chairperson
MSSI Delhi

We invite your feedback and comments. Write to us at : mssidelhi2@gmail.com

Acknowledgments:

We acknowledge the following prime sources and their articles for the information in this Edition. www.msif.org, MS Focus past issues, MS Society of Canada, NMSS, Mayo Clinic, 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.

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A TRIBUTE TO OUR FOUNDERS: 40 YEARS OF STELLAR SERVICE TO THE MS COMMUNITY

This year we are celebrating 40 Years of dedication to the cause of Multiple Sclerosis by remembering and saluting the Founders of this movement in India .

- Mr. A. H.Tobaccowala, former Chairman, Voltas India, Mrs. Rehmut S. Fazalbhoy , Mr. K. N.Randheria, Mrs. Sheela Chitnis, Mr. A.J. Joglekar and Major Sharan.

We honor these remarkable and visionary members, and the many volunteers who , over the years, devoted their valuable time and showered their boundless energy & love by supporting and empowering those affected by Multiple Sclerosis.

Today the MS Society of India , with the tireless efforts of its 9 chapters' members has been able to make a profound impact on countless lives - providing comfort, guidance, and hope to individuals navigating the complexities of MS. All the volunteers over the past 40 years have contributed with selflessness and compassion, each sharing their unique expertise, which in turn has earned the society respect and gratitude of patients, families, and healthcare professionals alike.

Our Founder Mrs Rehmat Fazalbhoy, a well known social worker, met Sylvia Lawry in London and got MSSI affiliated with MS International Federation. Sylvia Lawry was an American social campaigner on behalf of people with multiple sclerosis who single handedly established the National Multiple Sclerosis Society (United States) after her brother was diagnosed with MS and doctors told her there was nothing they could do for him. She founded the NMSS in 1946 and co-founded the Multiple Sclerosis International Federation in the following year.

Throughout the journey MSSI volunteers have:

- Provided unwavering support and advocacy for those affected by MS
- Helped advance our understanding of the condition through research and education
- Inspired others to join the fight against MS through their leadership and example

As we mark this milestone of 40 years of dedication, we celebrate not only the achievements but also the countless lives the society touched. MSSI's legacy will continue to inspire and motivate future generations to work in this field selflessly till a cure comes in.

Let us continue to be a beacon of hope and a champion for those affected by MS. Here's to many more years of making a difference !

A BRIEF HISTORY : THE EARLY YEARS

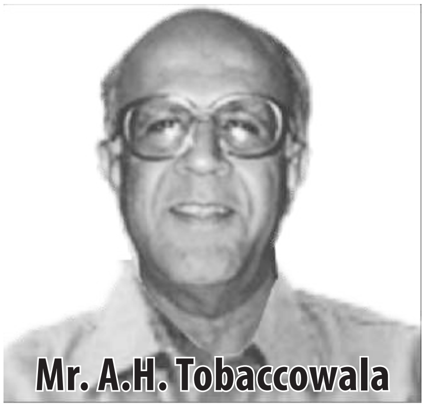
1. **Founding-** MSSI was founded in 1985 by Mrs. Rehmut S. Fazalbhoy and Mr. A. H. Tobaccowala, Mr. K. N. Randeria, Mrs. Sheela Chitnis, Mr. A. J. Joglekar & Major Sharan, along with a handful of MS patients and caregivers in Mumbai.
2. **Initial Objectives:** The primary goal was to provide emotional support and connect patients with resources.
3. **Challenges:** Limited awareness, scarce resources, and inadequate healthcare infrastructure.

A TRIBUTE TO OUR MSSI FOUNDERS

L-R: Mohini Giri, Uma Tuli, Sheila Thadani,R Fazalbhoy, Aruna Dalmia, Diana Khambatta

Mrs Rehmut Fazalbhoy with Mrs Sheela Chitnis

The Multiple Sclerosis Society of India (MSSI) is a registered voluntary, non-profit organization established in 1985. We work for the welfare of people affected by Multiple Sclerosis and are affiliated to MSIF UK (Multiple Sclerosis International Federation).



Mr. A.H. Tobaccowala

Our founder members Mrs. Rehmut S. Fazalbhoy & Mr. A. H. Tobaccowala, former Chairman, Voltas India, Mr. K. N. Randeria, Mrs. Sheela Chitnis, Mr. A.J. Joglekar and Major Sharan gathered together with a view to promote the welfare of Multiple Sclerosis persons in India.

DELHI CHAPTER MANAGING COMMITTEE AT OUR 1ST DAY CARE PROGRAMME

REPRESENTING MSSI INDIA AT MSIF CONFERENCE, IN BERLIN, GERMANY 2002

EXPANSION AND GROWTH (1987-2017)

1. Establishment of Chapters- MSSI Head office started Mumbai Chapter in 1985 then expanded to other cities, establishing chapters in Bengaluru in 1987 followed by Pune and Delhi Chapter in 1989 ,Kolkata Chapter in 1990 .Chennai Chapter in 1997 (1997), Hyderabad in 2005 and the most recent in Thiruvananthapuram in 2017.
2. Educational Programs- MSSI introduced educational programs, workshops, and awareness campaigns to educate patients, caregivers, and healthcare professionals.
3. Collaborations: Partnerships with healthcare institutions, research organizations, and NGOs helped amplify MSSI's impact.

NATIONWIDE REACH

1. Expansion to 9 Chapters: MSSI has now expanded to 9 chapters , covering almost all of India.
2. Regional Support Groups: Regional support groups and online forums were established to connect patients and caregivers.
3. Advocacy Efforts: MSSI is now a prominent force advocating for accessible healthcare, access to public places, fighting for rights for the disabled and influencing policy changes.

CURRENT INITIATIVES : (2015-PRESENT)

1. Advocacy and Policy Change: MSSI continues to advocate for policy changes, improved accessibility, and affordable healthcare.
2. National Conferences, Workshops and Webinars: MSSI organizes national conferences, workshops, and awareness events to educate and empower patients and caregivers.
3. Rehabilitation Services: MSSI provides rehabilitation services, counseling, & employment support to help patients reintegrate into society.

IMPACT AND ACHIEVEMENTS

1. Improved Quality of Life: MSSI's efforts have improved the quality of life for thousands of MS patients and families.
2. Increased Awareness: MSSI has increased awareness and understanding of MS among healthcare professionals and the general public.
3. Policy Changes: MSSI's advocacy efforts have led to policy changes, improved accessibility, and increased support for people with disabilities.

FUTURE DIRECTIONS

1. Expanding Reach -MSSI aims to expand its reach to more cities and rural areas.
2. Enhancing Services-MSSI plans to enhance its services, including rehabilitation, counseling, and employment support.
3. Advocacy and Research- MSSI will continue to advocate for policy changes, improved healthcare, accessibility, insurance coverage and increased research into MS. The Multiple Sclerosis Society of India's journey is a testament to the power of dedication, resilience, and community.

As MSSI continues to grow and evolve, its commitment to empowering individuals with MS remains unwavering.

KNOW YOUR SOCIETY: MSSI DELHI & YOU

The Multiple Sclerosis Society of India was established on 24 July 1985 This year we shall complete 40 years of dedicated work.

MSSI Delhi Chapter was established soon after in 1989 and has grown steadily over the years with a team of dedicated volunteers working to enable & empower persons with MS (PwMS) and their families.

MSSI DELHI offers a variety of programmes & services to help people affected by multiple sclerosis effectively manage and cope with the disease. The programs are aimed at people living with MS and their families or waiting for a diagnosis with respect to MS or an MS allied disease.

The effort of the Delhi Chapter is to work together with Doctors & healthcare professionals providing preventive, curative, promotional or rehabilitative health care services in a systematic way to the MS community .

Delhi Chapter's aim is to improve the Quality of Life of MS persons, families and their caregivers.

We are part of the larger MS family, with 9 Chapters spread over the country. Our registered office is located in Mumbai. MSSI is affiliated to the Multiple Sclerosis International Federation in the UK. MSIF is the global movement of MS organisations, by and for people affected by MS. The MS International Federation has 48 members in 45 countries and links to many other organisations all over the world.

We network, learn from each other, mobilise and enable global collaborations, to achieve the vital goals that can only be reached by coming together as a movement.

Our vision is a world without MS
Our mission is to bring the world together with urgency to improve the quality of life and well being of everybody affected by MS and to end MS forever!

Our Delhi Chapter has over 875 registered members from all over North India (Delhi/ NCR, Haryana, Punjab, UP, Rajasthan, J&K, Himachal and Uttarakand) For people with MS and their families, access to healthcare, support and information are vital, as is the knowledge that scientists around the world are collaborating to develop better treatments for MS and eventually stop MS. We are working with our member organisations in India & around the world to make this happen.

What Do We Do?

As members of a large international organisation, MSSI connects to align our efforts and resources to be stronger together. Working together across the globe, we boost scientific progress to prevent, treat and stop MS. We strive for a world where everyone living with MS can access treatments.

These associations provide opportunities to connect, innovate, share tools, skills, experiences, and become stronger together.

We benefit from our partnerships with research communities and health professionals all around the world.

This helps us to participate in medical conferences & seminars to learn about the latest treatments, therapies and techniques being used to improve the lives of PwMS around the world We also leverage our relations with the global NGO community, and intergovernmental organisations to further our common goals. As new MS organisations emerge we will include them, help them grow, and in return others in the movement will benefit from their experience and contributions.

For people with MS and their families, access to healthcare, support and information are vital, as is the knowledge that scientists around the world are collaborating to develop better treatments for MS and eventually stop MS. We are working with our member organisations in India & around the world to make this happen.

> **“We provide leadership, advocacy information and education to MS affected families across India-connect with the society closest to you, today.”**

Together we will inspire and grow the global movement to place MS higher on the global health agenda, and to tackle the challenges for everyone affected by MS.

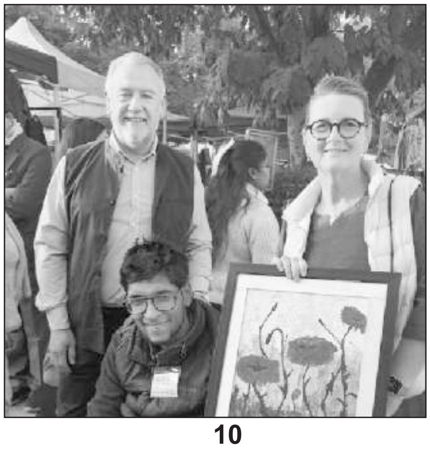
Our values:

Our core value is people affected by MS are at the heart of everything we do, shaping decisions and driving positive change.

Collaborative We are strong because we work together, inspiring each other, sharing resources, ideasand influence.

Inclusive We are open and inclusive, embracing the richness of diversity and experiences. Our motto is #LeaveNoOneBehind

Driven We are strategic and determined, acting with urgency to find solutions with and for people affected by MS, wherever they live.



All Chapters have a formally structured Managing Committee consisting of volunteers , PwMS and their caregivers. This ensures that the interest of PwMS is always at the heart and core of every decision that is taken with regard to projects and welfare programmes. Each and every member of every Managing Committee right across the 9 Chapters of MSSI is a committed VOLUNTEER and earns no salary or honorarium.

Members from different Chapters meet each year at an Annual General Meeting, to pass an Audited Accounts Balance Sheet of all Chapters . We share challenges , success stories, best practices, learn from one another and plan for the future. Every 3 years all Chapters elect the Governing Council and vote on any resolutions, such as when the Articles of Association, the legal document that governs the MSSI – needs amending.

How we work with the healthcare industry; Raise Funds:

MSSI has built strong relationships with the corporate sector over the years Whilst always protecting its independence, MSSI has formed a mutually beneficial relationship with the corporate sector over many years.

The development of MS treatments and other products has led to a growing interest in the work of the MSSI by healthcare companies. As a result, from time to time they have supported MSSI projects that have benefited people with MS around the country. Healthcare companies are important stakeholders in the MS space and where we have shared goals we welcome their support of our work.

We also recognise that not all of our goals are aligned so we do not accept any interference or influence over any programme design or delivery. In support of this we also always try to secure multi-stakeholder funding for projects to reduce the risk of individual influence.

Although much attention has been focused on the pharmaceutical and biotech industries, there are other health sectors that also support us. These include manufacturers & suppliers of medical devices and aids to daily living, dietary supplements, health management organisations, and other Corporates who have vast CSR (Corporate Social Responsibility) funded programmes.

We have developed a set of guidelines to support MS organisations when negotiating and deciding how to acknowledge financial contributions from pharmaceutical companies. These international guidelines are based around a traffic light system of green (the ideal situation to aim for), amber (not the ideal situation but still acceptable), red (the situation to avoid).

It is for these reasons that 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.

Come, join us as a volunteer and let us take this movement to new heights!

OUR AIM:

To listen and respect your wishes

To be honest and transparent about how we utilise funds

Respect any personal information you share with us

Be accountable and committed to the highest standards

To listen and learn - and adapt our programmes to your needs

Together we are stronger than MS

Multiple Sclerosis Society of India (MSSI) is a charitable non-profit organization working with and for the welfare of persons afflicted with Multiple Sclerosis. MSSI is the only support group in India that helps MS persons to manage a better Quality of Life with all the necessary support. (For details Visit: www.mssocietyindia.org.)

THIS IS WHAT WE DO!

Whenever a new member joins MSSI Delhi they ask what we do , and how we can help them. Simply put, we do whatever we are able to, to bring comfort to the lives of MS persons and their caregivers. Our effort is to improve their Quality of Life, using all means within our limited resources-both financial as well as volunteers.

All of us are committed to work towards the welfare of MS persons in every way possible , by just listening to you and trying to meet your requests for help & information as you navigate this challenging disease.

Here is a quick glimpse of our ongoing welfare projects:

KEEP MOVING:

Our flagship project of Home Physiotherapy - Our specially trained physiotherapists make over 600 house calls a month across Delhi/NCR, ensuring that our MS patients "keep moving.." Each MS patient gets 3 sessions of physiotherapy per week / 12 sessions per month in the comfort of their home.

MS NURSE/ ATTENDANT AT HOME :

We offer home care services of a trained Nurse for home visits to patients within Delhi / Noida. We also have a home care attendant who visits women patients who require help. Our Nurse looks after the nursing care needs of MS patients for administering injections, changing catheters, treating pressure sores and helping with other hygiene requirements.

The Attendant assists with bathing, sponging patients, changing bed linen, and other personal hygiene needs. This service provides relief to the primary caregiver and includes counselling families in hygiene & patient care.

SCHOLARSHIPS: We help school going children of MS members with an education allowance to ensure that they do not have to worry about completing their education.

HOSPITAL & DOCTOR APPOINTMENTS: Assistance with priority appointments with leading neurologists & Hospitals in Delhi / NCR.

HOME VISITS: Our volunteer teams make regular home visits to cheer up & counsel PwMS & their families and assess their needs.

COUNSELLING: Practical advice on living with MS , medicines or personal issues, given with compassion & empathy . And total confidentiality, both in person & on phone/ video calls .We now provide access to professional advice on legal matters concerning disability rights & family matters.

MOBILITY & OTHER AIDS: Wheelchairs, walkers, canes, other hygiene products and nutritional supplements /essential medicines (T&C apply).

SOCIAL & MEDICAL PROGRAMMES: Celebrating special events and organising regular interactive Webinars & Seminars with leading Hospitals, Doctors, specialists etc.

AWARENESS & FUNDRAISING: Social media awareness, events at public places, radio talk shows & proposals to raise CSR funds or individual funding for all of the above.

All this and more work is carried out by unsalaried but dedicated volunteers with help of a small team of admin staff.

MSSI services are offered FREE to those who need it most and are financially weak. We do not receive any government funding and depend entirely on donations from private trusts, individual donors or companies.

I HAVE BEEN DIAGNOSED WITH MS:

Navigating a Health Crisis

Finding yourself unexpectedly in the middle of a health crisis can be a shock. Life after D-Day (diagnosis day) often looks very different than the life you enjoyed before getting sick. Life doesn't have to be gloomy while you reclaim your health, though.

Here are 4 tips for finding your way to positive thinking through a health crisis:

1. Write it out.

Beyond the actual fear of what your diagnosis means for your future, there are other factors you need to process, like how your perception of yourself changes when you go from a healthy person to someone who is ill. Journaling can be a great way to work through these feelings and help you come to terms with your current situation. It can also be a great tool for tracking your symptoms. You don't need to write a daily list of every ache or pain, but if something new pops up it doesn't hurt to record it so you can give your doctor an accurate timeline of what you're experiencing. As an added bonus, your journal doesn't ask stupid questions or try to fix you: it just listens and understands.

2. Love yourself.

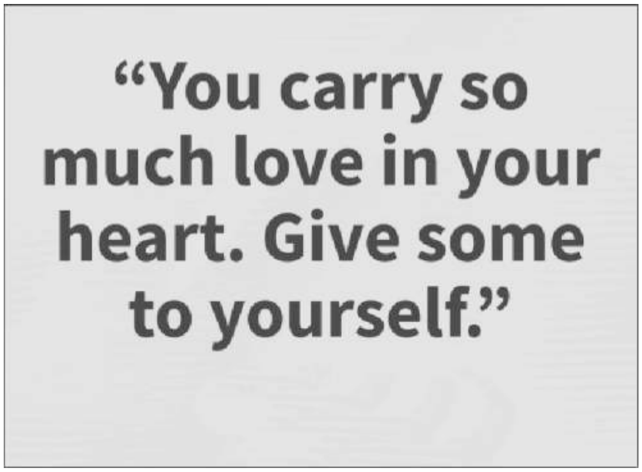
Don't skip the self-care. You will be touched and poked and prodded by all kinds of medical professionals in sterile environments and scary MRI machines. Taking care of your emotional health is important, too. Schedule a spa/ beauty parlour day whenever you feel like the medical stuff is getting a bit too intense. The gentle, calming touch of a massage or facial can soothe your weary nerves. Be kind to yourself and recognize that being sick is hard work and you deserve a little pampering.

3. Sweat it out.

Even if the last thing you want to do is exercise, getting out (with your doctor's blessing) can be a huge mood booster. Get the blood pumping and the endorphins running through your veins. Exercise or even just a walk in the park is an excellent way to work off stress and tension and is a positive change to make toward leading a healthier life. It can also help you see yourself as healthy and vital instead of sick and frail.

4. Connect with your inner child.

You don't have to do anything reckless , but developing a mindfulness practice can bring comfort during a chaotic time. Keeping your mind in the present without worrying about the future is tremendously difficult when you're faced with a serious illness. Try meditation (there are lots of great apps out there to guide you through it if you're a beginner) or join a yoga studio. Or dance under the light of a full moon. There's no judgment here.



"You carry so much love in your heart. Give some to yourself."

NAVIGATING A HEALTH CRISIS:

How do you stay happy while navigating the turbulent waters of a health crisis?

Learning that you have a health condition you may need to manage for a long time can be extremely difficult. You might be afraid for your health or unsure of what day-to-day life will now look like. You might also feel alone in your diagnosis. But many others face the same thing. You will be surprised to know that almost 40% of most populations live with one chronic illness or another Chronic diseases are medical problems that last one year or longer. They also need ongoing care and may limit daily activities. Chronic conditions can affect both physical and mental health. And the list of chronic diseases is long-: Multiple sclerosis (MS) is one of many - like thyroid, diabetes, hypertension, arthritis, asthma etc Some have more than one such illness.

Here are some simple ways to stay positive after a diagnosis.

Give yourself time to process a new diagnosis: Gyaan
A new diagnosis can be overwhelming because it indicates change. This isn't only a change in a person's health status, but it likely means changes in medications and daily life as well. Be sure to take the time to own your feelings, and to accept the range of emotions. Keep in mind that it can be days, weeks or months before a diagnosis really sinks in.

"Sometimes emotions can show back up again, even after you think you've resolved them. Be patient and kind to yourself," says Meghan Beier, PhD. She's an assistant professor at the Johns Hopkins University School of Medicine Give yourself the space to feel whatever pops up. And remember to surround yourself with loved ones. Don't reject people who love you and are there for you, simply because you are angry with the world because you are unwell.

If they turn their back to you at this time, they may not return when you are ready

Learn about your health problem: Vigyaan
Arming yourself with knowledge can be empowering. Understanding your symptoms and side effects can help make it easier to take care of yourself. Talk with your doctor, specialist or health care team about your illness. If you need a doctor you can trust, we can help. Reach out to MSSI for answers. We are here to help.

Practice mindfulness : Vartamaan
Try practicing mindfulness. It may help with mental skills like paying attention, organizing and planning. It can also help you stay positive, says Dr. Beier. When dealing with chronic illness the future can sometimes feel uncertain and scary. Mindfulness brings you back to the now. You focus on what's going on in the moment. This means looking at both what's inside you and what's outside you. Being in the moment can give you a deeper sense of balance. This presence, even in moments of pain, can help improve your overall well-being.

Get back to your hobbies
People who pursue their passions have an easier time coping. "Find activities or events that spark joy," says Beier. And then include them in your daily routines or do them more often. Getting back into your favorite hobby is a major way to reclaim your life.

Embrace gratitude : Shukrana
It can be hard to see the positive when the fears and concerns about your illness are always on your mind. But this can be a good time to be grateful. Gratitude can help you see your life from a different perspective. Write down the things you're grateful for every day. Or share them with a friend. It reinforces the positive in your life.

Find workarounds : Shortcuts

Our brains are hardwired to dwell on the negative. And negative thinking can impact all aspects of our lives. To counter that, make a list of the things your illness prevents you from doing. Then make a list of workarounds for each limitation.

If it's too painful for you to chop veggies, for instance, get the pre-cut kind at the grocery store. If there was a sport you loved, seek out a local adaptive group. What's important is to retake control of your situation in small ways. It'll make you feel more optimistic and less powerless. Learn more ways to cultivate a more positive mindset.

Pursue spiritual interests : Meditation or Dhyaan

Spirituality can be an important resource for coping. It can help people find inner peace and comfort. And it can help you feel more connected and supported by a larger community.

Lean into generosity : Share

When your thoughts are consumed with your own illness, it can be difficult to think of others. But research has shown that giving back can improve your outlook. Do whatever works for you. Volunteer your time or help with your local community- like an NGO or temple or Gurdwara. Perform random acts of kindness. These are powerful ways to brighten your mood.

Manage and respect your limits

Work with your health care team to balance where you are now with your future goals. For example, an occupational therapist can help you find easier ways to do daily activities. And they'll show you how to change activities to make them work for you. This isn't about trying to get back to where you used to be. All experiences change us in some way, and chronic illness is no different.

Multiple Sclerosis is the same for everyone.

Everyone's **MS** is unique. People may experience different symptoms at different times and the impact of these symptoms can vary.

Life might not look the way it did a few years ago. But it can be just as fulfilling and enjoyable. Beier adds, "Many people find new meaning and purpose in their chronic illness."

POSITIVE THINKING: Stop Negative Self-talk To Reduce Stress

Positive thinking helps with stress management and can even improve your health. Practice overcoming negative self-talk with examples provided.
By Mayo Clinic Staff

Is your glass half-empty or half-full? How you answer this age-old question about positive thinking may reflect your outlook on life, your attitude toward yourself, and whether you're optimistic or pessimistic- and it may even affect your health.

Indeed, some studies show that personality traits such as optimism and pessimism can affect many areas of your health and well-being. The positive thinking that usually comes with optimism is a key part of effective stress management. And effective stress management is associated with many health benefits. If you tend to be pessimistic, don't despair -you can learn positive thinking skills.

Understanding positive thinking and self-talk

Positive thinking doesn't mean that you ignore life's less pleasant situations. Positive thinking just means that you approach unpleasantness in a more positive and productive way. You think the best is going to happen, not the worst.

Positive thinking often starts with self-talk. Self-talk is the endless stream of unspoken thoughts that run through your head. These automatic thoughts can be positive or negative. Some of your self-talk comes from logic and reason. Other self-talk may arise from misconceptions that you create because of lack of information or expectations due to preconceived ideas of what may happen.

If the thoughts that run through your head are mostly negative, your outlook on life is more likely pessimistic. If your thoughts are mostly positive, you're likely an optimist — someone who practices positive thinking.

The health benefits of positive thinking

Researchers continue to explore the effects of positive thinking and optimism on health. Health benefits that positive thinking may provide include:

- Increased life span
- Lower rates of depression
- Lower levels of distress and pain
- Greater resistance to illnesses
- Better psychological and physical well-being
- Better cardiovascular health & reduced risk of death from cardio - vascular disease & stroke
- Reduced risk of death from long term illness
- Reduced risk of death from respiratory conditions
- Reduced risk of death from infections
- Better coping skills during hardships and times of stress

It's unclear why people who engage in positive thinking experience these health benefits. One theory is that having a positive outlook enables you to cope better with stressful situations, which reduces the harmful health effects of stress on your body.

It's also thought that positive and optimistic people tend to live healthier lifestyles-they get more physical activity, follow a healthier diet, and don't smoke or drink alcohol in excess.

Identifying negative thinking

Not sure if your self-talk is positive or negative? Some common forms of negative self-talk include:

- Filtering. You magnify the negative aspects of a situation and filter out all the positive ones. For example, you had a great day at work. You completed your tasks ahead of time and were complimented for doing a speedy and thorough job. That evening, you focus only on your plan to do even more tasks and forget about the compliments you received.

- Personalizing. When something bad occurs, you automatically blame yourself. For example, you hear that an evening out with friends is cancelled, and you assume that the change in plans is because no one wanted to be around you.

- Blaming. You try to say someone else is responsible for what happened to you instead of yourself. You avoid being responsible for your thoughts and feelings.

- Saying you "should" do something. You think of all the things you think you should do and blame yourself for not doing them.

- Magnifying. You make a big deal out of minor problems. You automatically anticipate the worst without facts that the worse will happen. The drive-through coffee shop gets your order wrong, and then you think that the rest of your day will be a disaster.

- Perfectionism. Keeping impossible standards and trying to be more perfect sets yourself up for failure.

- Polarizing. You see things only as either good or bad. There is no middle ground.

Focusing on positive thinking

- You can learn to turn negative thinking into positive thinking. The process is simple, but it does take time and practice-you're creating a new habit, after all. Following are some ways to think and behave in a more positive and optimistic way:

- Identify areas to change. If you want to become more optimistic and engage in more positive thinking, first identify areas of your life that you usually think negatively about, whether it's work, your daily commute, life changes or a relationship. You can start small by focusing on one area to approach in a more positive way. Think of a positive thought to manage your stress instead of a negative one.

- Check yourself. Periodically during the day, stop and evaluate what you're thinking. If you find that your thoughts are mainly negative, try to find a way to put a positive spin on them.

- Be open to humour. Give yourself permission to smile or laugh, especially during difficult times. Seek humour in everyday happenings. When you can laugh at life, you feel less stressed.

- Follow a healthy lifestyle. Aim to exercise for about 30 minutes on most days of the week. You can also break it up into 5- or 10-minute chunks of time during the day. Exercise can positively affect mood and reduce stress. Follow a healthy diet to fuel your mind and body. Get enough sleep. And learn techniques to manage stress.

- Surround yourself with positive people. Make sure those in your life are positive, supportive people you can depend on to give helpful advice and feedback. Negative people may increase your stress level and make you doubt your ability to manage stress in healthy ways.
- Practice positive self-talk. Start by following one simple rule: Don't say anything to yourself that you wouldn't say to anyone else. Be gentle and encouraging with yourself. If a negative thought enters your mind, evaluate it rationally and respond with affirmations of what is good about you. Think about things you're thankful for in your life.

Here are some examples of negative self-talk and how you can apply a positive thinking twist to them:

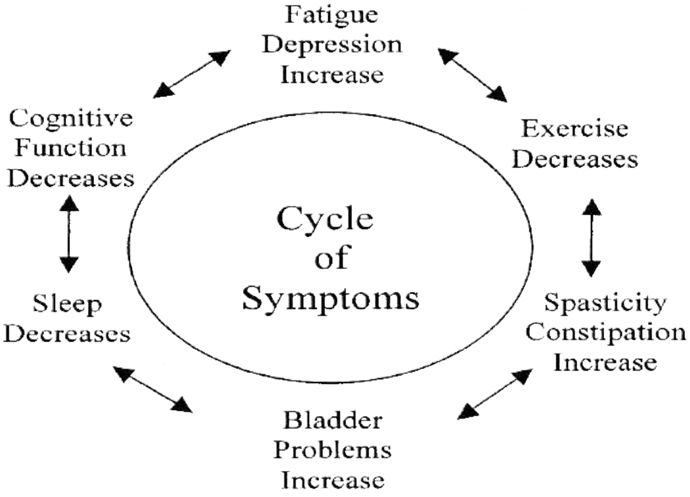
Putting Positive thinking into practice

Negative self-talk	**Positive thinking**
I've never done it before	It's an opportunity to learn something new.
It's too complicated	I'll tackle it from a different angle.
I don't have the resources	Necessity is the mother of invention.
I'm too lazy to get this done	I couldn't fit it into my schedule, but I can re-examine some priorities.
There's no way it will work	I can try to make it work.
It's too radical a change	Let's take a chance.
No one bothers to communicate with me	I'll see if I can open the channels of communication.
I'm not going to get any better at this	I'll give it another try.

Practicing positive thinking every day

If you tend to have a negative outlook, don't expect to become an optimist overnight. But with practice, eventually your self-talk will contain less self-criticism and more self-acceptance. You may also become less critical of the world around you.

When your state of mind is generally optimistic, you're better able to handle everyday stress in a more constructive way. That ability may contribute to the widely observed health benefits of positive thinking.



CAN I CONTINUE WORKING WITH MS?

Symptoms of multiple sclerosis (MS) can sometimes affect the ability to work. There are many factors to consider before deciding whether a person can continue working. Requesting job accommodations can increase accessibility and safety.

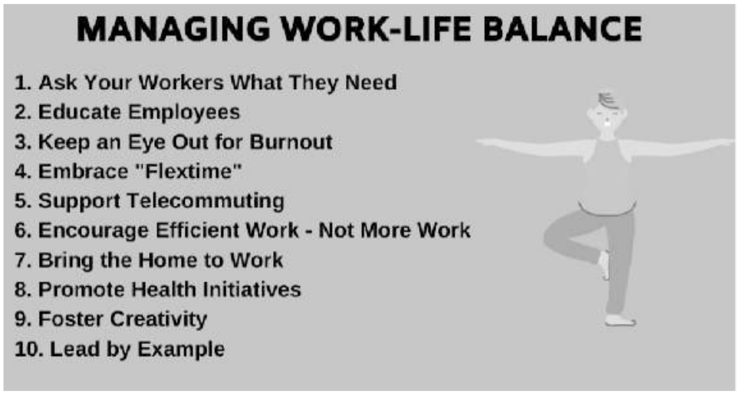
MS is a progressive neurological condition that can affect many aspects of a person's health, functionality, and well-being. It is an autoimmune disorder and develops when the body's immune system attacks the protective layer surrounding nerve fibers, disrupting signals to and from the brain. Symptoms of MS, such as fatigue, loss of muscle control, and weakness, can sometimes make it difficult to complete regular activities. As a result, people with MS may need to make changes to their routine, including their work life.

Let us explore how MS can affect a person's ability to continue working, including accommodations that can help improve accessibility and safety.

Is it necessary to stop working with MS?

The decision to stop working after a diagnosis of MS depends on a combination of personal and disease-specific considerations. People with MS may weigh a variety of factors, including:

-personal preferences
-the type of work they do
-the severity of their symptoms
-how quickly they expect their disease to progress



MANAGING WORK-LIFE BALANCE

1. Ask Your Workers What They Need
2. Educate Employees
3. Keep an Eye Out for Burnout
4. Embrace "Flextime"
5. Support Telecommuting
6. Encourage Efficient Work - Not More Work
7. Bring the Home to Work
8. Promote Health Initiatives
9. Foster Creativity
10. Lead by Example

According to a 2022 study of over 1,100 people living with MS, nearly 85% were still in employment at the time of diagnosis. However, the number of people who are able to or who choose to continue working declines over time. Research estimates that about half to two-thirds of people with MS are no longer working within 12–15 years of diagnosis.

Determining the ability to work

A 2018 study found that fatigue is an important indicationof a person's ability to continue working with MS. Fatigue affects up to 80% of people with MS and is one of the most common reasons for leaving the workforce.

Other factors that may affect a person's ability to continue working include:

- mental health symptoms, such as anxiety or depression
- vision changes
- level of disability
- coping strategies

The ability to continue working with MS depends on the symptoms a person is experiencing and the nature of their work. A 2023 survey in Sweden found that, in general, people in office jobs or managerial positions were more likely to be able to continue working than those in manual labor roles.

When deciding whether they can or should continue working, a person should consider how their symptoms may affect their ability to do their job safely and effectively. For instance, people who have muscle spasticity may experience difficulty with fine motor tasks. Dizziness or fatigue may make it unsafe for others to operate heavy machinery.

> " We know that 10 years after the onset of MS, approximately 50% of people with MS remain in employment and this decreases to 20 to 40% after 15 years "

Requesting accommodations (Work Environment)

Various accommodations may be possible to help people with MS continue working in a safe and effective manner.

For many people working in western countries like USA the Americans with Disabilities Act (ADA) requires that employers make reasonable accommodations to help create a work environment that is safe for people with disabilities and allows them to meet their job expectations. In India too now the govt is looking at certain 'reasonable accommodations' to include the differently abled at the workplace.

Reasonable accommodations may look different for everyone, depending on their symptoms and their jobs. Some examples of accommodations that a person can request include:

- installing ramps, mechanized door openers, rugs, or grab bars to improve accessibility
- disabled friendly toilets, or work cabins which are close to lifts, entry/exit spots or washrooms
- adjusting job responsibilities
- modifying work schedules
- providing assistive technology, such as voice-to-text software
- allowing for remote work (WFH)

Specialists such as physical or occupational therapists can help identify accommodations for a person's specific needs.

Individuals with MS who require accommodations to continue doing their jobs can talk with their employer to determine what changes can reasonably be made based on their needs, work environment, and job responsibilities. While it is necessary to disclose that a disability affects their ability to do their work, it is not a requirement for a person to disclose the nature of their disability unless they choose to.

Temporary Leave

Reasonable accommodations may include provisions for temporary leave for hospitalisation or therapy. Temporary disability-related medical leave typically comes under the ADA as a reasonable accommodation, but some restrictions apply. As with the ADA, not all employees have this facility, eg part time staff. A person can review these protections and how they may apply to their situation before approaching conversations with their employer.

Summary

Many people who live with MS continue to work after their diagnosis. Working may become challenging or unsafe for some individuals, especially as the disease progresses. Today, in India too there are laws are in place to help protect many people with disabilities, and accommodations may be possible to help ensure a person is able to continue working should they choose to do so.

People who require accommodations to continue working can talk with their care team and employer to determine what changes to their work environment, responsibilities, or expectations are possible to help ensure they can continue working safely and effectively. Please contact the MSSI advocacy team for information and assistance in this matter.

Caring for the Caregiver

CAREGIVERS & THEIR CHALLENGES :

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

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

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

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

Caregivers need to be recognised and supported. MSSI and caregivers' organisations are often best placed to offer this help.

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

All MSSI events and programmes are also open to the families of people with MS who are caregivers.

Emotional Support

Providing emotional support and physical care to someone with MS is often deeply satisfying, but it is sometimes distressing, and-now and then-simply overwhelming.

The strain of balancing employment, child-rearing, increased responsibilities in the home and the ongoing care of a loved one can lead to feelings of martyrdom, anger and guilt. One of the biggest mistakes support partners make is thinking that they can — and should — handle everything alone.

The best way to avoid burnout is to have the practical and emotional support of other people. Sharing problems with others not only relieves stress but can also give new perspectives on problems. "Why doesn't anyone ask how I am?" It is easy to feel invisible. Everyone's attention goes to the person with MS and no one seems to understand what the support partner is going through. Many support partners say, "no one even asks." Mental health experts say it's not wise to let feelings of neglect build up. Support partners need to speak up and tell other people what they need and how they feel.

If you're a support partner who fears being labeled selfish, a complainer or disloyal, remember the importance of "putting on your own oxygen mask before assisting the person next to you." Self-care is essential to being able to care for someone else. For help with your feelings and concerns, reach out to support groups, spiritual advisors, or mental health counselors for information, support and resources.

A Guide for Support Partners

Self-help groups can provide an outlet for emotions and a source of much needed practical information. The MS Society has Chapters with self-help groups all around the country for people with MS, and many groups for support partners exist as well. Religious and spiritual communities often provide support and guidance. Many support partners say it is difficult to find time to attend group meetings.

STRESS MANAGEMENT for the caregiver

- Accept help
- Set goals you can meet
- Join a support group
- Set personal health goals
- Focus on what you can do
- Get connected to community resources
- Stay in touch with family and friends
- Take care of your own health

SELF-CARE for the caregiver

Self-Compassion

Treat yourself with the same kindness as a good friend

Breath Awareness

Stop, relax, close your eyes, slow your breathing, and focus on each breath for 10 minutes

Mind-Body

Try a mind-body practice like yoga, tai chi, meditation, and deep relaxation techniques

Eating and Sleeping

Eat well and create a routine to get a more restful sleep

Social Connection

Stay in touch with family and friends. Find support through caregiver support groups

They want to use their limited time for other things. The benefits of a group might be obtained through the internet. There are many useful online groups for support partners/caregivers. Effective ways to acknowledge feelings Some people find that talking about their care partnership happens more easily when they schedule a regular time for conversation. They also feel more open to talking to professionals or volunteers from the MS Society because they hesitate to share their inner feelings with family members for fear of being misunderstood or labelled as " selfish"

Taking time out to sort out your feelings before bringing them up for discussion will make it easier to speak clearly and calmly. Ignoring a problem will not make it disappear. Anger, grief and fear are natural responses to challenges that can sometimes feel overwhelming. Talking about them can lead to productive and collaborative problem-solving. Trying to keep them under wraps may simply lead to guilt, numbness and resentment.

Two-way communication
Discuss concerns and fears openly; everyone needs emotional support. Although collaboration isn't always easy or possible, work out long-term plans and goals together

The MS Society will help care-partners to feel more secure. Many emotional stresses are the result of poor communication. The emotional and cognitive symptoms of MS are often more distressing than the physical changes. If memory loss, problems with problem solving, mood swings or depression are interfering with open communication or disrupting daily activities, consult a healthcare professional. Mental health professionals address mood and cognitive issues and offer communication tips and strategies.

Caring For The Carer: Many support partners focus so much attention on the needs of the person with MS that their own physical health is compromised. They ignore their ailments and neglect preventive health measures like exercise, diet and regular medical examinations. Many support partners do not get adequate rest or uninterrupted sleep. If sleep is regularly disrupted because the person with MS wakes in the night needing help with toileting or physical problems, discuss the problems with a healthcare professional. The person with MS needs a healthy support partner, and an effective partnership depends on the physical and emotional well being of both partners.

Outside activities are essential:

Researchers report that the emotional stress of caring has little to do with the physical condition of the person with MS or the length of time the person has been ill. Emotional stress seems more related to how "trapped" caregivers feel in their situation. This, in turn, seems to be closely related to the satisfaction they have in their personal and social relationships, and the amount of time available to pursue their own interests and activities. Successful support partners keep up enjoyable activities. Many organizations including MSSI have respite care programs. Other family members are often willing- even pleased- to spend time with the person with MS. It may be possible to arrange respite care on a regular basis. Keep a list of people to ask on an occasional basis as well. It is important for both the person with MS and the support partner to stay involved in activities that have meaning for them and to make time for regular physical exercise.

Handling unpredictability Living with MS means expecting the unexpected, making backup plans and focusing on what can be done rather than what can't.

The unpredictability of MS can be very stressful, but it can be managed. If you are making plans for outings, for example, always include extra time for travel. Calling ahead to check out bathroom facilities and entrance-ways is wise. Buildings are not always accessible, even when they say they are. Don't make plans too complicated. And when plans fall through, have an alternative ready. If the night out is impossible, order in pizza. Keep a list of backup people who can be contacted for help.

Dependency and isolation Concerns about dependency and isolation are common in families affected by chronic illness. The person with MS could become increasingly dependent on the support partner, and the support partner needs others for respite and support. Many support partners feel shame about being dependent on others. As a result, many don't ask for the help that they need. Anxieties are greatly reduced for support partners who are able to develop a personal and social support system for themselves.

Sex and Intimacy:

Support partners who are also spouses or partners usually face changes in their sexual relationship. These changes can have physical or emotional causes. MS can interfere with both sex drive and function. Problems can include decreased vaginal lubrication, numbness or painful sensations, decreased libido, erectile dysfunction, or problems reaching orgasm. MS fatigue can interfere with sexual activity. Spasticity or incontinence problems can negatively affect sexual desire. Most of these symptoms can be managed, so it is a good idea to seek the help of a healthcare professional. In addition to MS-related functional problems, changes in roles may change the sexual relationship. Support partners providing hands-on care may feel that they are performing more of a nursing role, rather than being a lover or spouse, and this can dampen intimacy. Sexuality does not have to disappear. Partners might begin by discussing what they find most rewarding about their intimate relationship. Many preconceived ideas of what sex "should be" get in the way of satisfying needs and giving and receiving pleasure. Discussion could lead to the discovery of more imaginative sexual behaviors. Open and honest communication about sexual needs and pleasures without fear of ridicule or embarrassment is the crucial first step. Counseling with a sex therapist can be helpful in this process.

Anger:

The situation feels-and MS is-unfair. Sometimes anger and frustration can build until it begins to seep out in hurtful words or actions. Talking about feelings with each other and with a counselor or religious advisor is an effective way to keep feelings from becoming overwhelming or spinning out of control. Physical exercise, meditation, and other self-care activities are also healthy outlets for anger and frustration.

Avoiding abuse:

As care partners, it is critical for both people to care for each other's emotional and physical well-being. While circumstances that produce frustration and anger are often unavoidable, an emotionally damaging or physically aggressive response is not okay. Tensions can mount in the most loving of families and both care partners may struggle with strong emotions-but abusive behavior is never acceptable. If tensions are mounting, call for a time-out, and call for help. Physical abuse usually begins in the context of giving or getting personal help- the support partner might be too rough while providing assistance.

The person with MS might scratch a support partner during a transfer, or use abusive language out of frustration. Once anger and frustration reach this level, abuse by either partner may become frequent. The dangers of physical abuse are obvious, but emotional abuse is also unhealthy and damaging. Continued humiliation, harsh criticism, or manipulative behaviors can undermine the self-esteem of either partner. Therapists and marriage counselors can help partners work out problems. Sometimes having another person (a counselor) facilitate conversations around the real challenges in MS for the person with MS and the support partner can help both people understand each other better. If the relationship is no longer sustainable, a counselor may also assist with the difficult choices regarding divorce or long-term care options.

Roles and gender differences:

Women and men who act as support partners face the same day-to-day responsibilities, frustrations and satisfactions. However, women support partners may feel more comfortable than men support partners since providing care has traditionally been viewed as a more feminine role. Studies have found that many men who are support partners report difficulty in discussing their problems and are more likely to suppress emotional reactions. They find it more difficult to ask for help and many do not use the resources available to caregivers.

On the other hand, men may be more willing to participate in social and recreational activities that contribute to their overall well-being. Women are often better at expressing their feelings and accessing supportive networks. But women support partners are more likely to neglect their own health and their need for outside activities. They tend to report more physical and emotional ailments than their male counterparts

When a child is a support partner:

Sometimes children assume major household & personal care responsibilities when a parent has disability due to MS. This is more likely to occur in single-parent households. While it is positive for children to take on household responsibilities, their needs must be carefully balanced with the amount and level of caregiving they are expected to do. Children are not equipped to handle the stress of being a primary support person. They should never be responsible for a parent's medical treatments or daily functions such as toileting. Children under 10 can certainly handle some household chores. Young teenagers can take on more responsibility, but they also need to spend some time with their peers. Older teenagers and young adults may be competent support partners, but they should not be expected to undertake long-term primary support. primary support. They have their own futures to attend to.

When a parent is a support partner:

The return of an adult child to the home can be stressful for both the parents and the adult child. Often, this homecoming resurfaces the earlier struggles that occurred before the child became independent. Parents probably have house rules that they want to have respected. But the adult child needs to be treated as an adult, and some house rules may presume the wrong kind of dependence.

As parents age, providing care often becomes more difficult. They also have the added pressure of worrying about the MS person after them. In time, one or both parents may become ill and require care themselves. Alternative care plans and living arrangements should be discussed with the adult child well before such a crisis occurs.

Safety and Security: Leaving a person with significant disabilities home alone can be a frightening proposition for both partners. Advance planning and adaptation of the home can decrease these worries

The advances in technology have increased the safety devices available. Some devices can even detect falls and notify emergency services without needing to be manually alerted. There are apps for smart phones that can notify you based on parameters you set, like get notified if your partner hasn't made coffee by 10 am. There are also cameras that can be placed in your home and viewed from a smart phone to ensure all is well. If there is no secure way to leave a person with a severe disability home alone, then don't do it!

Find help or alternatives by discussing with other family members & if that is not an option, look for professional help.

MULTIPLE SCLEROSIS AND PREGNANCY:

Miriam Fedicová, MD Dept. of Neurology
(Louis Pasteur University Hospital, Slovak Republic)

Multiple sclerosis (MS) affects women three times more often than men, especially during their reproductive period of life. For that reason, the often discussed topics are about the issue of pregnancy, parenthood, and heredity of MS. In the second half of the 20th century, women with MS were advised not to become pregnant due to the risk of worsening the disease and in extreme cases even being disabled after childbirth. Abortion has sometimes been recommended.

These facts were based on the lack of information about the effect of pregnancy during the course of this particular disease. At present, we do not discourage women with multiple sclerosis from planning a pregnancy.

A woman with MS can easily get pregnant and give birth to a healthy baby. MS is not considered an inherited disease, although genetic factors play a role in the development of the disease. There is a 98% chance that their child will not inherit MS.

Pregnancy Planning : Expectant mothers should plan their pregnancies more carefully due to their illness. It is most favorable to wait for the period of stabilization of the disease, it means at least 8-12 months from the last outbreak (attack).

Pregnancy and treatment: Some medicines used for MS treatment are not safe during pregnancy and need to be stopped before conceiving a child. In certain cases, we also have medicines available that patients with MS can take during pregnancy.

Research has shown that pregnancy does not have a negative effect on the course of MS even in the long term. It is a period when sex hormones cause changes in the immune system, which is reflected in a reduced number of attacks of the disease.

Many patients feel very well at that time and do not have relapses at all.

Childbirth and MS Multiple sclerosis does not increase the risk of complications during pregnancy and does not have an adverse effect on the foetus, or premature birth, or miscarriage. Women with multiple sclerosis can naturally direct childbirth unless there are other complications or a cesarean section. The decision is a matter for the obstetrician. Epidural or spinal anesthesia during childbirth is safe and is not accompanied by an increased risk of any other complications. The period of childbirth and the first three months after it are considered risky due to the hormonal imbalance in terms of the outbreak of disease activity. This can be closely monitored by the Obstetrician & neurologist to ensure least stress.

Breast feeding and MS Breast-feeding is a condition in which the hormone prolactin is secreted in the mother's body, which has an adverse effect on multiple sclerosis and can lead to a relapse of the disease. In stabilized patients without attack or new changes in the control magnetic resonance imaging of the brain, it is recommended to stop breast feeding within 4 months, no later than half a year after delivery. If a patient with MS was enrolled in a long-term treatment before pregnancy, this treatment should be continued after breast feeding. With high disease activity, breast feeding is not recommended and treatment for MS should be returned as soon as possible.

Infertility In developed countries of the world, the infertility of women of childbearing age is estimated at 15%. It is important for a woman to know that multiple sclerosis does not affect fertility. If for some reason, a patient with MS cannot become naturally pregnant, she may seek the help of assisted reproduction. In general, it is recommended to undergo the procedure at the time of stabilization of the condition, not at the time of disease activity.

Life management during pregnancy Expectant mothers with MS can support pregnancy without disease relapses with a proper diet, moderate exercise (with respect to pregnancy), and adequate rest. An important supplement that has a protective effect on the course of MS is vitamin D that may be used during pregnancy and even reduces the risk of developing MS in adults. Mothers with MS should not forget that there´s the family and their partner who happily help them so that they can fully devote themselves to the child and enjoy parenthood.

* **As an MS patient what can I do?**

✓ Don't be in a denial

✓ Regular follow up with my clinician

✓ Avoid doctor shopping

✓ Regular physiotherapy/yoga

✓ Healthy eating habits and Vitamin D sufficiency

✓ Adhere to treatment

✓ Discuss about not just about your DMT but also your mental health

* **As an MS clinician what can I do?**

✓ Discuss about starting/switching/stopping the DMT

✓ Educate my patient about evolving available therapies/trials in India

✓ Emphasize about mental health, cognitive function monitoring

✓ Regular serial investigations

✓ Look at EDSS in each visit

✓ Educate about pregnancy, lactation and family planning!

MENOPAUSE & MS:

Menopause is the natural end to a woman's periods (menstruation). It usually occurs between the ages of 45 and 55 years.

Why discuss MS and menopause?

The majority of people with MS are women. About 3 in every 10 women with MS are going through menopause currently or have finished menopause.

Menopause can bring a range of symptoms and body changes. Some of these overlap with the effects of MS, and some women find that menopause temporarily worsens some MS symptoms. Many symptoms of menopause are treatable. It's therefore useful to know what happens to our bodies during menopause and how these changes can be managed.

Menopause is not always spoken about openly. This has left some women unsure what to expect and what help and treatments are available for menopausal symptoms. We hope this guide provides some clarity.

What happens during menopause?

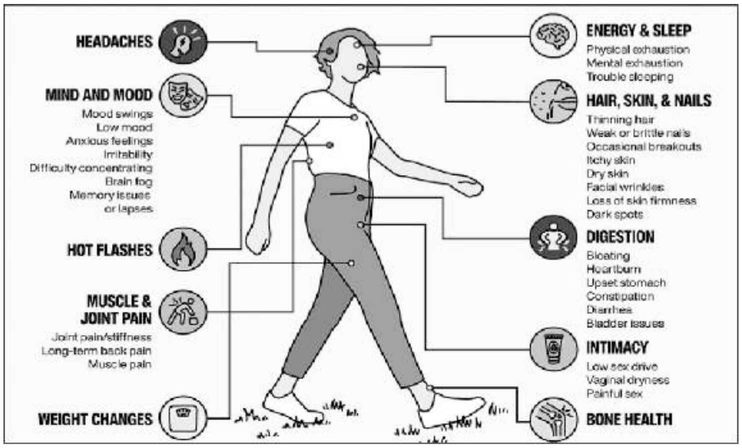
Most women go through menopause in their late 40s or early 50s, although a small proportion have an earlier menopause. MS does not affect the age of menopause.

During menopause, the levels of the reproductive hormones oestrogen and progesterone gradually fall. A woman's menstrual periods eventually stop. After menopause, levels of natural oestrogen and progesterone remain low.

Women can have symptoms in the years when their hormone levels are falling (the perimenopause) and afterwards (post menopause). Some women find that menopausal symptoms have a big impact on their life, while others do not.

The more common changes that occur during menopause are:

- Less regular periods
- Hot flashes, chills & night sweats
- Sleep problems
- Mood changes
- Memory problems
- Weight gain
- Thinner hair, drier skin
- Loss of breast fullness



How does menopause affect women long term?

After menopause, women commonly find that symptoms such as hot flashes, mood changes and memory problems end. However, some effects remain, such as changes to body shape, hair and skin.

- Post-menopausal symptoms
- Changes to sex drive
- Thinner hair, drier skin, and loss of breast fullness
- Weight gain
- Sleep problems
- Depression

Due to lower levels of oestrogen and progesterone, post-menopausal women are at higher risk of some health conditions as they get older.

Increased post-menopausal health risks:

Cardiovascular disease
Weaker, more brittle bones (Osteoporosis)
Reduced bladder control
Bladder infections

Are your symptoms due to menopause or MS?

Some of the effects of menopause overlap with the symptoms of MS.
For example, symptoms common to both can cause:

- Difficulty sleeping
- Mood changes, such as feeling low, anxious or irritable
- Bladder problems
- Memory problems, such as being forgetful or struggling to find the right word
- Changes to sex life.

If you have troublesome symptoms, speak to your family doctor, neurologist or gynaecologist (a specialist in the female reproductive system). Together you can work out the likely cause of your symptoms (whether it is menopause, MS or something else). This can make a difference to which treatments are most suitable for you.

What can help menopausal symptoms?

Although menopause is a natural process, you don't need to suffer its effects without help. Many symptoms and risks can be reduced with treatments and self-help.

Treatments include:

- Hormone replacement therapy (HRT)
- Vaginal oestrogen creams, tablets (pessaries) and rings
- Medicines to reduce hot flashes
- Medicines to improve bone health
- Medicines for short-term use to improve sleep.

These treatments have been tested in large groups of women but not specifically in women with MS.

HRT increases the levels of reproductive hormones in your body. It's usually very effective at reducing menopausal symptoms but has some risks. For women with troublesome symptoms who are younger than 60 years old, the benefits usually outweigh the risks.

Vaginal oestrogen creams, tablets (pessaries) and rings can help with vaginal and bladder symptoms.

Self-help techniques for menopause include:

regular pelvic exercises to strengthen bladder control
bedtime routines and techniques to improve sleep
relaxation techniques to reduce stress and anxiety
avoiding caffeine and alcohol to lessen hot flashes.

Your doctor or gynaecologist can talk you through the options that could be useful for your symptoms.

Can menopause worsen MS symptoms?
Although there have been a few studies on this, the results don't give a clear answer.

For most women, menopause doesn't seem to affect MS greatly. For some women, hot flashes might temporarily worsen some MS symptoms.

In surveys, some women say their MS symptoms and level of disability got worse after menopause. However, sometimes MS tends to worsen as we get older. With age, both men and women with relapsing remitting MS have fewer periods of time where their symptoms come and go. As people get older their level of disability due to MS is also likely to increase.

It's not clear whether any increase in MS symptoms women experience after menopause is due to getting older or hormone changes too.

How do menopause and MS affect bone health?

Women who have been through menopause are at risk of osteoporosis. This makes bones less dense, more fragile and more likely to fracture if you fall or have an accident.

MS can also increase the chance of osteoporosis. It's estimated that almost 2 in every 10 women with MS have osteoporosis. About 4 in every 10 show a smaller amount of bone weakness (called osteopenia).

Osteoporosis is a condition where bones are less dense, more fragile, and more likely to fracture if you fall or have an accident

Osteopenia is a condition in which the bones are less dense than healthy bones, but it is not as bad as osteoporosis. Women with osteopenia might need treatment to reduce their risk of osteoporosis.

Our bones are made of living tissue. At a microscopic level, they're being replenished and restructured all the time. Menopause increases the risk of osteoporosis because lower levels of oestrogen affect the balance between the amount of new bone being made and the amount of old bone being broken down.

MS can increase the risk of osteoporosis due to:

-The effects of some medicines, such as certain steroids and antidepressants
-Reduced mobility and weight bearing (meaning the bones are 'trained' less)

In some countries, women over 65 years have screening tests to check their bone health. These are called bone density tests.

You can help to keep your bones stronger through particular types of exercise, a healthy diet and bone-strengthening medications. Ask your doctor for advice.

Tips on managing menopausal symptoms:

If you have menopausal symptoms, talk to your doctor or gynaecologist. Treatments are available to ease many symptoms.

Talk to others. Chatting to other women your age about menopause can be valuable. You can help each other by listening, understanding and sharing tips on what has helped you. Support groups can be useful for getting advice on intimate issues that you may find it harder to discuss with others.

Keep a diary of your symptoms. This will help your doctor, neurologist or gynaecologist to understand how menopause is affecting you and to distinguish the signs from those of MS, getting older or other health conditions.

Take up invitations for screening tests for osteoporosis. If your screening test shows you have weak bones, this can be treated to reduce your risk of fractures.

Be regularly physically active, including weight-bearing exercises. This can strengthen your bones, balance your mood, help with MS symptoms, and improve your general health and wellbeing.

See your doctor if mood changes develop into signs of depression, anxiety or other mental health problems. These can be treated through therapies, medications or a mixture of both.

The Power of Collective Advocacy: Driving Change Together- Dr. MV Padma Srivastava-MD, DM, FRCP, FAMS, FNASc, FIAN, FNA

Chairperson Neurology - Paras Health, Gurugram

The Fight against Multiple Sclerosis :

In the fight against Multiple Sclerosis (MS), the most powerful tool we have is *our collective voice*. Every policy shift, every new healthcare initiative, and every improvement in patient rights has been born from communities coming together with a shared purpose. For members of the Multiple Sclerosis Society of India (MSSI), this is more than just a call to action-it's a reminder of the transformative power that unity holds. Across India, patient groups have successfully broken barriers, redefined policies, and secured life-changing rights for those living with chronic and rare diseases. These victories didn't happen in isolation; they were achieved because individuals stood together, spoke out, and demanded change. Today, MS patients and caregivers have the same power-to influence policies, push for better treatments, and ensure that no one faces this journey alone. Together, we can turn voices into movements and challenges into victories.

Palliative Care: Ensuring Dignity in Healthcare

Palliative care in India witnessed a paradigm shift due to the concerted efforts of organizations like Pallium India whose mission to improve access to quality palliative care played a pivotal role in the declaration of a National Program on Palliative Care by the Government of India in November 2012.

A landmark achievement was the amendment of the Narcotic Drugs and Psychotropic Substances (NDPS) Act in 2014 to enable patients to access essential pain relief medications, ensuring that patients , especially those with terminal illnesses, have better access to necessary medications.

Thalassemia Advocacy & Sickle Cell Disease: Championing Awareness and Policy Reform

Collective advocacy has been successful in raising the voices of diseases like Thalassemia & Sickle Cell Disease for bringing about policy change.

Thalassemia is a genetic blood disorder prevalent in India, has long posed significant challenges to patients & their families. Sickle Cell Disease (SCD) predominantly affects tribal populations in India and has historically been under recognized. Through relentless efforts spanning over three decades, the late Sampat Ramteke, founder of Sickle Cell Society of India succeeded in bringing SCD to the forefront of national health discussions.

Similarly, in a short time the Thalassemia Patients Advocacy Group (TPAG) has been instrumental in advocating for the rights and needs of thalassemia patients. One significant achievement is the inclusion of thalassemia as a benchmark disability under RPWD (2016).

The power of collective advocacy & action led to the inclusion of SCD in the Rights of Persons with Disabilities Act (2016), ensuring patients receive necessary support and recognition, including a Government resolution that provides free blood transfusions and other essential medical services.

Conclusion: These narratives exemplify the profound impact of collective advocacy in reshaping healthcare policies in India. Unified patient movements amplify the voices of those affected & drive systemic changes that lead to improved care, support, and recognition. By fostering collaboration, raising awareness, and engaging with policymakers, patient advocacy groups can continue to influence positive change, ensuring that healthcare systems are inclusive, responsive, and equitable for all.

KEEPING HEALTHY IN MS:

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.

Multiple sclerosis is a life-long neurological illness that creates variability and uncertainty in the day-today 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.

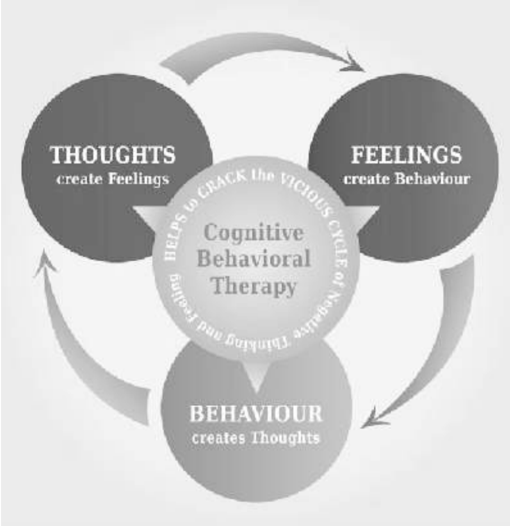
Although there is no cure for MS, there is hope that one can renew and refresh along the way, and create a balance in life that promotes harmony. Deciding to adhere to a healthy lifestyle or to maintain healthy habits is a choice for each person.

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.

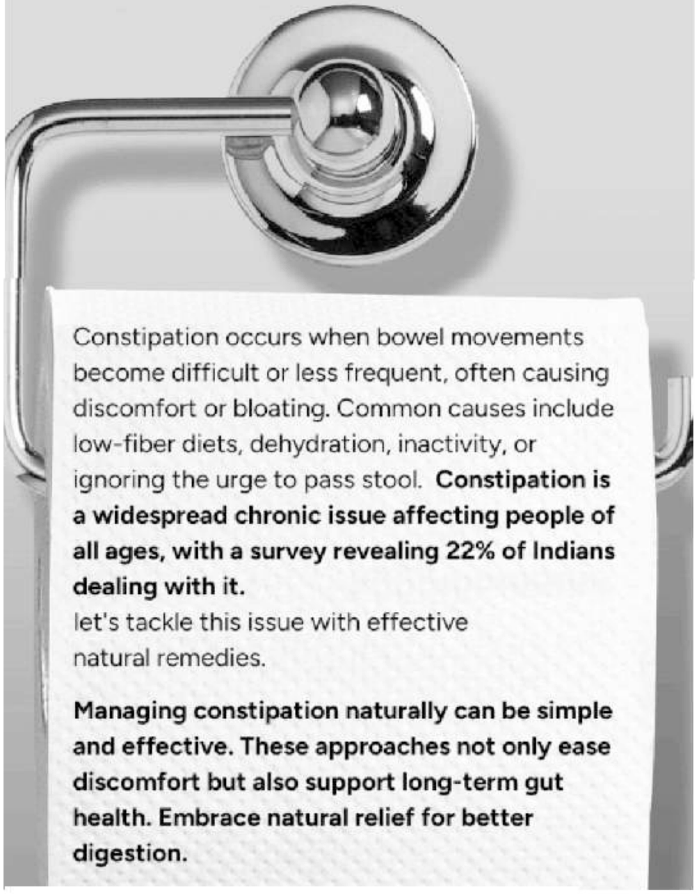
Some people enjoy the relaxation found in nature, art, music or other sources. The important message is that people should incorporate whatever brings a calm and serene feeling into their daily routines. Travelling is fun, but can be stressful when one has MS. There are many travel agencies that work 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 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 medications 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.

Get Things Moving, The Natural Way



Constipation occurs when bowel movements become difficult or less frequent, often causing discomfort or bloating. Common causes include low-fiber diets, dehydration, inactivity, or ignoring the urge to pass stool. **Constipation is a widespread chronic issue affecting people of all ages, with a survey revealing 22% of Indians dealing with it.**
let's tackle this issue with effective natural remedies.

Managing constipation naturally can be simple and effective. These approaches not only ease discomfort but also support long-term gut health. Embrace natural relief for better digestion.

4 Natural Remedies For Constipation

1 Prunes

Prunes are a traditional remedy for constipation, rich in natural sorbitol that helps soften stools and stimulate bowel movements. Their high fiber and sorbitol content can make them an effective, natural option for digestive relief.

How To Use It?

- Soak a handful of prunes in water overnight, then eat the prunes and drink the water in the morning.

2 Triphala

Triphala is a traditional Ayurvedic herbal blend made from three fruits: *amla, haritaki, and bibhitaki*. It can help relieve constipation by promoting bowel movements, improving digestion, and gently detoxifying the digestive system.

How To Use It?

- Mix 1 teaspoon of Triphala powder with warm water and drink it before bedtime.
- You can use it for 3-6 months, take a one-month break, and then resume.

4 Ghee

Ghee, or clarified butter, is a traditional remedy for constipation. Rich in butyric acid, it helps lubricate the intestines, improve metabolism, and alleviate symptoms like bloating and abdominal discomfort.

How To Use It?

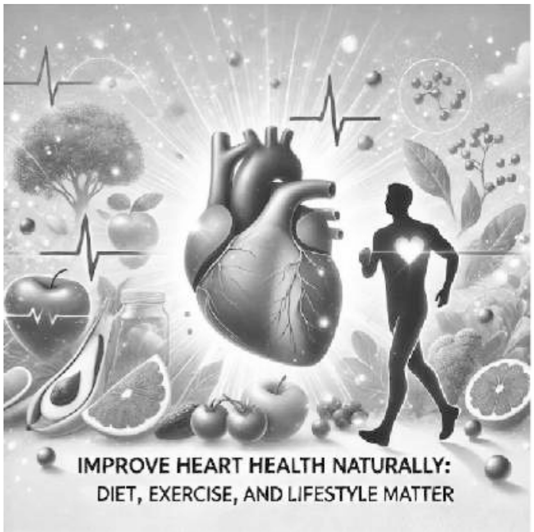
- Consume 1-2 teaspoons of ghee mixed with warm milk or warm water at bedtime.
- Due to its high saturated fat content, people with diabetes, high cholesterol, heart disease, or obesity should limit their ghee intake.

3 Flaxseed

Flaxseed, derived from the flax plant, is rich in dietary fiber, particularly mucilage fiber. When mixed with water, this fiber forms a gel, softening stools and acting as a natural laxative to ease constipation.

How To Use It?

- Mix 1-2 tablespoons of roasted flaxseed with water or add it to your meals daily.



CAN DIET HELP MY MS?

In 2015, the National Multiple Sclerosis Society (NMSS) reviewed several diets and their impact on MS.

The authors of the review concluded that there is not enough evidence to recommend one diet over another and acknowledged that most diets restrict or leave out the same types of food.

In general, a person with MS should avoid foods that:

- Are highly processed
- Are high in saturated fat
- have a high glycemic index

Foods to Eat

Certain foods may benefit people with MS by affecting the function of the immune system, nerves, and body.

Probiotics and prebiotics

Changes in gut health may contribute to immune disorders. Research indicates that gut health plays a role in many health conditions.

The intestinal flora, or gut flora, is a highly complex system of microorganisms living in the intestines. In humans, these microorganisms are largely bacteria.

These bacteria are responsible for breaking down food and nutrients and play a key role in digestion and immune system health. Healthy gut flora thrives in the intestines when there is ample fiber in the diet.

The authors of a 2021 review suggest that adjusting the gut flora by using probiotics, for example, may be helpful for people with MS.

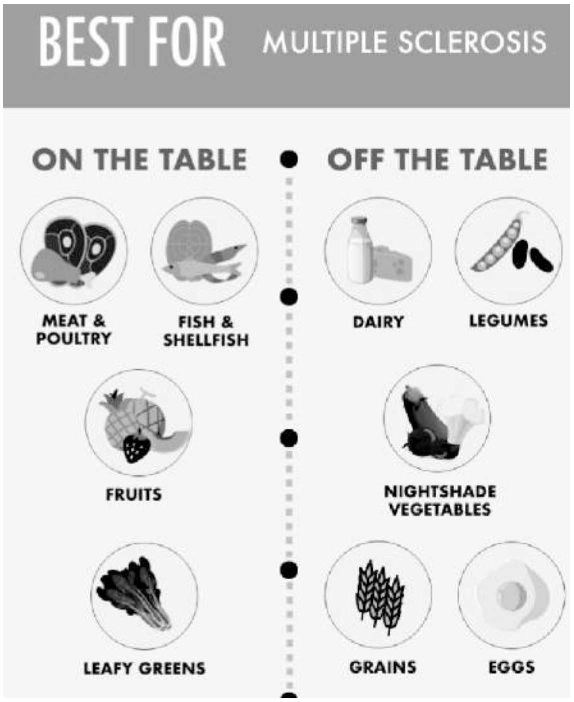
Probiotics

Probiotic bacteria are present in a range of fermented foods. They are also available in supplement form. The following foods contain healthy levels of Lactobacillus, a type of beneficial bacteria:

- Yogurt
- Butter Milk or Chhach
- Kaanji
- Kimchi Salad
- Kombucha, which is fermented tea

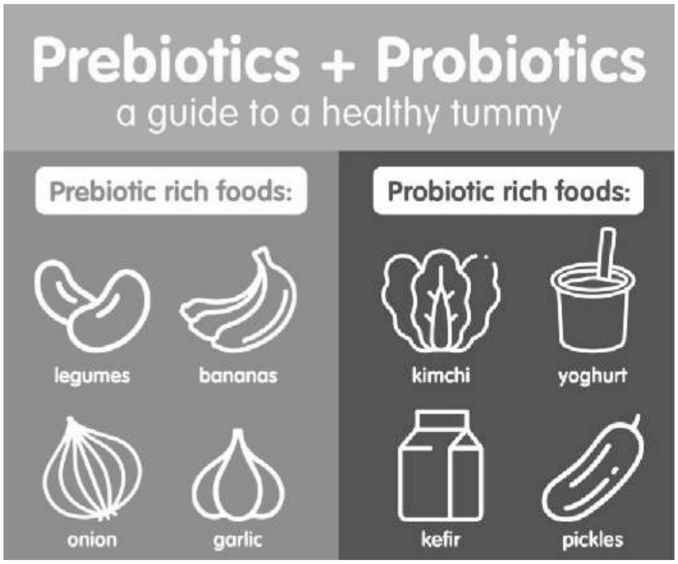
Prebiotics

After filling the gut with good bacteria, it is important to feed them. Foods that nourish probiotic bacteria are called prebiotics. Some dietary fibers are prebiotic.



Foods that contain healthy levels of prebiotic fiber include:

- Artichokes
- Garlic
- Green Onion
- Asparagus
- Onions
- Chicory
- Fiber



High levels of fiber are present in many plant-based foods, including:

- Fruits
- Vegetables
- Nuts and Seeds
- Legumes, such as Lentils
- Whole Grains
- Brown Rice/ Red Rice

Consuming these products may have a range of health benefits for people with MS. A high fiber diet can positively affect the body in several ways, including:

- Nourishing the gut bacteria
- Promoting regular bowel movements
- Regulating blood pressure
- Keeping the heart healthy by helping manage cholesterol

reducing the likelihood of weight gain by leaving a person feeling full longer.

People with MS may have a higher risk of certain types of heart disease due to reduce movement and mobility. While dietary measures may not reduce these risks, a balanced diet benefits overall heart health for the whole family.

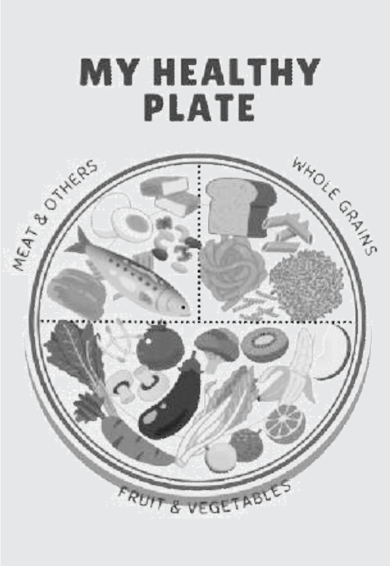
Vitamin D

Vitamin D is important for everyone, but it may be especially beneficial for people with MS. According to the National Institute of Neurological Disorders and Stroke, people with high vitamin D levels appear to have a lower risk of developing MS.

Vitamin D is also important for bone health. People with MS may be more likely to have low bone density and osteoporosis, especially if they cannot move around easily. An adequate intake of vitamin D may help prevent this.

Most of the body's vitamin D comes from exposure to sunlight, but a person can also get it by consuming oily fish fortified dairy products some fortified cereals, yogurt, and orange juice egg yolks

A 2018 review notes that while evidence of a link between low vitamin D levels and MS is increasing, confirming this will require more research.



Biotin

Biotin is a form of vitamin B. It is present in many foods, but foods particularly high in biotin include:

eggs
sunflower seeds
almonds
spinach
broccoli
whole wheat bread

Small studies indicate that a high dosage of biotin-at least 300 milligrams per day-could help people with progressive MS.

Confirming and specifying the benefits of biotin supplementation will require more research, but following a balanced diet can often ensure that a person consumes enough of this vitamin.

Polyunsaturated fatty acids

There is evidence that polyunsaturated fatty acids (PUFAs) may help support a healthy body and manage inflammation.

For example, the authors of a 2017 study concluded that a low intake of PUFAs may increase the risk of MS.

PUFAs appear to boost bodily functions such as heart health and the ability to think. Foods containing PUFAs include fatty fish, such as salmon and mackerel, and some plant-based oils.

Antioxidants

Many vegetable-based foods contain polyphenols, which have antioxidant and anti-inflammatory effects on the body's cells.

These effects may help prevent cell damage, making polyphenols potentially useful for people with MS.

Sources of polyphenols include

Fruits
Vegetables
Spices
Cereals
Legumes
Herbs
Tea

Antioxidants can also help prevent oxidative stress, which researchers have linked to the development of several chronic conditions, including neurological and cardiovascular disease.

Foods to Limit
Components of some foods may be harmful to people with MS, so people should limit them in their diet.

Saturated fats and highly processed foods
Highly processed foods may affect a person's health, especially if they contain high levels of:

saturated fats, trans fats, and hydrogenated oils
added sodium, or salt
added sugar

Sodium
A 2017 randomized clinical trial found that a high sodium diet does not directly affect MS disease progression. High sodium consumption can increase blood pressure and the risk of cardiovascular complications in everyone, but it is particularly important for people with MS to moderate their intake.

People with MS have an increased risk of coronary artery disease, heart failure, and heart attacks due to reduced mobility and sedentary life style. As a result, maintaining a moderate sodium (Salt) intake is essential to promote heart health.

A person with MS may benefit from limiting their consumption of:

sugar-sweetened drinks such as Colas and energy drinks
processed meats, including burgers and sausages
fried foods such as french fries and potato chips
highly processed ready-made meals, including frozen pizzas
trans fats such as margarine and dalda

Weight management
According to a 2019 research article, obesity during childhood and adolescence may increase the risk of developing MS. The authors also note that obesity could affect the progression of the disease.

Moreover, a person with MS who loses mobility or finds movement more challenging may be more likely to gain weight.

Managing the diet to prevent weight gain may also help prevent MS symptoms from worsening. Dietary changes may boost a person's well-being and reduce the risk of additional health conditions such as cardiovascular disease.

MULTIPLE SCLEROSIS DIET:

What to eat, lifestyle changes, and more:

While there is no single best diet for multiple sclerosis (MS), consuming or avoiding certain foods may help a person manage their symptoms. Certain lifestyle changes may also be beneficial for managing MS.

When a person develops MS, the myelin that coats nerve fibers becomes damaged. As a result, the nerves lose the ability to transmit electrical signals.

In relapsing-remitting MS, the symptoms come and go. A person experiences symptom flare-ups (relapses) and periods of remission. In other types of MS, which are progressive, the symptoms gradually worsen.

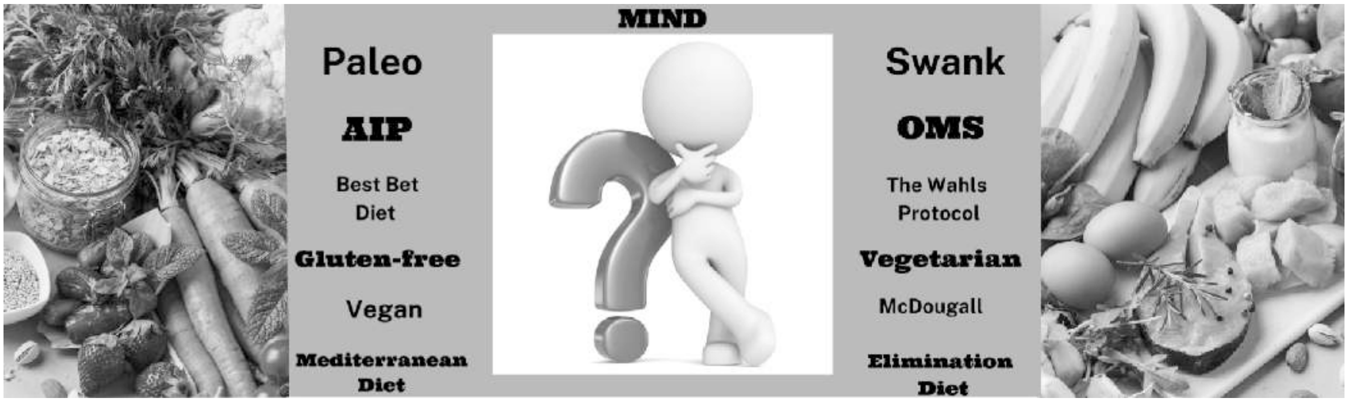
Treatment for MS focuses on managing symptoms and helping people live with the condition. A well-balanced diet can improve a person's overall health and may assist in managing MS.

Understanding the role of diet in MS and making certain changes may result in fewer relapses, a lower risk of health complications, and a better quality of life.

MS is an autoimmune disease in which the immune system mistakenly attacks the central nervous system.

The relationship between the diet and MS may involve:

- the role of gut bacteria in immune disorders
- vitamin deficiencies
- nutrients that can support and protect the central nervous system
- the benefits of a healthy, balanced diet for overall well-being



Is there a best diet for MS?

Anyone following a specific diet needs to consume all the necessary daily nutrients. Before making large dietary changes, a person should speak with a registered dietitian to ensure they can replace any lost nutrients.

Gluten-free Diet:

A 2020 review assessing the effectiveness of a gluten free diet in people without celiac disease did not find enough evidence to support a link between gluten sensitivity and MS.

However, people with MS may be more likely to develop celiac disease, which prevents the body from tolerating gluten. As a result, some people with MS may benefit from avoiding gluten.

Gluten is a protein present in wheat, rye, and barley. Therefore, people avoiding gluten should avoid foods containing these grains.

Don't Ignore the Signs:

Know How Obesity Can Impact Your Health

Are you aware of the subtle yet significant effects that unhealthy weight can have on your health? Recognizing the symptoms early can be crucial in preventing more serious issues down the line.

Joint Pain and Swelling

Chronic joint pain could signal joint inflammation. Without proper weight management, this can worsen, leading to reduced mobility and chronic pain. Losing weight can relieve joint pressure, reduce pain, and improve mobility.

Digestive Issues

Persistent digestive problems may suggest poor gut health. Ignoring these symptoms can lead to nutrient deficiencies and weakened immunity.

Unexplained Weight Changes

Sudden, unexplained weight loss or gain can indicate hormonal imbalances or more serious health conditions. It's important to have these assessed by a professional.

Persistent Fatigue and Shortness of Breath

These could be signs of underlying cardiovascular issues or anemia. Ignoring them might lead to severe heart conditions. Managing your weight can enhance cardiovascular health and boost your energy levels.

Varicose Veins

Swollen veins, commonly seen in the legs, are caused by poor circulation and are worsened by being overweight.

Frequent Thirst and Urination

These symptoms might indicate diabetes. If left unmanaged, diabetes can cause severe complications like kidney damage, nerve damage, and vision problems. Weight loss can help regulate blood sugar levels and reduce these risks.

Foods that contain gluten include:

wheat products such as bread and baked goods
many packaged soups and salad dressings
barley products such as malt, soups, beer, and brewer's yeast
rye, which is often present in bread and cereals

People who follow a gluten-free diet may miss out on important nutrients, including fiber, which is present in whole grains. They can boost their fiber intake by eating plenty of fresh vegetables, fruits, nuts, seeds, and pulses.

Anyone considering a gluten-free diet should consult a doctor first.

Paleo Diet

Many people who follow the Paleolithic or "paleo," diet believe that the human body has not evolved to eat the highly processed foods people now commonly consume.

The diet involves switching to foods that hunter-gatherers likely ate. The first step is to choose natural foods over processed foods, emphasizing meat and plant-based foods but not grains.

In a small 2017 study people with relapsing-remitting MS who consumed a modified paleo diet reported improvements in fatigue severity and quality of life scales. However, the authors concluded that larger controlled studies are necessary to fully assess the benefit of a paleo diet for people with MS.

Wahls Diet

The Wahls diet, or Wahls protocol, is a modified version of the paleo diet. Dr. Terry Wahls developed the plan specifically to help people with MS.

Like the paleo diet, the Wahls diet features nutrient-dense, minimally processed foods. A person following the Wahls diet will prioritize green, leafy, and sulfur-rich vegetables; intensely colored fruits; and minimally processed animal proteins.

Small studies have linked the Wahls diet with an improvement in MS symptoms. However, larger, better-controlled randomized studies are necessary to fully examine the effectiveness of the diet.

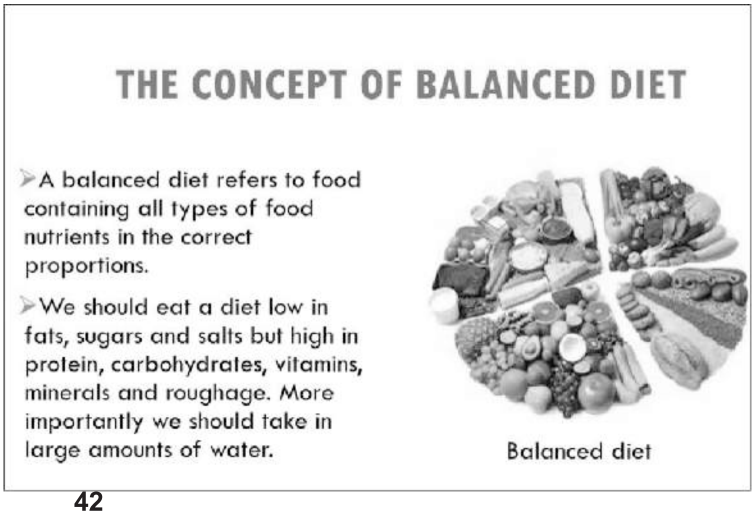
Swank Diet

Doctors developed the Swank diet as an MS treatment in the 1950s. It reduces saturated fat intake to 15 grams (g) per day & recommends limiting unsaturated fat intake to 20–50 g per day.

People on this diet:

- Cannot eat processed foods or dairy fats
- Cannot eat red meat during the first year
- Can eat as much white fish and shellfish as they like
- Should eat at least 2 cups each of fruits and vegetables every day
- Should eat whole grain pasta
- Should take cod liver oil & multivitamins daily

While some consider the diet to be outdated, others report that it helps. Possible risks include deficiencies in folic acid and vitamins A, C, and E.



THE CONCEPT OF BALANCED DIET

➢A balanced diet refers to food containing all types of food nutrients in the correct proportions.

➢We should eat a diet low in fats, sugars and salts but high in protein, carbohydrates, vitamins, minerals and roughage. More importantly we should take in large amounts of water.

Balanced diet

Lifestyle and Diet Tips

Certain lifestyle and habit changes may benefit a person's overall health and help them manage their MS. These include:

- increasing sunlight exposure to boost vitamin D levels
- exercising to help maintain strength & flexibility & support overall health and well-being
- quitting smoking, if applicable, and avoiding secondhand smoke

According to the NMSS, there is not enough evidence to recommend specific diets for treating MS.

A healthy diet for a person with MS is one that supports the immune system and provides all necessary nutrients. A varied diet that includes all the core food groups and avoids heavily processed foods and saturated fats is key to overall health.

Anyone considering making major changes to their diet or lifestyle should seek guidance from a doctor first.

Outlook

MS affects the nervous system and can lead to various primary and secondary health issues. It is a lifelong condition that may come and go or progress steadily.

Some people experience only mild tingling, while others lose the ability to move or talk. However, most people with MS remain mobile, and most have the same life expectancy as people without MS.

Summary

Healthy dietary choices can benefit people with MS by boosting overall well-being and quality of life. Certain dietary habits may change the condition's progression or prevent specific symptoms or complications, such as cardiovascular disease.

A range of special diets may help manage MS symptoms and reduce the chance of complications. However, more research is necessary to assess the effectiveness of these diets, and a person should consult a doctor before making any major dietary changes.

People with MS may wish to avoid highly processed foods, saturated fats, and added salt and sugar. Minimally processed whole foods, such as fruits, vegetables, pulses, legumes, and oily fish, are better choices.

A person can find more tips for living with MS by consulting experts on MS and peer support through one-on-one conversations and live group discussions.

Smiling Depression

What are you hiding behind that smile?

While sadness and unexplained crying are common signs of depression, not everyone who is depressed appears visibly sad. When someone masks their depression behind a smile, they might have a Smiling Depression.

What could be the possible reasons of Smiling Depression?

People may hide their depression behind a smile for various reasons, such as:

- Worrying about others' judgments
- Not wanting to burden others
- Fearing job loss
- Believing depression will disappear if they fake happiness
- Unawareness of their condition
- Uncertainty about how to seek help

Smiling Depression may often go unnoticed

Outwardly, people appear happy, but inside, they may be struggling with deep feelings of hopelessness and sadness.

If you're experiencing something like this, you might reassure others that you're okay while not showing your true feelings. This can lead to your family and friends not recognizing your need for support. Please remember you're not alone.

Hidden danger of Smiling Depression

While classic depression can leave individuals with suicidal thoughts but lacking the energy to act on them, those with Smiling Depression may appear functional and maintain their daily routines. This façade can sometimes mask a dangerous reality: they might have the energy and capability to plan or execute any unfavourable action.

Such situation calls for regular discussions and encourages those struggling to share their feelings and seek help.

What is Smiling Depression?

Smiling Depression isn't listed as a medical diagnosis and is thought to be a form of major depressive disorder with atypical symptoms. Although it shares the same core symptoms as major depression, it differs in that the distress is internal and not visible on the outside. Those with this condition might even show a temporary lift in mood in response to positive events, developing coping skills to mask or hide their true struggles and giving the impression that they are "doing fine."

let's raise awareness, encourage open conversations about mental health, and support the youth in seeking the help they need.

Is Smiling Depression treatable?

Yes, Smiling Depression is treatable.

Doctors address Smiling Depression in a manner similar to other forms of depression, typically using a combination of the following approaches:

- **Medication:** Certain classes of medicines like antidepressants and mood stabilizers can be advised. Regular doctor follow-ups are important. Patience is the key here, it may take some weeks to see results.

- **Exercise and sleep schedule:** Regular exercise can help to strengthen the connection between your mind and body, promoting a greater sense of self-awareness. In addition, sleep hygiene can help improve mood.

Other tips to cope with Smiling Depression

- **Stress Management:** Mindfulness and deep breathing techniques can help manage chronic stress. Unaddressed, long-term stress could often be the precursor to serious mental health concerns.

- **Psychotherapy:** Talk therapy can help people understand their thoughts and feelings, with options including cognitive, psychodynamic, group, and family therapy.

Signs and symptoms to look out

One way that Smiling Depression differs from other types of depression is that it's **often invisible.**

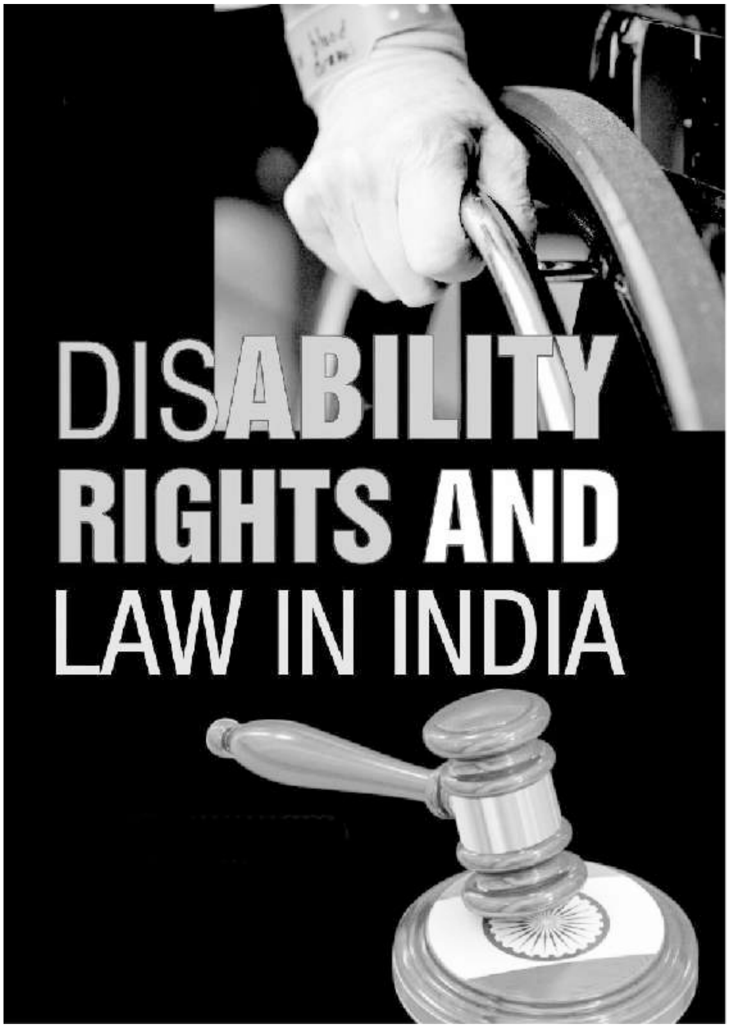
Smiling Depression exhibits many of the classic signs of depression, such as persistent sadness, loss of interest in previously enjoyed activities, and trouble concentrating.

Here are some signs to look for:

- **Changes in appetite:** Depression can cause either overeating or loss of appetite, often leading to noticeable weight changes.

- **Feelings of hopelessness:** Common feelings include guilt, worthlessness, and a sense of hopelessness.
- **Altered sleep patterns:** Some may sleep excessively, while others experience insomnia or significant changes in their sleep schedule.

- **Loss of interest:** They might show a lack of enthusiasm for activities they once enjoyed.



LEGAL HELP NOW AVAILABLE:

MSSI Delhi often receives requests from members to assist them with advice on legal matters-this includes issues pertaining to jobs under rights of people with disability in matters of job security, marital issues, property rights & other personal matters.

It sometimes becomes difficult of MSSI and our counsellors to take a dispassionate point of view or give advice keeping in mind the options available to them under the provisions of the Right to Disability laws

We are pleased to announce a streamlined and transparent process for providing legal assistance to Persons with Multiple Sclerosis (PwMS) through the support of MSSI Delhi. This initiative is designed to ensure ethical and professional guidance while keeping all stakeholders informed. Direct communication between PwMS and the Advocate is not permitted to maintain proper coordination and records.

1. Legal Advice through our Panel Advocate :

All legal advice will be facilitated exclusively via MSSI Delhi for consulting MSSI panel Advocate Mr Yadavendra Saxena. Mr Saxena practices in the District Courts as well as Delhi High Court. He has acquired relevant knowledge & experience in the field of Disability Rights.

2. Scope of Initial Legal Advice:

The Advocate on the Panel will provide the following complimentary sessions:

Session 1: (45min -1hr.) Understanding the case - To gather details and facts related to the legal matter.

Session 2: (45min -1hr.) Verbal Advice on Future Action – To guide the PwMS on potential next steps, ensuring support is provided ethically and within lawful boundaries. Please note, no improper or unfair means will be supported under any circumstances .

Any legal representation in court or extended involvement of the Advocate beyond the above two sessions will be chargeable.

Payment for such services must be made directly to the Advocate keeping MSSI Delhi informed.

MSSI Delhi will discuss with the Advocate the possibility of offering discounted fees for PwMS cases as a goodwill gesture.

Coordination and Feedback:

- To ensure transparency and effective management:
- All cases must be routed through MSSI Delhi- Please do not contact the Advocate directly.
- The PwMS and the Advocate are required to provide feedback to MSSI Delhi through email at key stages of the case to keep everyone informed about the progress and outcomes.

COMMITMENT TO ETHICAL ADVOCACY:

MSSI Delhi is committed to supporting PwMS with professional and ethical legal assistance. While every effort will be made to advocate for the interests of PwMS, this will always be within the framework of lawful and fair practices. Any information shared with MSSI will be treated with utmost confidentiality.

Disclaimer:

MSSI Delhi serves as a facilitator for legal assistance and does not directly provide legal advice or representation. The voluntary advice and services offered by the Advocate on MSSI Delhi Panel are independent and based on their professional judgment.

MSSI Delhi is not liable for any unintentional outcomes, delays, or disputes arising from the legal process or the engagement between the Advocate and the PwMS.

PwMS are advised to exercise due diligence and make informed decisions based on the Advocate's guidance.

Fees for services beyond the initial sessions are to be settled directly between the PwMS and the Advocate always keeping MSSI in the loop.

We believe this policy will help us provide structured, fair, and effective legal assistance to PwMS while fostering accountability among all parties involved.

For any further clarifications or to initiate a case, please contact - MSSI Delhi :

Bipasha Gupta 9312210645, **Meenakshi Bhujwala,** 9811012334

Felicitating Advocate Yadavendra Saxena for providing pro bono advice to MS Members

SC ensures equal medical access for disabled

The Supreme Court of India ruled that individuals with benchmark disabilities must not be denied medical education opportunities, promoting inclusivity and equal access under Article 14. *By Yash Pal Ralhan*

A student in a wheelchair engaged in studying.

The Supreme Court of India has ruled that individuals with benchmark disabilities cannot be denied admission to medical courses solely based on the extent of their disability. The Court clarified that unless a disability assessment board deems a candidate unfit for pursuing the MBBS course, the mere existence of a disability is not a valid reason to deny them the opportunity.

In its judgment, the Court praised the efforts of disabled individuals who have overcome adversity to achieve greatness. It highlighted notable examples, such as Bharatanatyam dancer Sudha Chandran, mountaineer Arunima Sinha, sportsman Boniface Prabhu, and Dr. Satendra Singh, founder of Infinite Ability. These personalities embody how determination can transcend physical challenges.

The Supreme Court also emphasized that the opinions of disability boards are not absolute and can be reviewed by judicial bodies. It referred to a recent judgment where the Court exercised its powers under Article 142, reinstating a visually challenged candidate as selected for the Indian Administrative Service (IAS), despite his earlier disqualification. Similarly, the Gauhati High Court recently ruled that a disabled child's right to parental care allows for the transfer of the father's job to remain with the child.

The judgment was delivered by a bench comprising Justices B.R. Gavai, Aravind Kumar, and K.V. Viswanathan. The case concerned a petitioner with a 40-45% speech and language disability, seeking admission to an MBBS program. On September 18, the Court allowed his admission based on a report from a medical board that confirmed his capability to pursue medical education. In its detailed ruling, the Court provided comprehensive reasoning for this decision.

The petitioner had challenged the Graduate Medical Education Regulation of 1997, which barred individuals with disabilities of 40% or more from MBBS courses. The Court criticized the regulation as overly broad and discriminatory. It held that disqualifying candidates based solely on a percentage threshold without considering their actual abilities violated the principle of equality under Article 14 of the Constitution.

The Court stressed that equality must be examined beyond superficial uniformity. It urged the judiciary to ensure that regulations do not treat unequals equally and underscored the importance of real equality in assessing discrimination claims.

In its judgment, the Court also expressed hope that future guidelines by the National Medical Commission (NMC) would adopt an inclusive approach, aligned with the principle of "reasonable accommodation" outlined in the Rights of Persons with Disabilities Act, 2016. It praised the Ministry of Social Justice for its communication to the NMC, encouraging inclusiveness in the updated regulations.

The Court reminded both government and private entities to focus on how they can enable opportunities for disabled candidates, rather than searching for ways to disqualify them. The principle of "reasonable accommodation," it said, mandates an interpretation of regulations that fosters full and effective participation of disabled persons as equal citizens.

In its concluding remarks, the Court reflected on the immeasurable loss society would have faced if historical figures like Homer, Milton, Beethoven, and Mozart had been denied the opportunity to fulfill their potential due to disabilities.

The Court ordered the petitioner's admission to the medical seat, which had been kept vacant as per its earlier directive. It also referred to a previous judgment involving Jija Ghosh, reinforcing the idea that society often locks doors on the disabled, throwing away the key. The rare individuals who persist and find or create their own key are the ones society must support and uplift. This judgment affirms the importance of inclusivity and the need to break barriers, ensuring equal opportunities for all, regardless of physical challenges.

Yashpal Ralhan is an activist & PwMS He is a Member of MSSI Delhi based in Jallandhar

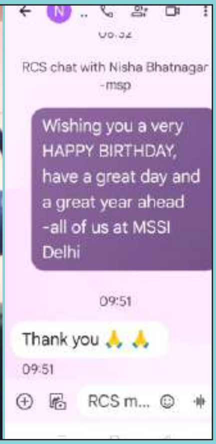
Multiple sclerosis, or MS, is a disease affecting the central nervous system (the brain and spinal cord). Everyone's symptoms vary, but can include:

- Loss of balance or coordination
- Tremor and weakness
- Blurred or double vision
- Eye pain
- Difficulty moving legs, arms and hands
- Numbness and pain
- Cognitive and memory issues
- Sexual problems
- Fatigue
- Changes with bladder or bowel functions

MS can be effectively managed with medication, physiotherapy, maintaining a nutritious diet, fatigue management, and incorporating exercise.

Free Health Supplements

Birthday wishes video calls



RCS chat with Nisha Bhatnagar -msp

Wishing you a very HAPPY BIRTHDAY, have a great day and a great year ahead -all of us at MSSI Delhi

09:51

Thank you 🙏 🙏

09:51

Ha nji tabni or two days derai hu 10:38

Gana bhi sunana hai aapko 10:38

Yes 13:21

Practice 13:21

Ok 13:22

Madam today my friend called up and said yr voice trainer has done a great job 17:07

Thnkw 17:19

Its makes me happy 17:20

Film Festival on Disability at the Spanish Embassy

Diwali Milan-2024

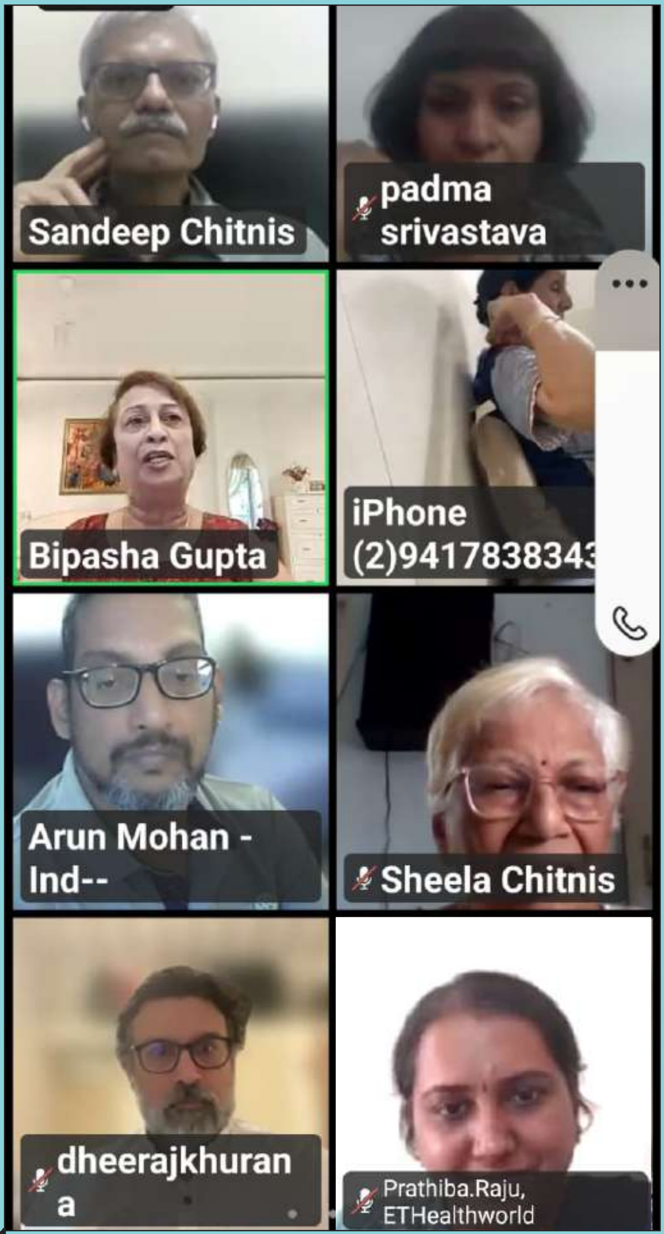
Dancing with the MS Stars!

MSSI AGM at Kolkata-2024

World MS Day: FM Radio programme

Bipasha Gupta with Dr. Vinay Goel

All India Webinar



Cheerful Home Visits

Our Scholarship Students

Laptop given for Achievement

India MS Day 2025-Fun at Dilli Haat

Cheerful Home Visits

Making Friends - Connect Groups

#MyMSStory- Deepshikha Gauba Arora

A Journey of Resilience: Marriage, Motherhood,
Multiple Sclerosis - Rediscovering Strength

Life has a strange way of testing us. Sometimes, it gives us everything we've ever dreamed of, and other times, it takes away what we thought was ours to keep. My journey-from being an Assistant Professor in IT, quitting my job due to unforeseen hurdles, battling Multiple Sclerosis (MS), and rediscovering my strength after 13 years-is one of struggle, resilience, and ultimately, hope.

The Diagnosis That Changed Everything

In just 10 months of marriage, my world took a sharp turn. It started with symptoms that seemed minor at first-fatigue, weakness, and occasional numbness. I dismissed them as the result of a hectic lifestyle. But when things worsened, and a few days later I sought medical advice.

The diagnosis was Multiple Sclerosis (MS)-a condition I had never heard of. There were days I questioned everything. Why me? How would I continue my job? How would I be the mother my child deserved? My family became my pillar of support, pushing me forward even on my hardest days. I was prescribed interferon-1a, a disease-modifying therapy to manage MS post weaning off my kid.

The side effects hit hard-fever, fatigue, and body aches became my new normal. The simplest tasks felt exhausting, and the emotional toll was just as challenging as the physical one.

Rebuilding Myself: Returning to the Gym After 13 Years

For over a decade, fitness took a backseat in my life. But after months of battling fatigue and adjusting to my new reality, I made a decision-I would not let MS define me. After 13 years of marriage , for the first time ever in my life, I stepped into the gym. The first few sessions were tough. My body, weakened by MS and years of inactivity, protested with every movement. But I reminded myself why I was there-to regain control, to strengthen my body, and to prove to myself that I was still capable. The gym became more than a place to exercise-it became a sanctuary where I reclaimed my strength. Every drop of sweat symbolized flexibility, every sore muscle reminded me of progress. MS may be a part of my life, but it does not own my spirit.

Finding Strength in Struggles

Through this journey, I've learned that strength is not just about lifting weights or running miles. It's about getting up every day, no matter how exhausted you feel. It's about embracing challenges and pushing forward despite the odds. My battle with MS continues, but so does my journey of resilience. I am still a wife, a mother, a professor, and now, a woman who refuses to give up on herself.

My message to anyone facing their own struggles-whether it's illness, exhaustion, or self-doubt-know that you are stronger than you think.

Keep pushing the boundaries, moving forward, one step at a time.

THE TRUTH ABOUT ALTERNATE THERAPIES:

Type the words "alternative therapies" and "multiple sclerosis" into google and thousands of articles are listed. It is likely that many people with MS have done this, as just over 50% of people with MS have reported using complementary and alternative medicines (CAMs) in the past year. It is therefore important to understand how and if these therapies work, if they are safe and whether they might interfere or interact with conventional therapies.

The World Health Organisation (WHO) defines CAMs as "a broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system." They include diets, exercise regimes, other forms of medicine like ayurveda, herbal, homeopathy, and some psychological therapies.

In a study published in the Journal of Neurology, Neurosurgery and Psychiatry, written by Dr Suzi Claflin, Associate Professor Ingrid van der Mei and Professor Bruce Taylor from the Menzies Institute from Medical Research in Australia, the authors conducted an in-depth review of published scientific studies into CAMs. They wanted to investigate the effects of CAMs in MS. They found that only a small percentage of the studies were well designed and used robust scientific methods.

In early 2017, the authors used the online Pubmed Database, that catalogues published research articles, to search for studies into the use of CAMs in MS. They found 1,916 studies. Of these, 38 studies were of the type that met the criteria to be included in the analysis, that is they were of a similar design to that used to test new drugs or other conventional therapies. These 38 studies mainly investigated the effects of cannabis, diet and supplements, exercise, and psychological approaches to treating MS.

The most consistent shortfall of the CAM studies was that the number of people participating in the studies were too small. This could result in the statistical analysis being skewed leading to a false result that in fact could be due to other factors or to chance alone.

Another common problem was lack of 'blinding'. This means that the participants of the study and the researchers conducting the measurements and assessments, knew whether they were receiving an active treatment or a placebo (dummy treatment). This can cause problems in a trial as it can affect behaviour and expectations of both the participants and the researchers and can potentially lead to a biased result(s).

Many of the studies also used very different health outcome measures to identify the effects of a treatment. This makes it very hard to compare the studies and know if the results are consistent and reproducible across studies.

The same conclusions were reached by the American Academy of Neurology in a similar review published in 2014.

Research papers studied in the past suggest that the use of some herbal and psychological treatments may improve specific symptoms, however the majority of results for other types of CAMs were found to be inconclusive with no confirmed results. Many Indian forms of medicine contain metals (Bhasma) which cause damaging side effects if taken in the long term. Allergen testing of certain herbs is also not carried out in a scientific way, which may also have adverse reactions.

These conclusions are disappointing as many individuals with MS feel that CAMs can help to put them in control and make a difference to their quality of life. However, as the authors say **"This is not to say that CAMs have no effect on MS, but that there is currently no rigorous scientific evidence to support their use."**

The authors suggest that one solution would be to establish a CAM trial group within the MS research community, to agree on consistent study designs and outcome measures to help improve the quality of the evidence.

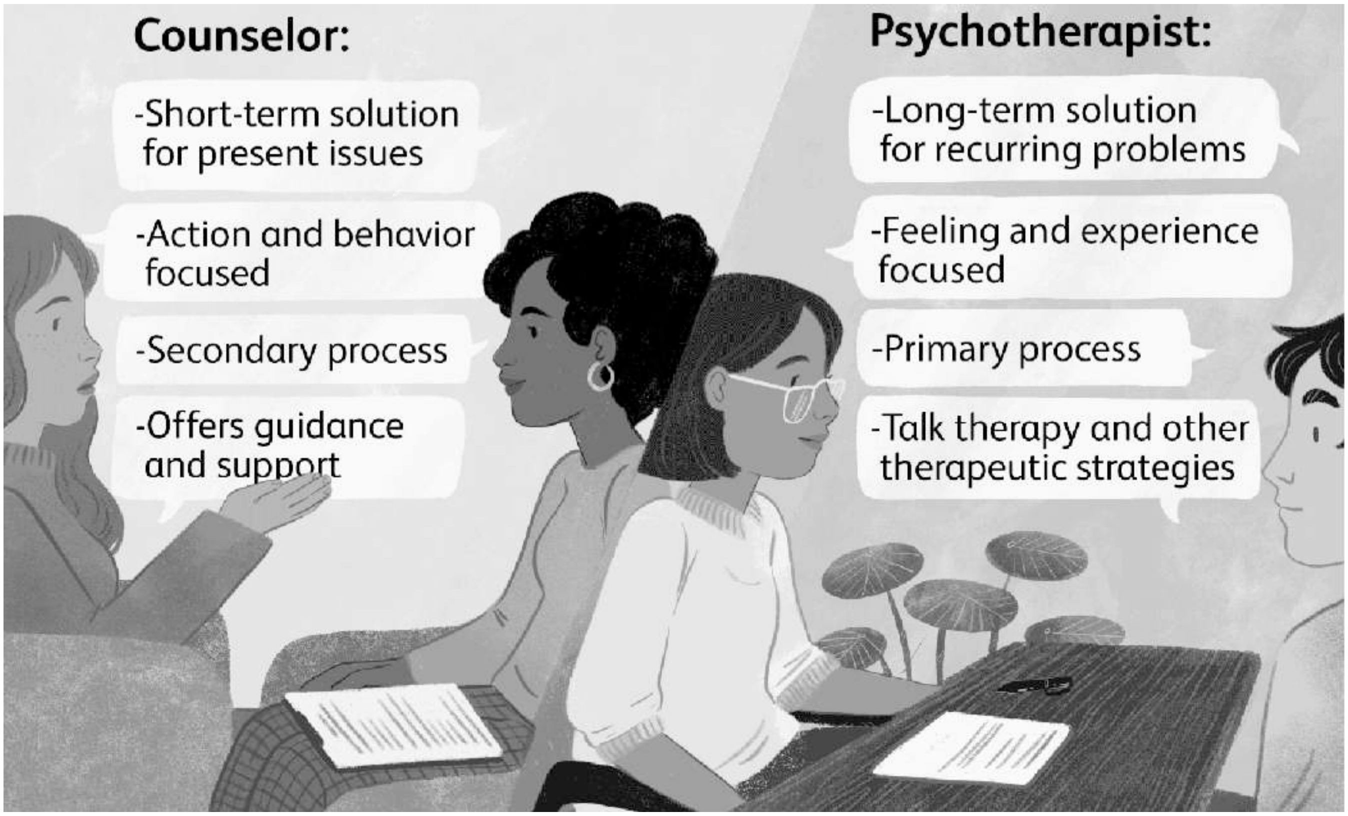
MS is a very varied disease and each person's individual experience is different. If you are considering taking a CAM instead of, or in combination with, a conventional therapy, we recommend that you discuss this with your treating physician.

THE ROLE OF COUNSELLING IN REHABILITATION:

By C.N. Tromp, Psychologist and R. Petter, Social Worker, MS Clinic, Groningen University Hospital, Groningen, The Netherlands

Counselling for people with MS focuses mainly on coping with the uncertainties and unpredictability of the illness.

Counselling people with MS is more than just listening and giving advice. It is a form of helping an individual to deal with personal problems relating to the disease that is often absent from conversations with family, friends and some healthcare professionals. It is about providing support and helping people change, and not primarily about promoting practical solutions. A counsellor is not committed to a certain medical treatment policy, and therefore, aspects of dealing with the disease can be discussed without direct consequences for treatment. Counsellors can also be helpful in shaping the style of living with MS according to the person's wishes and needs. An optimal treatment programme for a healthcare provider can be difficult and unsatisfactory for the individual treated. A person with MS can often exert more influence on his or her life and disease management than he or she may think. Helping people with MS realise their autonomy in decision making is part of the counselling process.



Aims of Counselling

Counselling for people with MS focuses mainly on coping with the uncertainties and unpredictability of the illness. Each person with MS, regardless of the type and course of the illness, must adapt continuously to changing symptoms and find ways to live with relapses and remission. Learning to assess the effects of these changes (both physical and cognitive) on daily life, setting priorities for where energy should be concentrated and recognising the need for new priorities for activities and tasks, making therapeutic decisions, redistributing responsibilities within the family, and making vocational choices, are some of the important topics that can be discussed during counselling with a professional counsellor who has an understanding of MS.

After diagnosis, the need for information, advice and reassurance, especially about the prognosis and therapy options, is foremost. Information about the illness, both from the medical side and regarding public resources, especially that taken from the Internet, can be evaluated and interpreted, with particular reference to the person's own opinion about it, with the assistance of the MSSI counsellor. When a person with MS is not followed and supported during this early period, dealing with the disease can be a lonely, isolating experience. A counsellor can be an important resource during this time and at various times throughout life with MS.

Discussing difficult topics

No one can read the minds of others, so the need to be specific and clear when communicating about personal and perhaps difficult subjects such as the amount of help and support that is required, can put a strain on relationships, especially when support needs may fluctuate from one day to another. This constant effort to be both candid and tactful can be very challenging and discouraging both for the person with MS and those around him or her. The situation often creates a need for the person with MS to be outspoken and assertive in expressing needs and desires with family members. These can often be misunderstood by the family or colleagues at the work place. Assertiveness that is appropriate for the situation and contexts may require practice. The counsellor can play a role in helping the person rehearse and prepare discussions on difficult topics with family members and can provide encouragement and feedback.

Topics of Counselling

Up to 50 per cent of patients with MS in the relapsing/remitting condition develop serious, and sometimes permanent psychological symptoms. Prevention or management of these symptoms is another aim of counselling efforts. Psychological problems include depression, stress reactions and chronic fatigue. Cognitive problems can be a major concern, requiring an understanding of not only the individual, but also of those around the person with MS. Shifts in the competence and roles of parents or children within a family structure are sometimes difficult to accept. For parents, dealing with the requirements of younger family members, who often come home from school or work and expect attention and care, exactly at a moment when their parents are most exhausted, can be frustrating.

Working out practical solutions can be part of the counselling process. Counsellors knowledgeable in MS can also have a role in working with children whose parent has MS. Meeting with the entire family, with the child or children individually, as well as participating in the development of programmes and activities organised for children of people with MS, are all ways in which a counsellor can help families to deal with the challenges of MS.

Counselling can be of value both for the person with MS as well as for those who are close to the individual who deal with MS in their personal lives – either directly or indirectly. Indications for counselling include a broad range of subjects, which require close and timely cooperation with other professionals, including the nurse, neurologist and social worker, in order to be a valuable supplement to regular care.

CHOOSING FITNESS EXERCISE AND MS:

There is a great deal of valuable information available on exercise. This article provides an overview of the major forms of exercise practised by people with MS, compiled from various sources.

Exercise is essential to general health and wellbeing and can also be helpful in managing many MS symptoms. An important study published by researchers in the United States demonstrated the benefits of exercise for people with MS, including improved cardiovascular fitness, improved strength, better bladder and bowel function, less fatigue and depression, a more positive attitude and increased participation in social activities.

While exercising has many health benefits, not exercising poses risks for people with or without MS, including heart disease, muscle weakness, joint stiffness, decreased bone density with an increased risk of fracture, and shallow, inefficient breathing.

A physiotherapist experienced in MS can be helpful in designing, supervising, and revising a well-balanced exercise programme. With some guidelines, a good programme can help to develop the maximum potential of muscle, bone, and respiration, thereby avoiding secondary complications and gaining the benefits of good health and well-being. Any person with MS who is starting on a new exercise programme should consult an appropriate healthcare professional in advance,

Strengthening, stretching and range of motion: Strengthening exercises help make the body stronger and work on the principle of resistance, which requires the muscles to work progressively harder. Resistance is achieved through using exercise machines, elastic bands or weights. These types of exercises can be focused on specific muscle groups that have been weakened by disuse. It is important to consult a physiotherapist before beginning any strengthening programme, since there can be a risk of worsening spasticity. The movement of joints may be impaired due to tightness of the joint capsule, ligaments and tendons.

If a joint is not used regularly it will become stiff and will eventually interfere with normal movement. The objective of range of motion exercises is to maintain joint flexibility. This is achieved by moving each joint throughout the full range of movement. Stretching exercises are recommended for muscles and tendons that have lost their elasticity, resulting in feeling stiff and having difficulty moving.

These types of exercises are often helpful in preventing contractures, which is a "freezing" of a joint so that it cannot bend through its full range of motion.

Aerobic Exercise: Aerobic activity is any sustained, rhythmic activity that is able to raise the pulse and breathing rate. Some examples of aerobic exercise include swimming and cycling (with foot pedals or hand cycling). It is important to be consistent in following an aerobic exercise programme, with the recommended amount of time being 30 minutes, three to five times weekly. This may seem like quite a bit of exercise, especially for someone with mobility difficulties or MS fatigue.

The 30 minutes can be broken down into shorter periods of time, although it is most effective, for cardiovascular fitness, to maintain an increased heart rate for a minimum of 20 minutes, at least three times weekly.

Yoga:

Yoga is an Indian form of exercise, which, in traditional practice, aims to achieve complete awareness and tranquillity through certain physical and mental exercises. Yoga involves concentrated breathing and a range of stretches that revolve around the spine, increasing the body's flexibility and releasing tension. Some of the movements may be easy for a person with MS while others may need practice or adaptation.

A recently published study from the United States found that, similarly to aerobic exercise, people with MS participating in a weekly yoga class along with home practice, had improved levels of energy and decreased fatigue. While yoga and aerobic exercise have many similar properties, yoga has particular benefits for people with MS in that it has a stress reduction or relaxation component and it can also improve balance.

Tai Chi: Tai chi is a Chinese martial art of Buddhist tradition that, as a conditioning regimen, is gentler than most forms of yoga and can be performed seated. Tai chi is usually performed as an ordered set of slow, elegant motions that promote balance through thoughtful consideration of movement and heightened body awareness. The movements focus on proprioception, which is one's perception of movement and spatial orientation. This concept is especially important for people with MS who often experience difficulties with touch and balance.

Aquatic exercise: Aquatic exercise or exercise in water is often recommended because it provides optimal exercise conditions for the person with MS. Water reduces the effects of gravity, and the weightlessness that occurs in water helps a person with weakened limbs attain a greater range of motion. In addition, chest-high water can provide support, enabling many people with MS to stand and maintain balance for exercises with less effort than normally required. The resistance that water provides can be used to strengthen muscles. Water also helps reduce the body heat that can be generated by exercise. Because the core temperature of the body remains lower, there is less over-heating, which is often a cause of temporary worsening of MS symptoms. Water temperatures of low heat eg 27-29°C are usually recommended.

Since MS symptoms can worsen with heat, aerobic exercise that is too vigorous may put a person at risk. Exercise in a cool environment (AC, Cooler) Exercise in a swimming pool with a temperature of 27-29°C.Drink cold fluids to be well hydrated & to lower body temperature. Sit in a cool bath before and after exercise. Wear light clothing Wipe down skin with a cool towel during exercise Maintain a moderate pace.

Conclusion:

A person with MS has many fitness and exercise options and the choice will depend on one's lifestyle, physical functioning, and the availability of suitable facilities. The key is deciding, together with a physiotherapist or other healthcare professional, the most appropriate form of exercise, and then getting started.

(Adapted and reprinted from: Keeping Active When You Have MS, MS Society of Great Britain and Northern Ireland)

Benefits of Flexibility:

- Enhanced physical fitness
- Improved ability to learn and perform skilled movements
- Increased mental and physical relaxation
- Development of body awareness
- Reduced muscular soreness
- Reduced muscular tension
- Decreased stiffness
- Feeling Energised & happy

(Adapted from Multiple Sclerosis Society of Canada's publication "Everybody Stretch: A physical activity workbook for people with various levels of multiple sclerosis"

FAQs:

Q. My neurologist suggested that I be evaluated for an exercise programme that I can do at home. Wouldn't a more intensive, inpatient rehabilitation programme be more effective?

A. Studies have found some benefits for both inpatient and outpatient rehabilitation approaches. The most important aspect to keep in mind is that the frequency, intensity, and setting of a rehabilitation programme must be based on individual needs. A comprehensive evaluation prior to beginning any rehabilitation programme will help to determine what is most appropriate for you.

Q. If people with MS experience extreme fatigue why would exercise be helpful? Wouldn't it just worsen the fatigue?

A. Exercise can improve strength, stamina and cardiovascular fitness, as well as maintain a healthy weight. If practiced following some basic rules, these benefits can be achieved while avoiding the negative effects of MS fatigue. It is always important and helpful to consult a physiotherapist to learn what types of exercise are appropriate for one's capability and level of functioning. Avoiding exercising in excessively warm places, taking breaks and drinking fluids before, during and after exercise can all be helpful strategies in managing fatigue while exercising

Q. I can walk without help for short distances, although I gradually become unsteady if I need to walk for an extended period of time. In that case I hold on to whoever is with me for support. My neurologist wants to refer me to an occupational therapist for an evaluation of my walking. I'm afraid that the therapist will tell me I need a stick or even worse. I can't help feeling that it would be better if I kept on for as long as possible without any aid. It's like once you start with a stick a wheelchair is just around the corner. Plus, a stick is for the elderly and I'm only 35. Should I hold out longer or give in?

A. Many people with MS may feel like you do, that accepting a technical aid is a form of "giving in" to the disease. It doesn't help that our society values health and fitness and that technical aids such as sticks, braces and wheelchairs are often seen as "symbols" of disability.

Please do not get influenced by this attitude - Sticks or a Wheelchair will free you up so that you do not have to depend on others to go out or move around.

Diapers are a discreet way to head out of the house without worrying.

Technical aids are tools for maintaining independence that can permit a person with MS to overcome daily difficulties and to better manage MS symptoms, such as fatigue. In short, technical aids can help you to participate more easily in all of the activities that you enjoy and that make up your life.

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.

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.

POPULAR MEDICINES IN THE MARKET:

FOR INFORMATION ONLY: PLEASE CONSULT YOUR NEUROLOGIST FOR SUITABILITY

The first disease modifying therapy (DMT) was an injectable medication approved by the FDA in 1993. Subsequently there have been a variety of injectable, oral, and infusions (through intravenous drip) DMTs developed that have unique risks and benefits. Most drugs targeted mainly relapsing & remitting (RR Type) MS

Recent advancements in Multiple Sclerosis (MS) treatment include the development of new disease-modifying therapies (DMTs) that target B-cells, particularly with drugs like ocrelizumab, showing effectiveness in slowing disability progression in both relapsing-remitting and primary progressive MS; research into potential therapies focused on addressing inflammation outside the brain, exploring the role of factors like infections and lifestyle; and promising results from studies investigating biomarkers to better predict disease course and monitor treatment efficacy; with a growing focus on finding treatments for progressive MS, which has historically been more challenging to manage.

As our understanding of the disease has evolved, treatment options and treatment approaches have also advanced. Note- ALL DMTs ARE TO BE TAKEN ONLY IN CONSULTATION WITH YOUR NEURO PHYSICIAN

KEY DEVELOPMENTS:

Drugs like ocrelizumab (Ocrevus) have been approved for both relapsing-remitting and primary progressive MS, demonstrating significant efficacy in reducing disability progression by depleting B-cells, which are now considered key players in MS pathology.

NEW GENERATION OF DMTS:

Newer medications offer improved efficacy and potentially better safety profiles compared to older DMTs.

Moderately Effective Oral Ms Therapies (low end)

1. Gilenya (Fingolimod) Oral
2. Fingomod (Fingolimod) Oral
3. Teru MS (Teriflunomide) Oral
4. Denopsy (Teriflunomide) Oral
5. Tecfidera (Dimethyl Fumarate) Oral
6. Sclerogem (Dimethyl Fumarate) Oral
7. Scleteri (Dimethyl fumarate) Oral
8. Dyfira (Dimethyl Fumarate) Oral
9. Azathioprine (Off-label use/ generic) Oral

Highly Effective Infusion Therapies (high end)

1. Tysabri (Natalizumab) IV infusion
2. Ocrelizumab (Ocrevus) IV Infusion-RRMS & PPMS
3. Alemtuzumab (Lemtrada) IV infusion
4. Rituximab (Rituxan) Off-label use. IV Infusion

Moderately Effective Injectables (middle end)

1. Peginterferon Beta-1a (Plegridy) Sub Q pen device Once in 2 weeks
2. Avonex (Interferonbeta-1a) Once a week injection
3. Glatira (Glatiramer acetate) Everyday injection
4. Copaxone (Glatiramer acetate) Sub Q 3 times per week
5. Rebif (Interferonbeta-1a) : Once a week injection
6. Betaseron/ Extavia/ Actoferon (Interferonbeta-1b) Injectable

OUR SUPPORTER PROMISE:

Our donors & supporters make a huge difference to the lives of all those affected by MS. Our supporters change the lives of people affected by MS. We believe supporting MSSI should be a positive and rewarding experience, and so we set out our promise to supporters:

We'll use your donations carefully and responsibly making best use of our income by funding work that has a demonstrable positive impact on the lives of people affected by MS.

We promise to provide information about our finances and charitable spend so you can see how your money is being spent and the difference you're making to people affected by MS.

Your personal information is safe with us. We take our obligations very seriously and will endeavour to ensure its safety. We endeavour to fulfil all of our obligations under strict confidentiality guidelines.

We'll never sell on your personal details. We may share your details with researchers other like-minded organisations (e.g. our members) only after getting your explicit permission.
We'll only ever contact you via methods you're happy for us to use and for which we have received your consent.

If you'd like to change the way you hear from us, or don't want to hear from us again, we'll always respect your decision.

We'll strive to give you meaningful opportunities to donate to our work, but will never put pressure on you to do so.

Whenever we start a conversation, either on the phone or in person, we'll always try to ask if you're happy to speak to us.

We'll be especially careful and sensitive when speaking to people we believe to be vulnerable.

We strive for the highest possible standards in our fundraising bearing in mind best practice as laid down by recognised regulatory bodies around the world.

MSSI services are offered FREE to those who need them most. But we need regular and substantial funds to make these services available free of charge to our beneficiaries.

MSSI does not receive any government funding and depends entirely on donations from individual donors , private trusts or companies.

Our accounts are professionally audited & filed before the Charities Commissioner on an annual basis.

We'll always provide easy ways for you to contact us.
Our team is on hand to answer your questions, we really value your feedback.
Any questions? Please get in touch-we'd love to hear from you.
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Thank you for your continued support. Together we will beat MS.

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Our deep gratitude to the Faculty of the Neuro Sciences Centre at AIIMS Delhi.
Our sincere thanks to all Hospitals and Doctors of Delhi NCR for their patience, cooperation & dedicated service.
All our silent volunteers, donors & supporters, thank you. We could not have done it without you.

Thank you

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

Friends Take Care

Tips shared by our members

This information is passed on by a doctor who is also a care giver. It is worth referencing, especially if you or your loved one have become elderly.
One senior citizen MS person was admitted to hospital for choking in his lungs after drinking a glass of water. He was rushed to the hospital for emergency treatment and had to be hospitalized with pneumonia. When a patient spends long time lying in bed or develops swallowing problems, it is essential to take extra care. Do not eat or drink while lying down. Liquids can collect in the lungs.

Such people must take the following precautions:
One is to prevent falling and the other is to prevent choking.
One has to begin to train oneself when drinking water-Stop everything and concentrate on drinking water carefully and slowly.
The elderly are prone to choking because the throat and swallowing muscles have degenerated and lack muscle strength. Pneumonia caused by choking on drinking water, milk, soup, etc., which is a common problem in MS.

Please Note:

As you get older, you must drink water slowly, attentively and cautiously.

- Use a straw, if possible, while drinking water and keep your head down when swallowing.
- Please drink thick soup instead of clear soup. Clear soup flows quickly and it is easy to choke when breathing is not smooth.
- Please do not drink liquid while there is still solid food in your mouth, or while chewing. If the water stays in the mouth for too long, it will flow into the trachea and cause choking if you are not careful..
- Do not speak, laugh or turn your head when there is food or water in your mouth.
- Old people do not have the same physical strength and endurance as young people.

If liquid or food enters the trachea and is coughed out, the face will turn red and the blood pressure will soar. Sometimes choking can be fatal.

❖❖❖❖

Some Tips For Common MS Problems

Most people with MS have problems passing urine .. either it is delayed , or there is loss of control. For urine and constipation problems please take regular medicines after consulting a Urologist :
Urine - have plenty of water - you need to flush out the toxins from your kidneys and bladder otherwise you will land up with infections (UTI) For urine control there are meds which a urologist will prescribe . But you can start with low dose of oxybutanin once or twice a day. Try to go out with diaper - nobody needs to know. It is very convenient. There is no need to feel embarrassed, and don't stop drinking water because of loss of control.
For constipation please have a good diet containing leafy green veg like palak or other saag. Try foods which have gravy - avoid dry foods like bread or sookhi sabji at night. And you can regularly take isabgol or cremaffin (large spoon 15 to 20 minutes before your dinner)
There are many stool softeners that can help.

And most important DO NOT GET TENSE. All the nerves get tense , your body legs etc will also tense up and it affects your general condition.

You must stay mentally and socially active. Take some interest in life and your work - Most of all do not lose hope. Remember there are dozens of learned scientists and Doctors working towards a cure right now.
Be ready and be prepared for the breakthrough!


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