MSSI®

MULTIPLE SCLEROSIS SOCIETY OF INDIA
DELHI


Tele-consultation


Physiotherapy


Counselling


Scholarships

find your #ms connections


Home Visits


Priority Appointments


Home Nurse

Advocacy

MyMS Diagnosis

2023-2024

MULTIPLE SCLEROSIS SOCIETY OF INDIA

MEET YOUR MSSI DELHI MANAGING COMMITTEE


Bipasha Gupta
Hony. Chairperson


Mridula Murgai
Hony. Vice Chairperson


Prabal Malaker
Hony. Secretary

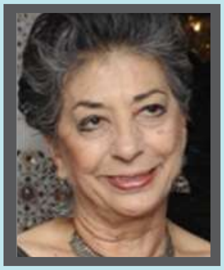

Ragini Mathur
Hony. Joint Secretary


Meenakshi Bhujwala
Hony. Treasurer

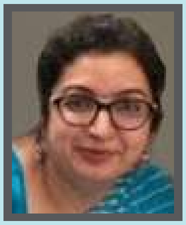

Meera Pinky Hora
Executive Member


Praveen Khetarpal
Executive Member


Ameeta Gupta
Executive Member


Nina Kochhar
Executive Member

OUR DEDICATED ADMIN AND FIELD TEAM


Puja Chowdhary


Shashi Verma


Raj Kumar


Shagufta Fatima


Raji Vijayen


Gopal Chakraborty

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

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

Our much awaited 21st issue of the Annual handbook is here ! We are sure you will find it very informative and interesting. It contains something for everyone

I am delighted to share with you that for the first time in the last 24 years of my association with MSSI we have noticed a remarkable but visible change in our MS members. We find them more independent, positive and mostly pursuing their careers in various fields. Recently at one of our programs two third of the young MS members came in alone without any attendant or caregivers. This remarkable change of attitude is happening due to quicker and better treatment early diagnosis and a better understanding of MS. This good news and positive change -as confirmed by Neurologists - is a result of newer and more effective drug treatments now available. Today there are 28 different DMTs in the market compared to only 1 in 1999, that too was expensive & had to be imported.

I am also extremely happy to share that as usual our MSSI Delhi team work is going on excellently with great dedication and enthusiasm.

Each one of us takes up a "project' and focuses on providing our MS members & their families the trust and understanding that they have come to expect from us. Today MSSI Delhi serves over 850 MS persons in Delhi/ NCR and 8 other states in North India. We are all part of one big family now !

Currently our focus is on fund raising to try and meet the growing needs of our large MS community. This is a tough job which is made more difficult with new policies. All our Committee members work selflessly as volunteers, giving their time, energy & also silent monetary support from time to time to meet requirements of running costs and staff salaries. For every service that we provide free or at highly subsidised rates, there are expenses to face. It is my earnest appeal to our generous members, friends & supporters to come forward and strengthen our hands in whichever way you can.

Our deep gratitude to those who have been supporting us over the years.

Thank you for standing by us,

Bipasha Gupta

Hony Chairperson- MSSI Delhi

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 Australia, NMSS , Mayo Clinic, among other online sources.

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

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

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

Editorial Team: Meenakshi Bhujwala, Mridula Murgai
Design & Printing by: Anil Saini Email: anilsaini.67@gmail.com

INDEX

THE TEAM BEHIND IT ALL

A GUIDE TO MS

Multiple sclerosis (MS) is a chronic autoimmune condition affecting the central nervous system, including the brain and spinal cord. It occurs when the immune system mistakenly targets and harms the protective fatty myelin sheath surrounding nerves. Myelin plays a crucial role in insulating and safeguarding nerves, ensuring the electrical signals from the brain to the body travel swiftly and effectively. The disease can lead to issues with *muscle coordination, vision, balance, sensation, and thinking, sometimes resulting in significant disabilities*.

Typically, MS manifests between the ages of 20 and 40 and is the most common disabling neurological disease in young adults. Currently, nearly 1.8 million individuals in India are afflicted with MS, but the number may be much larger due to a lack of census or data covering the disease.

What Are the Types of Multiple Sclerosis?

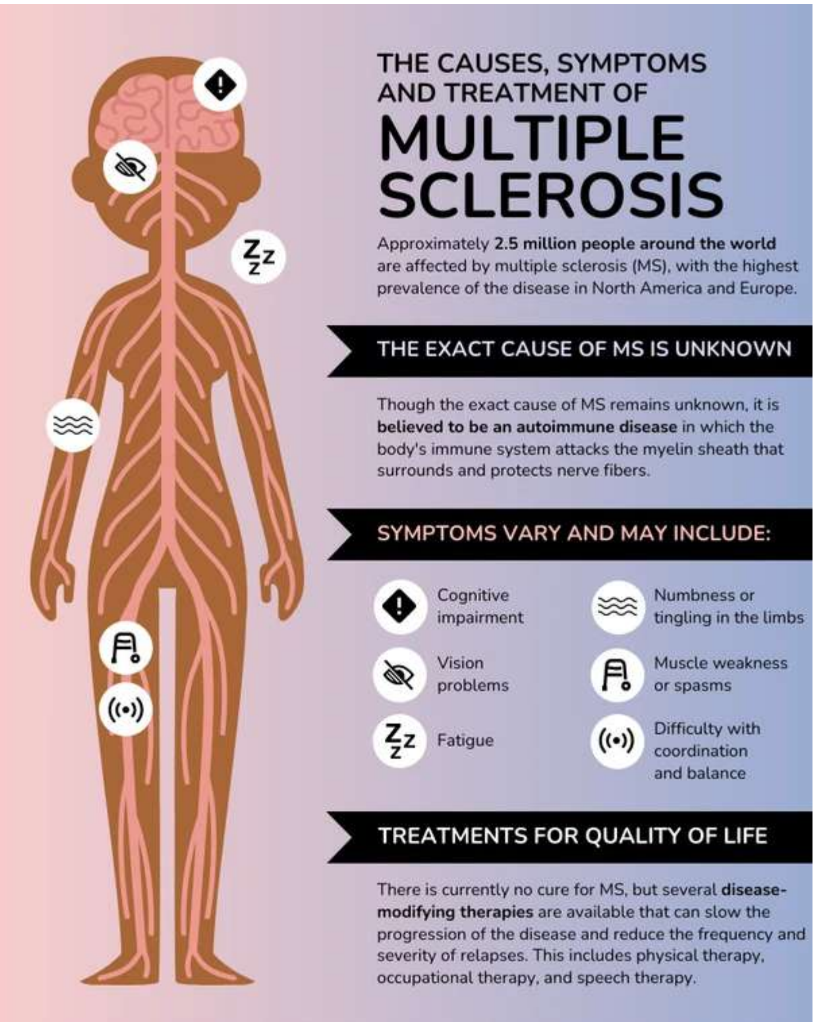
Different types of MS vary in their progression. Identifying a patient's specific type of MS helps in anticipating its course and making informed treatment choices.

There are four types of multiple sclerosis, including the following:

1. Relapsing-Remitting Multiple Sclerosis (RRMS)

Relapsing-remitting MS is the most common form of MS, as it accounts for the initial diagnosis in around 85 percent of all MS cases. RRMS is marked by distinct episodes of active disease activity (i.e., attacks or relapses) followed by recovery (i.e., remission) phases.

Also known as "attacks" or "exacerbations," MS relapses are abrupt, significantly worsening symptoms lasting at least 24 hours and not caused by infection, fever, or stress. They result from new areas of inflammation and demyelination. Demyelination is when the protective covering of nerve fibers, myelin, is damaged or destroyed. Most relapse symptoms improve with time, rest, and possibly therapy, but partial recovery can lead to permanent symptoms. MS relapses usually endure for days to weeks. People with RRMS who are not on disease-modifying therapy (DMT) typically have one to three relapses annually, but some experience much longer intervals between relapses.



THE CAUSES, SYMPTOMS AND TREATMENT OF

MULTIPLE SCLEROSIS

Approximately **2.5 million people around the world** are affected by multiple sclerosis (MS), with the highest prevalence of the disease in North America and Europe.

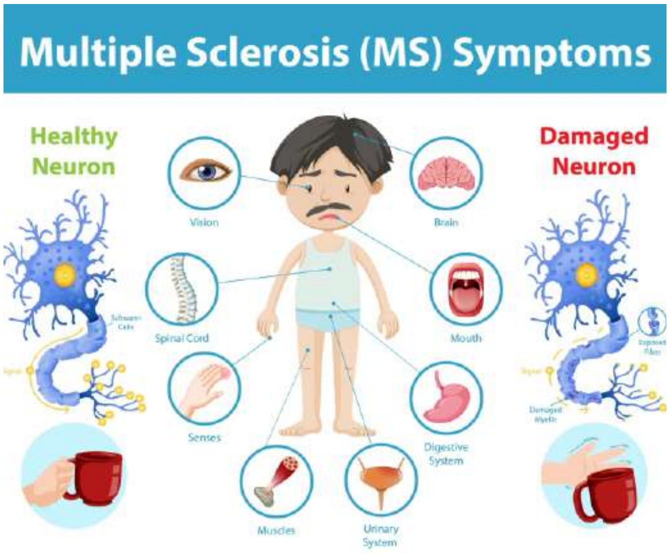
THE EXACT CAUSE OF MS IS UNKNOWN

Though the exact cause of MS remains unknown, it is **believed to be an autoimmune disease** in which the body's immune system attacks the myelin sheath that surrounds and protects nerve fibers.

SYMPTOMS VARY AND MAY INCLUDE:

TREATMENTS FOR QUALITY OF LIFE

There is currently no cure for MS, but several **disease-modifying therapies** are available that can slow the progression of the disease and reduce the frequency and severity of relapses. This includes physical therapy, occupational therapy, and speech therapy.



In remission, the disease seems to halt its progression. During this phase, symptoms may not worsen or completely vanish (non-worsening), or some may worsen and become permanent (worsening).Infection, fever, and stress can cause pseudo-relapses, which mimic real MS relapses but lack new inflammation or demyelination. Magnetic resonance imaging (MRI) scans aid in distinguishing between pseudo- and real relapses. Pseudo-relapses may be addressed by treating the underlying infection or stress source.

2. Primary Progressive Multiple Sclerosis (PPMS)

Primary progressive MS accounts for 10 percent to 15 percent of all MS diagnoses. It is identified by a continuous, worsening course from the start, marked by increasing disability and typically lacking remission periods or acute attacks. PPMS's progression rate can vary, with periods of stability or changes along the way.

3. Secondary Progressive Multiple Sclerosis (SPMS)

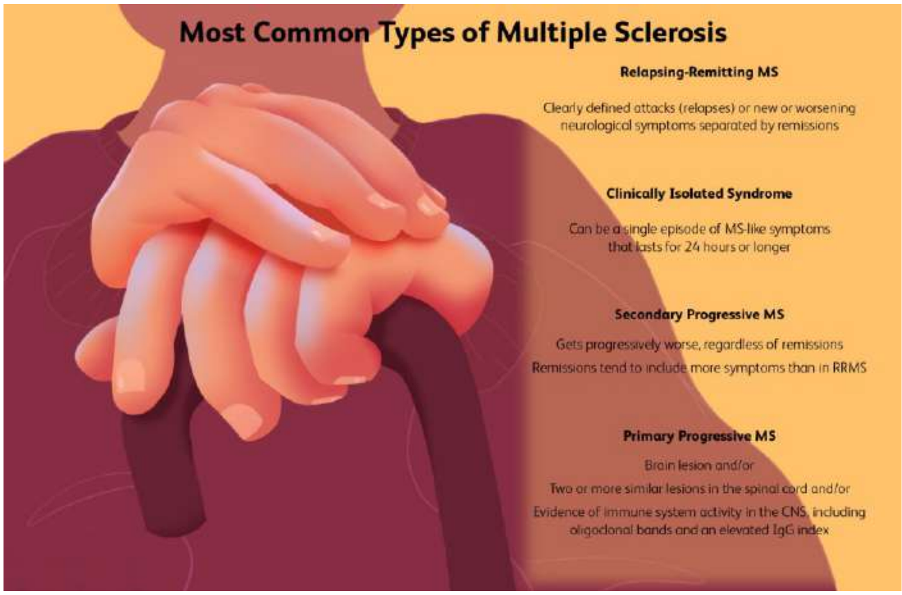
This is diagnosed when an initial RRMS phase is succeeded by an ongoing "progressive" phase in which the disease steadily worsens. For this reason, it is actually considered a subtype or phase of RRMS. This transition can be a complex and uncertain period in the diagnosis, as it is different for each individual and can take years or even decades to develop. During SPMS, attacks and partial recoveries may still occur. Transitioning to SPMS doesn't occur in all individuals with RRMS.

4. Progressive Relapsing Multiple Sclerosis (PRMS)

This rare form of MS initially inflicts continuous nerve damage with symptom onset, leading to steady deterioration. Although relapses may occur, with subsequent partial or complete recovery, nerve damage persists, and symptoms progressively worsen.

Clinically Isolated Syndrome (CIS)

Clinically isolated syndrome refers to an MS-like event in someone without a prior MS diagnosis, not a type of MS itself. While those with CIS have a higher risk of developing MS, not everyone will develop it. CIS typically involves one episode of MS symptoms that lasts days or weeks, but a confirmed MS diagnosis usually requires at least two such episodes. Many individuals with CIS eventually experience more episodes and are diagnosed with MS.



Most Common Types of Multiple Sclerosis

Relapsing-Remitting MS

Clearly defined attacks (relapses) or new or worsening neurological symptoms separated by remissions

Clinically Isolated Syndrome

Can be a single episode of MS-like symptoms that lasts for 24 hours or longer

Secondary Progressive MS

Gets progressively worse, regardless of remissions

Remissions tend to include more symptoms than in RRMS

Primary Progressive MS

Brain lesion and/or

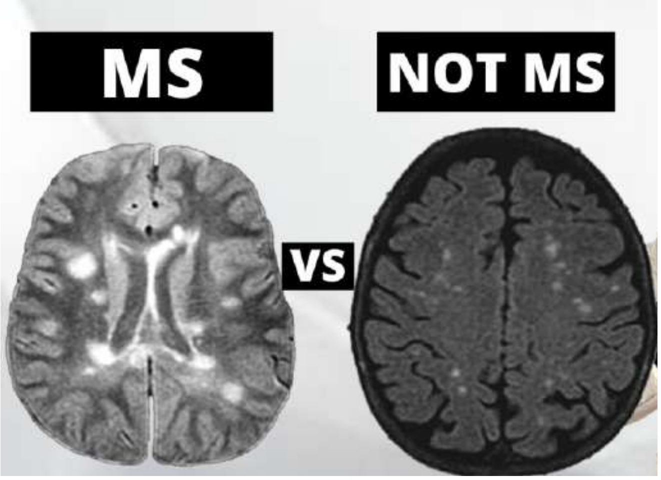
Two or more similar lesions in the spinal cord and/or

Evidence of immune system activity in the CNS, including oligoclonal bands and an elevated IgG index

HOW IS MULTIPLE SCLEROSIS DIAGNOSED?

An early diagnosis leads to better outcomes in MS. There is no definitive test for diagnosing it. The diagnosis is made only after ruling out other potential causes or symptoms, which can be a complex and time-consuming process. Unfortunately in India, even the medical fraternity is not very conversant with MS, and the process of a final diagnosis becomes even longer.

Medical history and neurological examinations can provide strong indications of nervous system issues. Diagnostic tests to confirm a diagnosis come into play only when the history and examination do not offer clear evidence of the disease.



To diagnose MS, two criteria must be met:

At least two attacks must have occurred, with a one-month gap between them. An attack is characterized by the sudden onset of a new MS symptom or the worsening of existing symptoms for at least 24 hours.

More than one area of the central nervous system myelin must show damage. This damage must have occurred at multiple points in time and should not be attributed to any other disease.

Tests to diagnose MS may include the following:

Neurological examination: A neurological exam assesses cranial nerves, reflexes, muscle strength, sensory perception, and vision to detect potential areas of damage from MS lesions. Walking speed and style may also be evaluated.

MRI scan: An MRI scan of the brain and spinal cord is typically performed. A contrast dye can help identify both active and inactive myelin damage.

Lumbar puncture: A lumbar puncture, or spinal tap, may be performed to assess cerebrospinal fluid, which surrounds and protects the brain and spinal cord from injury. In most cases of MS, this test reveals abnormal results.

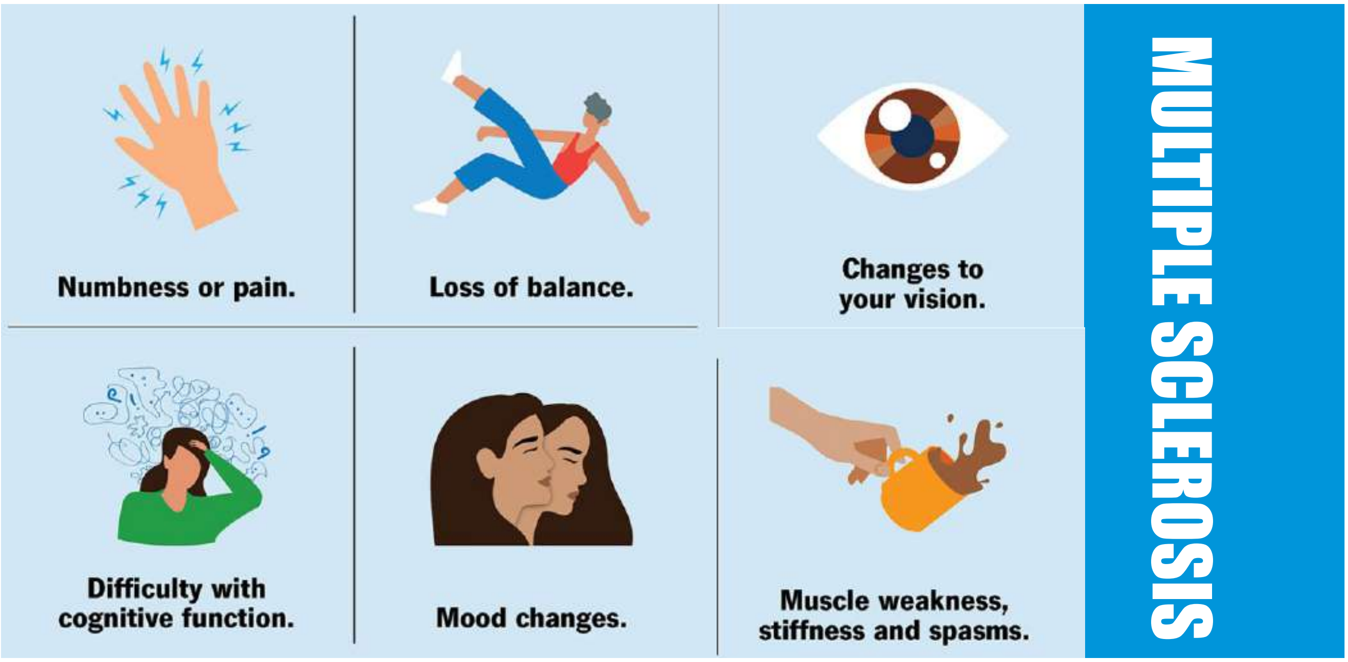
Evoked potential test: This test gauges the response time and size of nerve reactions to stimulation from various parts of the body. It can uncover abnormalities in the brain, spinal cord, and optic nerves of the eyes that might go unnoticed by other tests.

Blood tests: These are conducted to rule out other medical conditions.
Eye examination and visual field assessments.

Inner ear tests: These check an individual's balance.

Urine tests: Urinalysis may rule out other conditions.

Electrocardiogram: This noninvasive procedure evaluates the heart's rhythm and electrical activity, aiding in diagnosing various heart issues.



The following symptoms may develop more slowly:

Bowel problems: Bowel issues may result from the condition or be linked to the medications treating it. Constipation is the most common bowel issue in MS; bowel incontinence is less common. If stool becomes impacted, which is often a result of constipation, it can irritate the bowel wall, leading to increased fluid and mucus production, which can leak from the rectum.

Cognitive problems: Approximately 50 percent of people with MS experience cognitive issues. Symptoms of cognitive dysfunction may include brain fog, problems acquiring and retaining new knowledge, slowness in processing large amounts of information, difficulty multitasking, shortened attention span, poor judgment, problems processing visual information (e.g., reading maps), difficulty with planning and problem-solving, and reasoning problems (e.g., solving puzzles).

Disability: Frequent relapses can lead to a progressive and potentially permanent increase in disability.

Paralysis: Individuals with MS may experience partial or total paralysis at any stage.

Tremor: MS patients may experience the shaking of limbs.

Neuropathic pain: MS-related pain arises from nervous system damage and includes many symptoms, including stabbing pain in the face, torso, and limbs, burning sensations, pins and needles (a feeling of unpleasant tingling or prickling), and feelings of being hugged or squeezed.

Dysphagia: Dysphagia refers to difficulty swallowing. It can range from challenges with specific foods or liquids to a complete inability to swallow.

Dysarthria: Dysarthria is a speech disorder resulting from muscle weakness, leading to slurred or unclear speech. Thus, it may be challenging for individuals with dysarthria to pronounce words and articulate effectively.

Pseudobulbar affect (PBA): Pseudobulbar affect is a neurological condition marked by involuntary and abrupt episodes of laughter or crying, which can be challenging to manage.

Sexual dysfunction: Individuals may lose their libido. Men may have difficulty maintaining erections (erectile dysfunction), while women may have decreased vaginal lubrication or have difficulty reaching orgasm.

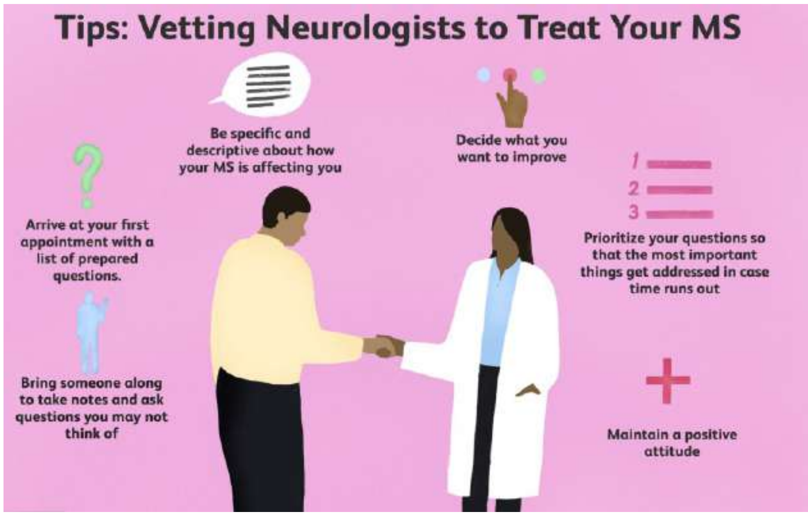
WHICH HEALTH PROFESSIONALS WILL SUPPORT ME?

Although you will be in charge of managing many aspects of your MS, like taking medication as prescribed or keeping up with exercises recommended by a physiotherapist, sometimes you might need a bit of extra support to make sure you're on top of your symptoms, you've selected the best treatment option for you, or if things change.

MSSI services work differently in different areas, so it's a good idea to check with us in advance who to contact, and how, if you're concerned about symptoms. Your symptoms may be reviewed by your neurologist, your MS nurse, or you may be referred to someone who specialises in a particular therapy such as a physiotherapist or speech and language therapist, or someone who specialises in the management of a particular symptom, for example a pain specialist, or urologist. Your GP can help with some symptoms or refer you to other services if you need them.

What if the treatment isn't helping?

Many treatments don't start working immediately, it may take a few weeks or months before you see any benefit. Hopefully you'll be given an idea of when you might expect to see results or be offered an appointment to review how you're doing after an appropriate time. For some medicines, the dose might have to be increased gradually until you find the best possible relief for you. Typically you'd start on a low dose and be advised when to increase the dose and by how much, or have a review before any changes are made. Not all treatments work for everyone, so if the treatment really isn't working, ask if there's an alternative you can try. Sometimes it can be a case of trying several options, or a combination of treatments, to find what works best for you.



Unfortunately, sometimes treatments don't get rid of symptoms completely. For instance, treatments for nerve pain may reduce the pain to a more manageable level, but you may still experience some pain in the background. The same is also true for fatigue.

Are there new or experimental treatments I should consider?

Experimental treatments

There is no cure for MS, so beware of anyone claiming they're offering a cure. The most important thing is to use reliable sources of information to inform your decisions, such as the MSSI Trust. Other sources may sound convincing but they may just be opinion, marketing hype or personal experience presented as facts.

If you do find a treatment that interests you, do your research. If there's been a genuine breakthrough, MSSI will be reporting it first. Look for different opinions on the research and consider what is being said. Often research reported in the press is at an early stage, so it might be a while before a treatment becomes widely available or it may never get to that point at all.

It can be tempting to try an experimental or controversial treatment, but you need to consider the risks of harm, potentially significant side effects and the costs involved. If in doubt, have a chat with your MSSI counselor.

How do I find out about new treatments?

MS is a very active area of research and new treatments are coming through all the time. Keep asking if there are any new options during appointments with your MSSI team, especially if you feel your symptoms aren't being managed as well as you'd like.

How is MS treated?

Disease-modifying therapies

Although MS can't be cured, there are medicines that can help people have fewer and less severe relapses. These are called disease-modifying therapies.

They are taken either as a pill, an injection or an infusion.

They aim to reduce the amount of damage and scarring to the myelin sheath (a layer surrounding your nerves), which is associated with MS relapses.

These treatments may also help to slow worsening disability in MS, although definitive research into their long-term benefits is limited.

Disease-modifying therapies aren't suitable for everyone with MS. They're only prescribed to those with relapsing remitting MS or some people with primary or secondary progressive MS who have relapses.

People with progressive MS who don't have relapses are very unlikely to benefit from the treatments and could still experience side effects from them.

There's currently no cure for multiple sclerosis (MS), but medicines and other treatments can help control the condition and ease some of the symptoms.

Treatment for MS depends on the stage of the disease and the specific symptoms the person has.

- treating relapses of MS symptoms (with steroids)
- treating specific MS symptoms
- treatment to reduce the number of relapses (disease-modifying therapies) You'll be supported by a team of different healthcare professionals working together.

This may include a neurologist (specialist in treating conditions of the nervous system), a physiotherapist, a speech and language therapist, and a number of other professionals.

Treatment for multiple sclerosis relapses

Contact your neurologist if you think you're having a relapse.

A flare-up of symptoms can sometimes be caused by something other than a relapse, such as an infection, so your GP needs to check for other possible causes.

Treatment for a relapse usually involves either:

a 5-day course of steroid tablets taken at home

injections of steroid medicine given in hospital for 3 to 5 days

Steroids can help speed up your recovery from a relapse, but they don't prevent further relapses or stop MS getting worse over time.

They're only given for a short period of time to avoid possible steroid side effects, such as osteoporosis (weak bones), weight gain and diabetes, although some people will still experience problems.

Not using steroids more than 3 times a year (if possible) will also help to reduce the risk of side effects.

IF YOU DON'T USE IT, YOU LOSE IT!

Impairments of muscle function are a central feature of MS. They can be manifest in stiffness or involuntary muscle actions as well as in weakness, which limits a muscle's functional capacity.

Muscle atrophy is the condition where muscles become weaker as we age or due to an injury. Atrophy can happen quicker if you are dealing with MS and that is often because of inactivity or lack of exercise.

In most cases muscle atrophy can be reversed with proper nutrition and exercise. Atrophy related to neurological diseases, such as MS, will require physical therapy to rebuild muscles.

Resistance training (with bodyweight, free weights, or machines) and swimming are effective ways to build strength with MS,

Unfortunately, many exercise programs lack enough intensity, progression and spasticity for you to reverse muscle atrophy. Sure, you might make some progress initially, but you will soon plateau as your muscles become used to the exercises you are performing.

Weight training

Strength in the postural muscles is crucial for people with MS. Strength and muscle are lost in those areas as the condition progresses. Standing row exercises can help strengthen these muscles.

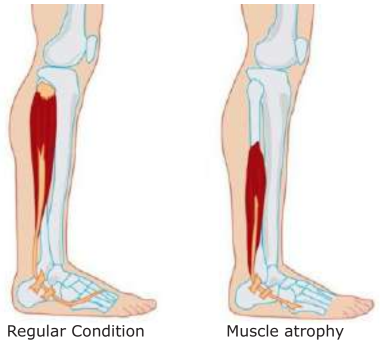
Benefits of exercise

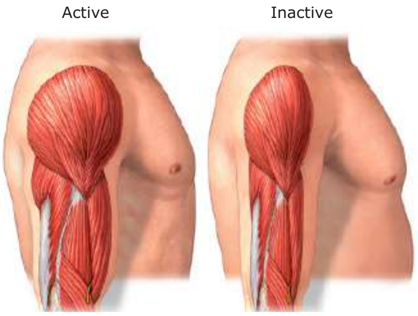
Exercise and physical activity can help manage many symptoms of MS. Studies have shown that aerobic exercise programs for people living with MS can improve:

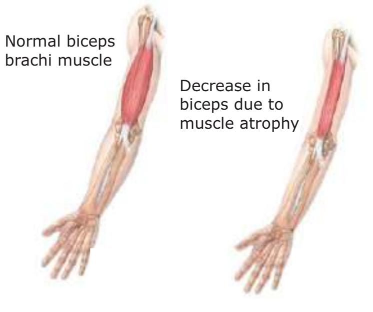
- cardiovascular fitness
- bladder and bowel function
- mood
- bone density
- strength
- fatigue
- cognitive function
- flexibility

RISKS: Some people with MS might overheat quickly when exercising, while others may experience balance issues or their legs may begin to tingle. Here are some tips to help reduce the risk

- Speak with a doctor or physical therapist before starting an exercise program, to check it is right for you.
- Keep a bottle of water nearby for rehydration.
- Take your time and build up slowly.
- Take breaks of 15 seconds or longer between activities.
- If possible, exercise when someone else is around, especially when you first start.







Muscle atrophy is the wasting or thinning of muscle mass. It can be caused by disuse of your muscles or neurogenic conditions. Symptoms include a decrease in muscle mass, one limb being smaller than the other, and numbness, weakness and tingling in your limbs.

Exercises That May Improve Walking Steadiness

If your walking steadiness is low or very low and you'd like to improve it, talk to your doctor, who can provide you with a set of strength and balance exercises tailored to you or refer you to an exercise programme shown to reduce fall risk.

You may also receive guidance on how often you should do the exercises. These sample exercises can give you a sense of what to expect.

SIT TO STAND

1. Sit on a sturdy chair with your knees in line with your hips and your feet facing forward.

2. With your hands on the sides of the chair, lean forward while keeping your back straight.

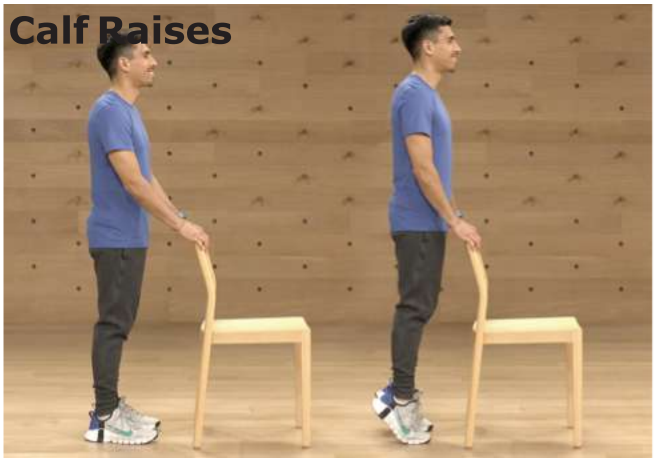
3. Push off with both hands to stand up.

4. To sit down, bend your knees, hinge at your hips, reach your hands to the chair, slowly lower your hips and sit on the chair.

Repeat 10 times.

For more support, you can place the back of the chair against a wall. And as you get stronger, go from two hands to one, and eventually do the exercise without using your hands to push off.

Calf Raises



1. Stand near a sturdy table or chair with your feet shoulder-width apart and look straight ahead.

2. Hold on to the table or chair for support.

3. Raise your heels off the floor and rock forwards onto your toes.

4. Lower your heels to the ground.

Repeat 10 times.

As you get stronger and your balance improves, you can do the exercise without a table or chair.

Hip Abduction

1. Stand near a sturdy table or chair with your feet shoulder-width apart and look straight ahead.

2. Hold onto the table or chair for support.

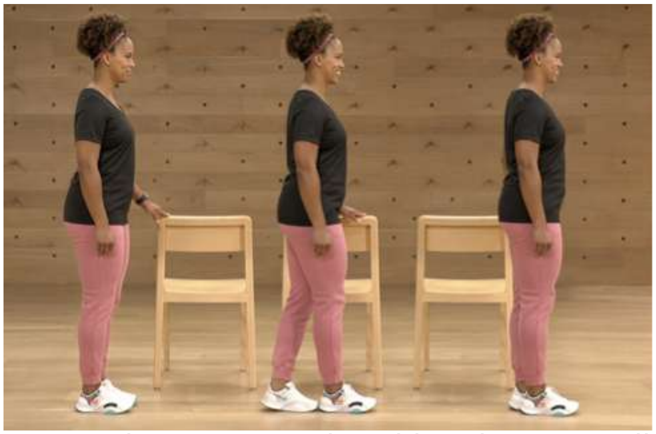
3. Keeping your legs straight, shift your weight to one leg and lift the other leg out to the side about 10–15 centimetres or as high as you can without tilting your hips.

4. Lower your leg back down.

Repeat 10 times with each leg.

As you get stronger and your balance improves, you can do the exercise without a table or chair.

Heel-Toe Walking



1. Stand near a sturdy table, chair or wall with your feet shoulder-width apart and look straight ahead.
2. Hold on to the table, chair or wall for support.
3. Place one foot directly in front of the other, heel to toe, to form a straight line, as if you're walking on a tightrope.
4. Step forward, placing the back foot in front in the same way, heel to toe.
5. Continue for 10 steps.

Turn round and repeat 10 times.

Walking and Turning Round

1. Stand with your feet shoulder-width apart and look straight ahead.
2. Walk at your regular pace for 10 steps.

3. Turn round clockwise.
4. Walk back to your starting position.
5. Turn round anticlockwise.

Repeat 10 times.

As you walk and turn, your path should create a figure of eight.

All exercises are to be done under supervision.

How can I improve my walking with MS?

Exercises that improve muscle strength and balance can help boost your ability to walk with MS. If you experience numbness, a mobility aid, such as a cane might be useful. Stretching, exercise, and medication can help manage muscle tightness and spasms and might be useful for balance. Finally, mobility devices and adjustments around the home, such as ramps, can help manage a fear of falling. While you may feel that using a mobility device means you have "given in," it actually allows you to get out in the community and participate in life events you may otherwise miss out on.

Can you improve your ability to walk with MS?

MS usually follows a pattern of flares and remission. While you may have difficulty walking during a flare, you may find you are able to walk again during times of remission. Physical therapy can help you maintain your walking ability and may help regain it when you think it is lost.

Why do people with MS struggle to walk?

Various features of MS can make it hard to walk. They include muscle weakness, muscle tightness and spasms, problems with balance, and the fear of falling itself. Doing exercises can help you boost your confidence and maintain your strength and flexibility for walking.

MANAGING MS OFTEN INVOLVES TWO DIFFERENT APPROACHES:

symptomatic treatments – to manage the individual symptoms of MS
disease modifying drugs – to treat the underlying condition.
This section focuses on the different options for treating MS symptoms.

Learning to manage your symptoms takes time and you may need to try several options to find out what works best for you. Reading up about the different options can be helpful, so you can talk them through with your GP or MS team.

Treatment for MS may include medication, therapies, such as physiotherapy, and self-management techniques. Some people explore the use of complementary or alternative medicines (CAMs).

There are also disease modifying drugs (known as DMDs or DMTs) which can reduce the number and impact of relapses and reduce the build-up of disability which can occur if you don't recover completely from relapses. Most DMDs are for people with relapsing remitting MS (RRMS), but there are some that are licenced for use by people with progressive MS. MS Decisions, our interactive decision aid can help if you are considering a DMD.

Treating MS symptoms

What are symptomatic treatments?

Symptomatic treatments help relieve the physical or mental symptoms of a condition. They don't treat the underlying cause, or change the course of the condition. There's a wide range of treatments which are used to manage MS symptoms, they include:

drug treatments–such as medication for pain or spasticity

therapies–like physiotherapy to help with muscle stiffness, or cognitive behavioural therapy for pain, anxiety or depression

management techniques – for example learning to pace yourself to minimise fatigue

rehabilitation–which can improve day-to-day living. Depending on your needs, this might include services such as physiotherapy, speech and language therapy, cognitive rehabilitation therapy or an occupational therapist may give you aids or equipment that can help

complementary & alternative medicines–this includes treatments such as acupuncture, Pilates and mindfulness which fall outside conventional medicine, but are recognised as being helpful in improving physical and mental wellbeing.

There's a wide range of possible treatments so we will point you to the relevant resources for more detailed information. You may prefer to focus on information about the symptoms that are troubling you now. It can be a bit overwhelming to read about all the possible symptoms of MS. Not everyone experiences all of them so you might like to leave aside information that is not relevant to you.

What are my treatment options?

Treatments are available for the symptoms of MS regardless of whether you have relapsing remitting MS or progressive MS. Often people with progressive MS are under the impression that there aren't any treatments for them.

Your options will depend on what symptoms you're experiencing, how much they're affecting your day-to-day life and sometimes what specialist services are available in your area.

Conventional treatments

In this section you'll find a brief overview of some of the typical symptoms seen in MS and the most common conventional approaches to their treatment. This might include drug treatments, therapies, rehabilitation strategies or management techniques.

Here are some common observations about MS fatigue:

- Tends to worsen as the day progresses
- Appears more easily and suddenly than 'ordinary' fatigue
- Is generally more severe than 'ordinary' fatigue
- Tends to be aggravated by heat and humidity
- Is more likely to interfere with daily activities than 'ordinary' fatigue

Fatigue

Learning strategies such as focusing on the tasks which are most important to you and how to carry them out in the most efficient way, can be helpful. These can be taught by a physiotherapist and/or occupational therapist. The drug treatment amantadine helps some people with mild to moderate fatigue, but medication usually isn't a solution on its own and is usually combined with techniques such as pacing, prioritising and breaking down tasks.

Pain

Treatment depends on the type of pain. Muscular or joint pain can be treated with painkillers such as paracetamol or ibuprofen. The drugs used for nerve pain include amitriptyline (Triptafen), gabapentin (Neurontin) and pregabalin (Lyrica). Physiotherapy can help some pain. Often the best results are seen with a combination of drug treatment and physiotherapy.

Eye problems

Treatment varies depending on the issue. Occasionally, steroids are used for optic neuritis. For double vision, patches or prisms on glasses are tried first, but botulinum toxin (Botox) may be used in more severe cases. Gabapentin may be prescribed for persistent nystagmus to reduce the twitches.

Cognitive problems

There aren't any drug treatments which are routinely used for memory and thinking problems in MS. A neuropsychologist, speech and language therapist or occupational therapist can teach you compensatory strategies to help work around your issues, this is known as cognitive rehabilitation therapy.

Bladder Issues

If you have problems with storing urine, such as needing to go to the toilet urgently or frequently, there are medicines that can help such as oxybutynin (Ditropan, Oxyspas) or tolterodine. Bladder training with the support of a continence specialist can help you increase the length of time between toilet trips. In more severe cases, where standard drugs haven't helped, botulinum toxin may be injected into the bladder wall. Another option to reduce symptoms of an overactive bladder, if you don't want to try botulinum toxin, is nerve stimulation.

If you have problems emptying your bladder (hesitancy) one option is to try using a catheter. A bladder scan after you've been to the toilet can help establish if your bladder is emptying completely. Holding a vibrating device over the pubic area can help relax the valve at the base of the bladder to improve emptying.

Bowel Issues

If you are constipated, there are a variety of laxatives or stool softeners that can be tried, such as ispaghula, lactulose syrup and docusate. Some people find that abdominal massage can help with constipation, this can be taught by a continence advisor.

If you have trouble controlling when your bowels open, a physiotherapist or continence advisor can suggest exercises to strengthen the muscles around your anus. There are also products available if bowel accidents are an issue. Some specialist centres offer biofeedback training where you're given help to retrain your bowel, advice on dietary changes that could help and psychological support.

Spasticity

Drug treatments which can be tried include baclofen, carbamazepine (Tegretol), gabapentin and botulinum toxin. Occupational therapists and physiotherapists can also offer support to help manage spasticity, this might include stretching exercises or advice on posture/positioning when you're sitting down or lying in bed, to make you more comfortable.

Sexual difficulties

Can occur in men and women. If MS causes erectile dysfunction, treatments such as sildenafil citrate (Viagra) and tadalafil (Cialis) are available. Talking therapies can be a good option if you're experiencing difficulties such as loss of desire, changes in sensation or you're struggling with self-esteem.

Walking problems

A physiotherapist or occupational therapist can support you with walking difficulties. The drug fampridine has been shown to increase walking speed in some people with MS, regrettably it's not always available. If you experience foot drop you may find that functional electrical stimulation (FES) helps, although results could be mixed.

The naming of drugs

You may have noticed that drugs often have more than one name. All drugs have a generic name, which is the official medical name for the active ingredient in the drug. They may also have a brand name, the trade name given by the manufacturer. Brand names always begin with a capital letter, whereas generic names don't.

Sometimes a drug is more commonly known by its generic name, for example gabapentin used for neuropathic pain; whilst others are better known by their brand name, like Viagra for erectile dysfunction. If a drug is produced by more than one manufacturer there can be more than one brand name for the same medication.

Complementary and alternative approaches

Complementary and alternative approaches (CAMs) are often talked about as being the same thing, but there is a distinction between the two.

A treatment is said to be 'complementary' when a non-mainstream approach is used alongside conventional medicine. An example would be having acupuncture sessions alongside taking prescription medication for pain.

If the non-mainstream approach is taken instead of a conventional approach, then the treatment would be considered 'alternative'. An example of this would be taking a homeopathic medicine rather than a conventional drug treatment.

There is of course some degree of overlap and many treatments can sit in both categories, for example osteopathy (the manipulation, stretching and massage of your muscles and joints) is used as a complementary treatment in some situations, but may be used on its own as an alternative therapy in others.

The following are a few of the complementary and alternative approaches that are commonly used in MS.

Diet

Several diets have been advised as being beneficial for MS, but none have been shown to work for everyone. Following a healthy diet benefits everyone, but it can be especially important in MS.

Maintaining a healthy weight can help with symptoms, such as fatigue and pain, by maintaining energy levels and avoiding putting excess weight on joints. Ensuring you're getting enough fluid and fibre in your diet can help combat bladder and bowel issues. It's also essential to help maintain a healthy heart as high blood pressure and heart disease can also impact on MS.

Exercise

There's lots of evidence that exercise can help with MS symptoms and benefit both your physical and mental well being. This might be something gentle like yoga, Pilates or Tai Chi which focus on flexibility, strength and balance; or it may be something more energetic or cardiovascular-based such as swimming, running or dancing. Exercise can help you maintain a healthy weight, improve mobility and also give your mental health a boost.

Relaxation techniques

Practices such as breathing exercises, meditation or mindfulness can be helpful if you're feeling under pressure or experiencing anxiety, low mood or depression. They can also be a distraction from symptoms such as pain and spasticity. Aromatherapy, reflexology and massage may also help.

If you're considering using CAM approaches, as well as considering the potential benefits, it's important to think about both the potential costs involved and any possible risks. Some alternative medicines can interact with prescription medicines. Some drugs that people use for depression can cause problems if used with some prescription depression medication and also reduces the effectiveness of contraceptive pills. Alternative medicines typically shouldn't be used if you're pregnant. It's best to have a discussion with a health professional if you're considering trying a CAM.

When should I seek treatment?

It can be difficult to know when to seek treatment and when to sit things out, especially if you're still learning about your MS. There are a few things you can look out for which may explain why your symptoms are worse at the moment.

Do you have an infection such as a cold, flu, tummy bug or a bladder infection? If so, this can cause a flare up of symptoms. Your symptoms will improve as you recover from the infection so you should look after yourself in the usual way for a cold, flu or tummy bug, or visit your GP to see if you need antibiotics for a bladder infection.

Are you too hot? Many people with MS are sensitive to heat. You may find that hot weather makes your symptoms worse and the same can happen if the central heating is too high. Do what you can to get cool and symptoms should improve.

Are you too cold? Some people find that being too cold makes their symptoms flare up although this is not as common as heat sensitivity.

Are you feeling under pressure? Stress can make your symptoms harder to live with and, for this reason, finding a technique that makes you feel more in control can be helpful.

When to seek support from a health professional is a personal decision. However, if none of the above apply, or your symptoms don't improve after a few days, you might want to consider getting support from your GP or MS team.

If you have new symptoms, your symptoms are suddenly much worse, or if you are having serious difficulty walking it's probably worth contacting your MS nurse straight away – especially if you experience relapses.

Sometimes symptoms creep up on you and suddenly a slow, gradual worsening over months or years might add up to a big change you can't ignore. You should have your MS reviewed about once a year but, if this isn't happening or your appointment is a long way off, you can ask for a review.

If your symptoms are worrying you, interfering with your quality of life, or impacting negatively on family or friends – don't suffer in silence.

Remember, new symptoms may not be due to MS, so speak to your GP or MS team if you're concerned. Also, make sure you keep up with any vaccinations, or health screening for conditions such as diabetes, high blood pressure or cancer, where appropriate

One more day with MS: . #InvisibleSymptoms

I do not look sick, but I live with an intense, deep exhaustion that makes every moment feel like I am moving to the bottom of the ocean, this pain, this struggle is real. Every day I wake up excited to achieve something new, my heart surges with optimism. At times, I forget about my MS and the pain it causes. Yet I rise every time, cheerful despite the fears and tears. This fatigue has taught me to appreciate the smallest of joys. More than 1 year has passed with this uncomfortable feeling, anxiousness, nausea, dizziness and yet I stand tall and not ready to fall.

Do you remember a time, when you were sitting and suddenly, your foot fell asleep? Now imagine living with that feeling every minute of the day, and not just in your legs but arms, legs, hands, face. Delirium is real. Muscle spasms is not a joke, a constant Charlie horse in the legs or at times any muscle is affected. Mood swings are real, and we patients, have them more than we do admit or you may imagine. Talking about fatigue, imagine someone who has hiked 20 miles up a steep hill after two days of no sleep while carrying a backpack loaded with rocks on the hottest day of the decade, yes that is fatigue. Its that moment when our legs can no longer hold us up and every muscle, bone, and even eyelids hurt. Then as soon as we sit down or more likely to fall, we are asleep. Now even if a tornado blows us up, we would sleep in the middle of it. Yes, we experience pain. Lots of it too. It is not pain like when someone is stepping on our foot. We are in pain because our nerves are misfiring and sending incorrect signals to our brain and just in case you were wondering, Tylenol does not help. If I could just stop the communication process, not the pain. Sadly, MS pain never gives us a day off or allows for a time-out.

Although, I never planned or asked for this journey, but now I choose to love and embrace life and fight this disease. Every time MS tries to knock me down, I will come back stronger. Anything, stresses or worries me, my body rebels any symptoms flares up just for the fun of it. If you ever see any MS patient, just do not roll your eyes and sigh with disbelief, because yes, this pain is real, the symptoms are real. Yet I am here, writing this. Underneath this MS monster, it is me and I am a fighter and nothing will ever take that away.

Hello! Tring Tring!

MSSI Delhi prides itself on its personal contacts with many of its PwMS. There are many ways in which we keep in touch with them and keep ourselves updated about their health and welfare, about their emotional and mental state of mind and above all we work towards giving them the confidence that we are standing with them, always.

There are many ways in which we maintain constant contact with them.

Video Calls to Members: Video Calls to our MS Persons started during Covid as an option to personal visits. It was our way of keeping in touch with them and being updated about their welfare and health issues. We got an immediate positive response as people were feeling isolated, confused and depressed.

We were already conducting regular telephonic counselling calls even before Covid, but the number of calls during and after Covid increased exponentially. Seeing the very positive response from our members we made this into a regular feature and now we are using this method to get in touch with our members on a daily basis.

Video Calls to new members: Our membership is rising steadily, and everyday many new MSP's join the organisation. They are confused & anxious and need information about the disease and its ramifications. The first call to them goes out through Bipasha Gupta. She understands their fears and their queries. Most of these initial calls last between 35-45 minutes, since everyone has so many questions! Many years of experience in dealing with their fears and concerns of new members she helps in answering all their questions.

The biggest positive aspect of these calls is the fact that they understand that there are many more like them and that doctors and medical help is available to them. The families understand that there is an organisation which will be able to guide them and help them.

Regular calls to members: Apart from the new members, regular video or audio calls are also made to our members who may have questions or just feel like talking. Meenakshi Bhujwala and Bipasha Gupta, our two stalwarts are the experts in this field. They know the answers to almost all the questions, since they have a close connection with MS within their family.

After more than 25 years of being associated with MSSI, the doctors know them and trust that they will give appropriate guidance . The patients know that they are the go-to persons to connect with doctors. Often just talking to these two ladies is good enough to make them feel better. It sounds so easy – doesn't it? But we must realise that these calls take up a lot of their time, and often our MSP's or their families do not realise that the time is not right or that our counsellors are busy with something else. It requires patience, knowledge and empathy. But it also produces good results in providing peace of mind, confidence and a belief that support systems do exist!

Birthday wishes: Our ebullient and enthusiastic volunteer and PwMS Shalini Monga makes at least six to eight video calls every day to wish our members a very Happy Birthday. She chats with them and shares the news about the organisation. They all love her calls and look forward to hearing from her. She recognises all the members and at our functions is one of our most popular members. It is amazing how just a single call to wish you a Happy Birthday can brighten up the day. We are sure all of you must have received a cheerful & colourful birthday greeting card on your special day. Our Managing Committee member Pinky Hora personally writes over 50-60 personally signed Birthday greeting cards which are posted to our MS members.

THINKING AND MEMORY PROBLEMS

Thinking and memory problems, also known as cognitive problems, are common in MS. Issues include memory, attention span, planning, decision making, understanding or concentration.

Problems with thinking and memory affect around half of all people with MS. Cognition is the medical term for thinking, and problems with thought and memory are known as cognitive problems. Strategies to compensate for cognitive problems and exercises to train your brain can all help.

You might experience issues with your memory, attention span, planning, decision making, understanding or concentration. Many people with MS talk about 'brain fog' or 'cog-fog' to refer to a sense that their thinking processes are sometimes not as organised or reliable as they used to be before they had MS.

Cognitive problems are often caused directly by MS although they may be the side effect of medication. Other MS symptoms such as fatigue, anxiety, or depression can make your cognitive issues worse. Cognitive problems are not the same thing as dementia.

For most people their cognitive symptoms are relatively mild and can fluctuate from day to day. Initially, you may not recognise them as an aspect of your MS and put them down to other reasons such as stress, overwork, tiredness or just getting older.

Living with cognitive problems

Problems with thinking or memory might sound trivial, but they can have a big impact on the day-to-day experience of living with MS. It can be frustrating to find that your cognitive issues go un-noticed by those around you. Your experience might not look as bad to the outside world as it feels to you. Other people don't see the extra, invisible effort you are putting in to get the same result.

You may need to explain your cognitive symptoms to friends, family or work colleagues in order to get understanding or appropriate support. It is worth remembering that in most cases you have not lost the skills you used to have, they just take a little longer to express. With the right support and plans in place you can continue to do things as you choose.

The longer you have had MS the more likely cognitive problems are to occur. Research suggests that cognitive symptoms usually stay the same over several years, or only very gradually worsen. You have time to develop strategies to compensate for any difficulties, or train your brain to slow down any cognitive decline.

What causes cognitive problems?

Cognitive problems in MS are the result of nerve damage in the brain interrupting the transmission of electrical messages, reducing the speed and accuracy of the information. It can be helpful to think of the nervous system as a telephone exchange - if the insulation on some of the wires is damaged and other wires are broken, this results in some wrong numbers and some calls not getting through at all.

Cognitive problems can be made worse by:

fatigue or poor sleep - which slows everything down. Try to pace yourself and plan demanding activities for times when you've got the most energy
physical effort - if you have difficulties with your balance or your mobility you may find that you need to concentrate more when you are moving about to ensure you don't fall. This means you have less capacity to concentrate on other things, such as carrying on a conversation at the same time as walking. Try and balance physical and cognitive activities so you only have to concentrate on one thing at a time emotions - stress, anxiety and depression can all impact on cognition. They can also be difficult to distinguish from other MS symptoms. Proper assessment by a psychologist may help in this situation.

infections - and other illnesses can worsen cognitive problems

medications - including some that are commonly used to treat MS symptoms such as bladder problems, spasticity and pain. A GP, pharmacist or MS nurse can advise on the likely effects of all medications

other things that generally worsen symptoms - such as heat, or tense or exciting situations. Try to stay cool in hot weather, or use relaxation techniques to cope.

What are the most common cognitive problems?

Memory

You may find that your memory isn't as good as it used to be. Usually memory problems in MS revolve around difficulties remembering recent events or information and forgetting to carry out plans. Diaries, smartphones or notice boards are useful tools to record information and act as reminders. Have a set place to keep things like your keys and glasses to make it easier to find them and stay organised.

Word finding

Do you feel like a word is 'on the tip of your tongue' but you can't quite recall it? This is a common problem, even for people without MS. It can be helpful to try and describe the word you are struggling with in other terms, for example 'the building with teachers and children' could be used to describe 'a school'.

Concentration and attention

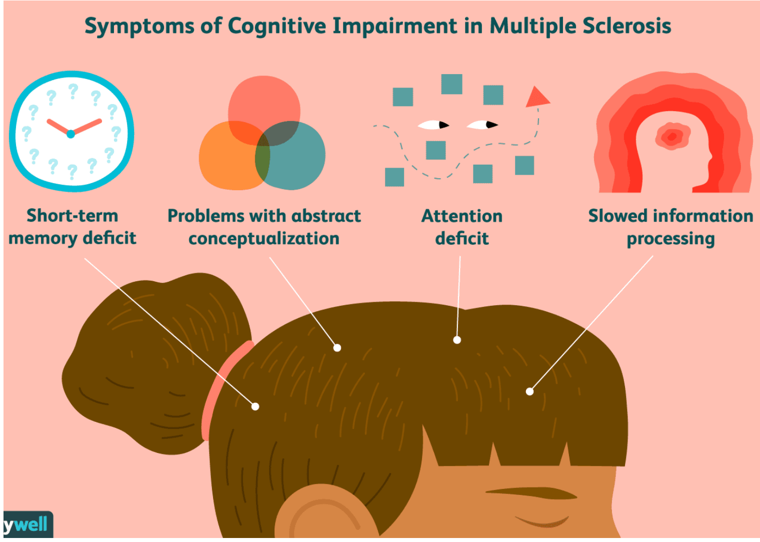
You may find it difficult to concentrate or find your mind wanders, particularly if lots of people are talking at once. This can make it harder to follow the thread of a conversation or give you a feeling of 'information overload' if only some of what you are being told is relevant. Try to reduce distractions such as turning the TV off before making a phone call, or dividing large tasks into more manageable chunks.

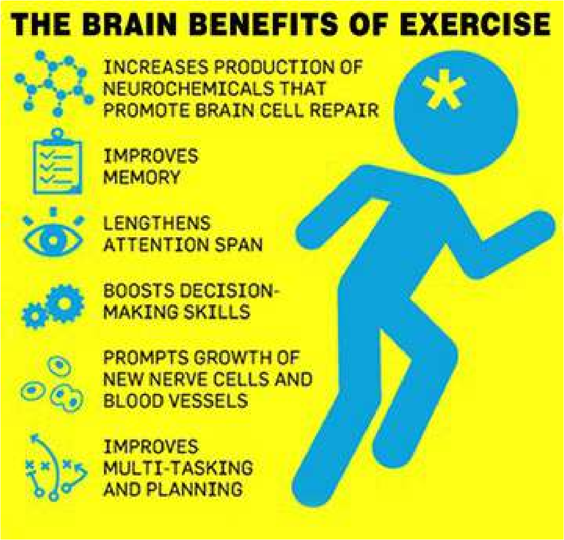
Information processing

This is when you experience difficulties with following a series of complex instructions. This can particularly be a problem if information is given rapidly. Reducing distractions and trying to avoid interruptions can help.

Visuospatial abilities

This refers to the way you relate to visual information, for example accurately judging speed and distance when driving, or judging where things are in relation to the space around you. It is the skill you use when you walk through a door rather than bumping into the door frame, or when you use a map to find your way somewhere. You might need to slow down and concentrate on moving around, or enlist a sat-nav to guide your journeys.





Planning and problem solving

Planning and solving problems are known as 'executive skills', and these may be impaired. It can be harder to see how your actions or decisions may affect you beyond the immediate future. This means that your decisions may not be as sound as they used to be. If your executive skills are affected it can be more difficult to manage your day, or even your healthcare.

Often, it is a family member or friend who picks up on this kind of issue before you recognise it yourself. It can be helpful to get another person's insight and talk through the implications before you make any important decisions.

How can I manage my cognitive problems?

I have a notebook that has lots of tabs, says Karan, one for each area of work I look after. This makes me look like Mr. Efficient, however the reality is it keeps me in check, as I can refer back more easily and the act of writing triggers my memory.

Compensatory strategies

Managing cognitive symptoms often involves finding strategies that work for you to minimise the effects of your symptoms.

Establishing a fixed routine-keeping things in the same place, or doing things in a certain order using verbal tricks to help you remember things-visual and verbal associations may be helpful-for example picturing your friend Raj Kumar as 'the man with a crown on', or putting meaningful tags onto words or names such as Simran the lady who works in the library using diaries or smartphones for reminders, planning or memory prompts, prioritising tasks to focus on one thing at a time and removing distractions where possible, for example sitting in a quieter part of the office or turning the TV down.

Breaking down longer tasks into more manageable chunks and carrying them out over a few days. Avoid doing things when you are tired or anxious so you have more chance of staying focused.

If your cognitive problems are worsened by your other MS symptoms, getting those symptoms treated can help. For example, if heat is an issue, using cooling therapies such as fans or air conditioning can be helpful. Equally, managing symptoms such as stress and anxiety can help. You could try these techniques:

- guided relaxation
- aromatherapy
- breathing exercises
- mindfulness
- meditation
- yoga

Boost your cognitive reserve

Cognitive reserve is the brain's ability to use its nerve pathways more efficiently or to find alternative pathways if the usual ones are damaged.

MS

Can affect cognitive function. Aka:

"Brain Fog"

This can include bouts of confusion, memory loss, lack of concentration, information processing, word-finding difficulties, & more!

Everyone's brain is different. Intelligence, experience and education contribute to your cognitive reserve, and people with higher cognitive reserve have more of a buffer against cognitive difficulties. The stronger and more resilient your brain, the more you will be able to cope with MS damage.

However, cognitive reserve is a moving target, not a fixed deal. You can build or maintain your cognitive reserve once diagnosed with MS. Keep your brain active and healthy as far as you can. Keep up your hobbies, even if they begin to get tricky, and find brain games, puzzles or crosswords that you enjoy. Reading, writing and physical exercise has also been shown to help reduce brain volume decline and cognitive decline.

Cognitive rehabilitation

If something is difficult, we tend to avoid doing it. This is likely to result in a decline in ability as we get out of practice at that task. Cognitive rehabilitation involves strengthening brain function and retraining neural pathways using a series of challenging exercises.

This approach used to be reserved for the most severe cases of cognitive decline. Cognitive rehabilitation is now recognised as being effective earlier on in MS as well, where previously you might have been advised to simply take the strategic approach to managing the situation. Cognitive rehabilitation works best if the exercises you do are properly tailored to match the situations you have trouble with.

Practicing well-designed cognitive exercises produces improvement, at least in test situations. Real world improvements are harder to prove, but verbal memory, working memory, information processing speed and phonetic fluency (language) can be improved with cognitive rehabilitation. Physical exercise has been shown to increase brain volume and connectivity.

For some people, cognitive problems can become more serious. They may not be aware of the true extent of their difficulties and more help may be needed than the above strategies. If this is the case, referral to a neuropsychologist can be helpful. A speech and language therapist or occupational therapist may also be involved. Rehabilitation professionals may be able to help strengthen impaired function. For the most severe cases, cognitive rehabilitation may be of benefit - this is the use of a structured set of activities designed to retrain an individual's ability to use their judgement and make decisions.

Medicines

There are no drugs that are specifically prescribed for the treatment of cognitive problems in MS. A small study looking at the effects of Ayurveda or herbal medicines like gingko biloba supplements in people with MS showed some improvements in concentration aAnd memory, but it didn't provide enough evidence to show it has a definite effect and further research is needed. A recent study found positive effects of simvastatin on brain volume, brain frontal lobe function and quality of life, and further investigations are underway to see if simvastatin could be a useful treatment in SPMS.

Fingolimod and the beta interferons have been investigated to see if they protect against brain volume loss and cognitive problems in RRMS. Fingolimod appeared to have a greater effect than beta interferon, but people taking these drugs may have been at different starting points in terms of their brain health. One big difficulty with interpreting the results of studies like this is the interaction of depression and quality of life with cognitive issues.

Who can help?

Your Neurologist should be the first port of call if cognitive issues are making life difficult. They can suggest strategies that might help and if appropriate make referrals for further help from an occupational therapist, a speech and language therapist, neuropsychologist or cognitive rehabilitation professional. MSSI can also make referrals if required.

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.[2] Chronic conditions can affect both physical and mental health. And the list of chronic diseases is long-: 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

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.

Learn about your health problem

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 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.[5] nd 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 work arounds : 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 league. 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 a fundraiser. 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.

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."

TELLING PEOPLE YOU HAVE MS.

Telling people that you have MS can be difficult. Accepting the diagnosis yourself is hard, let alone sharing the news with others. Being able to talk about being diagnosed with MS can take courage, but it can be helpful too. If people understand MS and the issues you are dealing with, they are much likely to be much more supportive and understanding. When you are considering talking to others about your MS, remember that everyone is different. Everyone you talk to has a different relationship with you, may want or need different information about MS, and may react in different ways to your news. You must decide, based upon how well you know them, as how much you should discuss with them.

Who to tell?

Spouses and potential spouses:

If you are planning to get married, it is ethically and morally correct to inform your potential partner about your MS. This will not be easy to do, but their response will give you a good idea of how you will live your future life together.

Do not begin a life together with secrets, begin it with sharing your thoughts and issues, and thus establish a comradeship which is important for your future life. If the person is right for you, they are likely to be supportive. If they aren't, then perhaps they weren't ready or right for you anyway.

If you are already married, then your MS will change their life too. This can be worrying for both of you, and you will need to support each other. Make sure you give your partner time to absorb the information and remember to keep communicating about it over time. As with all issues that affect couples during their relationship, communication and understanding are important.

Parents and in-laws:

Disclosing your MS to your family, who may have known something was wrong anyway, can help to begin the coping process. Grief and worry are normal emotions for family members to feel when someone they love has news about their health. Parents in particular worry about their children, even after they have grown up.

In India the relationship with in-laws is often fraught with issues and an MS diagnosis can make the situation even more complicated. You need to make them understand above all that you will need their support and encouragement, and that as family members they need to understand the whys and wherefores of MS.

You and your partner must make them a part of the healing process and share your thoughts about the future with them.

Your children

How to explain MS to your children can be worrying, but you are the best judge of how, when and what to tell your child about your MS. Children are naturally likely to have questions, feelings and worries about the impact of MS on you and your family, and it is a good idea to encourage them to share these with you. It may be important to explain, for example, that MS is not contagious. It is just as important to make them understand the fatigue /deterioration/mood changes etc., all of which are a part of MS.

Friends

It may be a good idea to start with your closest friends and with those that you feel most comfortable with. With time and practice, you'll be able to decide how much you want to share and with which friends. A change in someone's health can be a challenge to friendships, especially if symptoms such as fatigue affect a person's ability to take part in social activities, and many people with MS say that telling them helped them to identify their true friends.

Employers and colleagues

Disclosure at work can have a significant impact on your job security, employment options and career path. Before disclosing your MS in the workplace, learn about your rights and think carefully through the pros and cons of sharing this personal information. Many people say they have supportive employers and colleagues, but this is not always the case.

How will they react?

Each person will react differently to what you tell them, so be prepared for a range of reactions. People may be shocked, fearful, calm, distressed or quiet. Some, like your children, may not really understand and will need time to digest what you are telling them. There may be days when they are not willing to adjust to your fatigue or your mobility issues, but you must have patience with them.

Others may go out of their way to help and sometimes this can be frustrating if it is not wanted. Some people may avoid you because they don’t know what to say. They don’t know how to deal with you having MS, so they choose not to discuss it, which can be difficult.

Some may think that you are not telling the truth since most MS symptoms are invisible. Your partner may have occasional uncooperative days but remember that he /she is also having to adjust to a changing scenario and is worried about the increase in their responsibilities.

Whatever a person’s reaction, talking about it with them can be helpful. This may be easier once you have come to terms with the diagnosis yourself, so talk to people when you really feel ready.

Jaya Elizabeth Mathew
India MS Person of the
Year 2023, Bangalore

My Beautiful Brain

I woke up one morning feeling weird
Something wrong with me I feared
My limbs that easily took to flight
That morning just didn't feel alright!

I tried to move and I tried to walk
Heavens above! I couldn't even talk
I soon realized this has a name
Multiple Sclerosis is the one to blame!

What followed after was fatigue and pain
Numbness and zingers that drove me insane
Mental fog and a cloudy vision
Needles, pricks and monthly infusion!

I soon realized that life's not going to be easy
And to win this battle one needs to be gutsy
Guts to keep loving yourself and chasing your dreams
Guts to make peace with MS, by all means!

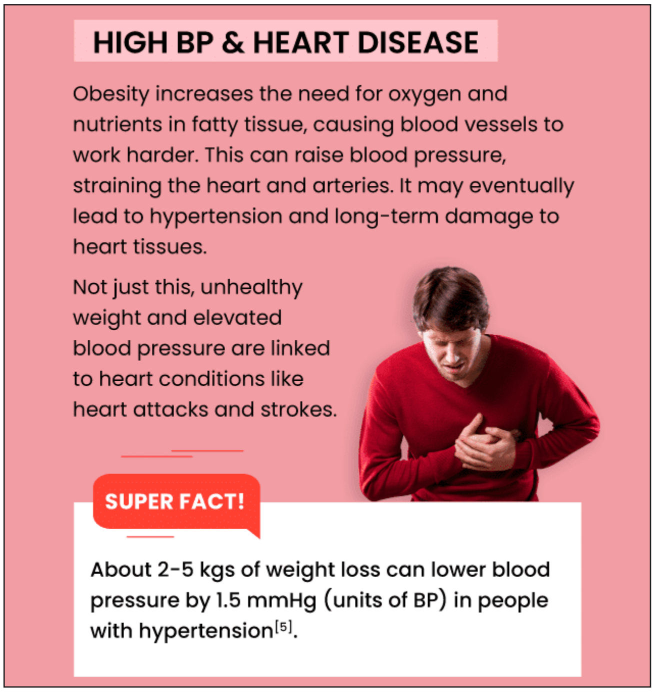
For life gives you the choice to love and hate
And the decision you take will settle your fate
To celebrate my beautiful brain is the decision I take
Scars it may have, but my spirit it can never break!

Size doesn't matter,

HEALTH DOES

Around 13.8% of Indian adults are affected with obesity[1]. If current trends persist, it's estimated that obesity will affect nearly 57% of the population in India[2]. **Contrary to popular belief, obesity isn't just about overeating. It's a complex condition influenced by factors like metabolism, diet, environment, and genetics.**

Obesity is not just a weight gain problem, it's a health concern that may need expert attention. Are you gaining weight but not sure if you are obese? Understand from an expert.



HIGH BP & HEART DISEASE

Obesity increases the need for oxygen and nutrients in fatty tissue, causing blood vessels to work harder. This can raise blood pressure, straining the heart and arteries. It may eventually lead to hypertension and long-term damage to heart tissues.

Not just this, unhealthy weight and elevated blood pressure are linked to heart conditions like heart attacks and strokes.

SUPER FACT!

About 2-5 kgs of weight loss can lower blood pressure by 1.5 mmHg (units of BP) in people with hypertension[5].

DIABETES

Almost 9 out of 10 people with type 2 diabetes are overweight or obese[3]. Being overweight or obese can mess up how your body uses insulin, leading to type 2 diabetes. When you carry extra weight, your cells become stubborn, resisting insulin's efforts to regulate your blood sugar.

SUPER FACT!

Shedding just 5% to 7% of your body weight can significantly lower your risk of developing type 2 diabetes[4].

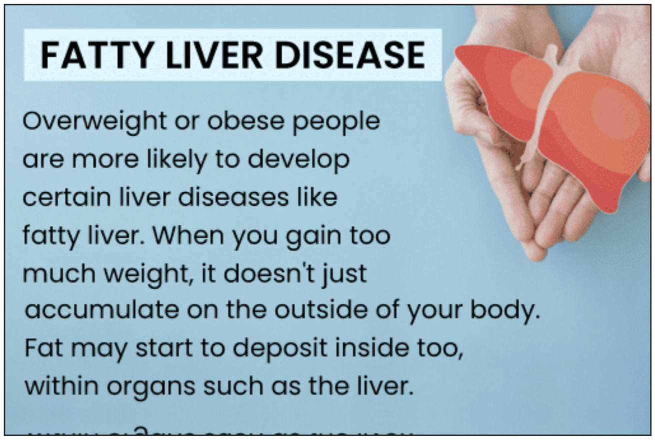
Obesity or just overweight?

Obesity is more often used interchangeably with overweight. Though there could be no specific symptoms of obesity or overweight, your Body Mass Index (BMI) can help demarcate both.

BMI is defined as a measure of a person's body fat as a result of the weight in relation to height. According to the World Health Organization (WHO):

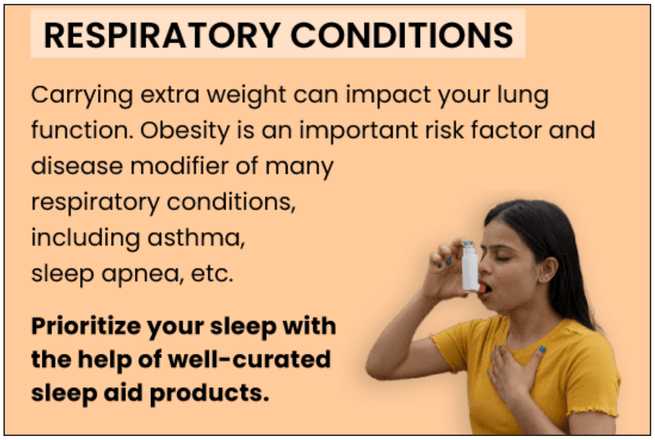
WEIGHT STATUS	BODY MASS INDEX, kg/m²
Normal	20 – 24.9
Overweight	25 – 29.9
Obese	30 or higher

Not sure if you are normal, obese or overweight?



FATTY LIVER DISEASE

Overweight or obese people are more likely to develop certain liver diseases like fatty liver. When you gain too much weight, it doesn't just accumulate on the outside of your body. Fat may start to deposit inside too, within organs such as the liver.



RESPIRATORY CONDITIONS

Carrying extra weight can impact your lung function. Obesity is an important risk factor and disease modifier of many respiratory conditions, including asthma, sleep apnea, etc.

Prioritize your sleep with the help of well-curated sleep aid products.

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.

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 and reduced risk of death from cardiovascular disease and 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:

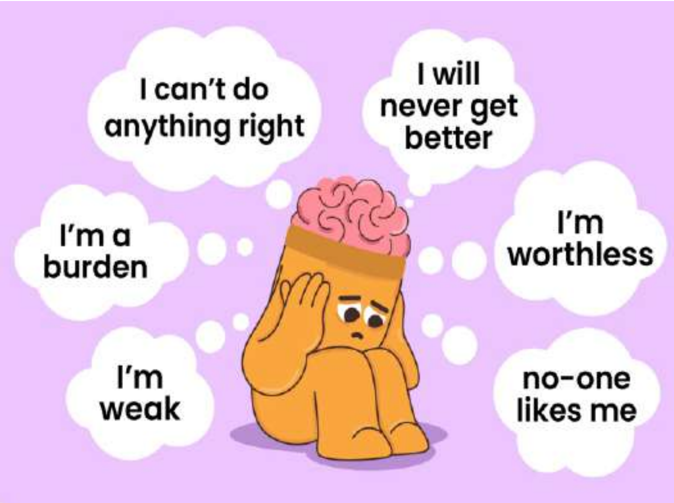
Putting positive thinking into practice

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.



DOES MS AFFECT MY LIFE CHOICES?

MS is often diagnosed when someone is in their 20s or 30s and is making some of the big life choices, like whether to follow a particular career path, settle down with someone or have children. If MS is diagnosed later, there may still be key decisions to make such as whether to financially support older children through university or change career.

There are many aspects of MS that may, or may not, affect your life choices. The symptoms you experience may affect decisions around your career or aspects of your lifestyle. There are also a wide range of disease modifying drugs available now to treat MS and these treatments may require you to consider future life choices too, such as timing around when to start a family and whether certain treatments will fit into your working life or around other personal commitments. Receiving a diagnosis of MS may also cause you to reflect on your lifestyle in general and you may start thinking about changes you could make to be healthier and stay as well as possible.

As everyone’s MS is different, it’s not possible to predict exactly how you’ll be affected and, consequently, whether this might mean significant changes to how you’d pictured your life would be. However, you’ll naturally need to review your life from time to time and choose the best option for you – just as we all do.

In the short term

Life doesn’t stop at diagnosis and it’s usually best not to make major decisions too soon. It’ll probably be too early to anticipate what life with MS might be like in the longer term. Like many things, MS may influence your life and the choices that you make along the way. Your friends, family and health professionals will all want to support you and will have their own opinions. Don’t feel pressured by others to decide something that you’re not ready for and, perhaps, may never need to decide.

Over the longer term

Your symptoms will vary from day to day and from year to year and this may take a bit of getting used to. If you do experience new symptoms, it’s important to let your MS team know. They can talk through treatment options to manage your individual symptoms and, if appropriate, disease modifying drugs to reduce future MS activity. You may need to make decisions around treatment which will influence your life choices, but these treatment decisions may improve your current and future daily life.

Many people periodically think about where their life is heading. For some people, diagnosis with MS, or experiencing new symptoms, prompts them to review their life and consider making changes. In the following sections, we offer some suggestions and highlight sources of information and support that may help you in making decisions for the future.

How can I make the best choices for me?

Making any choice in life is a very personal decision. There are many factors that can influence your choices, from your faith and spiritual views to your financial situation and family commitments. You may like to consult others and consider taking their views into account when making important decisions.

We aim to give you ideas, make suggestions and get you thinking. We can point you to sources of information that may help but *only you* can decide what you’d like to do in life and what’s possible in your particular circumstances.
Make the most of it.

What's important to you?

- What are the priorities in your life? This can include the people closest to you.
- What are your goals in the next few years? Write them down as simply as possible. Keep the list short- a top three or top five can be good.
- Where should you make a start? You can't do everything at once so you might begin with the most important or the most urgent goal.
- How can you get motivated and organised? Leaving things to chance is unlikely to get you to your target.
- How do you usually make decisions?
- Your usual approach to life may influence your choices.

Are you a risk taker or a more cautious person? Do you tend to carry on regardless?

- Do you usually make decisions on your own or do you like to get advice from others?
- Do you like to do some research and weigh up the pros and cons, or do you prefer to make decisions based on your gut instinct?
- Is your usual approach the one you'd like to adopt, or would it be better to go about making this decision in a different way?
- Is there an MS factor?

For some people, life with MS carries on much as before. For others, MS may have more of an impact and managing this well can make a big difference.

- Are symptoms affecting what you can do?

Has MS impacted, or made you more aware of, your mental health? Is this an area you'd like to focus on or consider more when making decisions?

- Are you still adjusting to a new treatment? Do you have any concerns, perhaps over possible side effects?
- Do you get fatigued, either mentally or physically? Are you pacing yourself well or trying to do too much?
- Would it help to negotiate some changes? This could be at work or college, in your family or social life, or in your leisure activities.
- Is there anything else you can do to help reduce the impact of your symptoms?

Getting the right balance

Although it can be good to set priorities or goals and then actively work towards them, many things in life are about getting the right balance.
You might like to think about the balances between:

-work and everything else in your life
-looking after others, like your family, and
 looking after yourself
-being busy and doing something relaxing
-taking care of your body and your mind
-being cautious and enjoying life.
-Working in partnership

We all have different priorities and only you can say what's most important to you. Your goal could be something big like a career change or something smaller like getting better sleep. You might like to get some further information or ideas.

Those around you can help you make decisions and offer you support to reach your goals. Involving your friends and family, talking to other people with MS and seeking advice from health professionals can all help you make the choices that are right for you and give you more control of your life.

You may want to sound out someone early on to see how they react to the possibility of a proposed change. That way you may get a good indication of what they think.

You may need to take their views into account if your life choice will have a significant impact on them too. Chatting it through to decide a way forward that works for all of you would be ideal but remember there may need to be compromises.

Your family and friends will naturally want the best for you but will have their own priorities, worries and pressures. You may need to explain clearly why making a particular change will make a difference to you and how you see it fitting in to all your lives. Listening is as important as expressing your own views. Keeping lines of communication open is key.

Health professionals

You may want to make some changes in how you manage your MS. These could be changes to lifestyle which may improve your overall health, getting better symptom management or adopting new ways of doing things so that you can achieve what's most important to you. Your MS team can help you.

Shared decision making is important. This is when you work with, and are supported by, health professionals to make decisions about treatment, based on the best possible information. There may be times when you'd like a lot of support in making decisions and others when you want to be more independent.

Of course, you're only one side of the equation. Some doctors and nurses are very willing to debate the most appropriate course of action. Others prefer to give clear-cut advice about what they think is right for you. Some take a more relaxed approach and leave certain decisions down to you once they've advised you on the options.

Decision making can feel more difficult if your health professional's approach doesn't quite match what you'd like in terms of guidance and support. If you feel like you need more direct guidance on the best choice for you, or if you'd like to explore more options than your health professional has presented, it's important to raise this with your MSSI support team so you can make an informed decision.

Each of you brings something significant to the conversation. Your health professional will have knowledge and experience in managing MS. You're the expert on your own values, expectations and priorities and only you know how your body is feeling. It's important that you state what's most important to you. Writing this down and taking it with you to your appointments can be helpful.

Family and friends

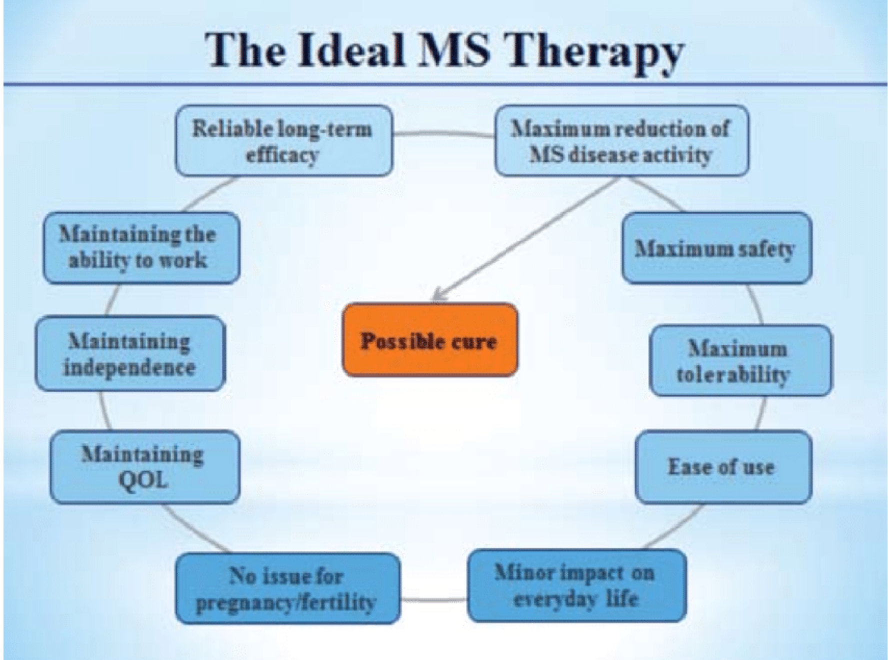
Any changes you make are likely to affect those around you, so you'll probably want to include them in your decision making. How much you involve them will depend on how close you are, how much you value their input and the nature of the choice you're making.

At work and in education

Work and education are important parts of many people's lives. Some people with MS may find that their symptoms have an impact on their ability to work or study, and you may need to decide whether to disclose your MS at work or in education.

Letting your employer or education provider know about your MS can open the discussion around adjustments that can be made to help you continue to work or study. This may include a dedicated parking space near the entrance to the office, more flexible working hours, or a desk in a cooler or quieter part of the office. In education this may mean extra time to complete assignments, having a quiet place to study, or studying part time instead.

Working with your employer or education provider, with the support of your health professionals, can help you find practical solutions that will enable you to continue to work and study, and fulfil your professional goals.



The Ideal MS Therapy

Reliable long-term efficacy

Maximum reduction of MS disease activity

Maximum safety

Maximum tolerability

Ease of use

Minor impact on everyday life

No issue for pregnancy/fertility

Maintaining QOL

Maintaining independence

Maintaining the ability to work

Possible cure

Many people with MS may worry about having to give up work or their studies in the future. Try to avoid making any big changes, like giving up work, soon after your diagnosis. Many people never experience symptoms severe enough to stop them working or studying. Take time to consider the future and make a decision at a time when your MS is stable and well managed.

Whether to stay in work, change your career path or leave the workplace should be your choice. You have options, and you do not need to feel under pressure from other people to make a change that you're not happy with. If you think you're under pressure to change your working life against your best interest, do seek legal advice, contact a HR representative or talk it over with a supportive colleague.

If you do decide to leave work or education, think about other activities you could do to keep connected to the working world and your peers. You may wish to volunteer for a charity or club, take up a new hobby or do some travelling. This can help you maintain your self-esteem, continue gaining skills and knowledge, and pursue your personal goals.

Professional advice

Sometimes the best course of action is to get professional advice so you're clear about your rights and responsibilities. Key areas where you may want to seek an opinion are on legal issues, housing, social care, benefits and finances.

You may need to pay for advice but there are organisations that may help free of charge. MSSI provides free, independent, confidential and impartial advice on a wide range of issues. It has a large network of local branches and community locations where you can talk to an advisor face to face. It also provides support over the phone, by email and through chats with a counselor.

There are organisations which support people with specific issues. The Disability Law supports people with a disability, their families and carers, who have legal issues including concerns about discrimination. MSSI provides free and confidential advice to employers, employees and their representatives on employment rights, best practice and policies including disability discrimination and reasonable adjustments.

MSSI can advise on adapting your home to make it more accessible. They can also guide you when buying or adapting equipment and computers to make them easier to use.

TREATMENTS FOR MS

There's currently no cure for multiple sclerosis (MS), but medicines and other treatments can help control the condition and ease some of the symptoms.

Treatment for MS depends on the stage of the disease and the specific symptoms the person has.

It may include:

- treating relapses of MS symptoms (with steroids)
- treating specific MS symptoms
- treatment to reduce the number of relapses (disease-modifying therapies)

You'll be supported by a team of different healthcare professionals working together.

This may include a neurologist (specialist in treating conditions of the nervous system), a physiotherapist, a speech and language therapist, and a number of other professionals.
Treatment for multiple sclerosis relapses
Contact your specialist or GP if you think you're having a relapse.

A flare-up of symptoms can sometimes be caused by something other than a relapse, such as an infection, so your Doctor needs to check for other possible causes.

Treatment for a relapse usually involves either:
A 5-day course of steroid tablets taken at home
Injections of steroid medicine given in hospital for 3 to 5 days
Steroids can help speed up your recovery from a relapse, but they don't prevent further relapses or stop MS getting worse over time.

They're only given for a short period of time to avoid possible steroid side effects, such as osteoporosis (weak bones), weight gain and diabetes, although some people will still experience problems. Not using steroids more than 3 times a year (if possible) will also help to reduce the risk of side effects.

Treatment for multiple sclerosis symptoms
MS can cause a range of symptoms that can be treated individually.

Fatigue
Many people with MS experience fatigue.
You may be prescribed a medicine called amantadine for fatigue caused by MS, although this may only have a limited effect.
You should also be given general advice on ways to manage fatigue, such as:

- regular exercise
- keeping healthy sleep patterns
- energy-saving techniques
- avoiding medicine that can worsen fatigue (including some painkillers)
- Specialist fatigue management courses or therapy, such as cognitive behavioural therapy (CBT), can also help some people with MS cope with their fatigue.

Your doctor may also look at whether anything else might be causing your fatigue, such as depression, trouble sleeping or a medical condition such as anaemia. They can then offer treatment, if needed.

Visual problems
MS-related visual problems will often improve on their own, usually within a few weeks, so you may not need any treatment. If your symptoms are particularly severe, you may be prescribed steroids to help speed up recovery.
If you have problems with involuntary eye movements, medicine such as gabapentin can sometimes help. Some people with double vision need help from ophthalmologists (eye specialists).

Muscle spasms and stiffness

Muscle spasms and stiffness (spasticity) can be improved with physiotherapy. Techniques like stretching exercises can help if your movement is restricted. If your muscle spasms are more severe, you may be prescribed a medicine that can relax your muscles.

This will usually be either baclofen or gabapentin . These medicines all have initial side effects, such as dizziness, weakness, nausea and diarrhoea, so discuss which of these would be best for you with your specialist.

Mobility problems:

Mobility problems or moving independently are often the result of muscle spasms and spasticity, but they can also be caused by muscle weakness, or problems with balance or dizziness.

If you have problems with mobility, you might benefit from:

an exercise programme supervised by a physiotherapist. Special exercises called vestibular rehabilitation if you have problems with balance medicine for dizziness or tremors mobility aids, such as a walking stick or occasionally a wheelchair. ome adaptations, such as stair lifts or railings will also help. An occupational therapist can carry out an assessment of your home and suggest adaptations that may be of help.

Neuropathic Pain:

Neuropathic pain is caused by damage to your nerves, and is usually sharp and stabbing. It can also occur in the form of extreme skin sensitivity or a burning sensation. This type of pain can be treated using medicines such as gabapentin or carbamazepine, or with a medicine called amitriptyline. This is an older type of antidepressant, but these days it's mainly used for pain control. Please consult your Doctor.

Musculoskeletal Pain

Living with MS can cause stresses and strains to the muscles and joints in your body. A physiotherapist may be able to help with this pain by suggesting exercise techniques or better seating positions. If your pain is more severe, you may be prescribed painkillers. Alternatively, you may have a device that stimulates your nerves called a transcutaneous electrical nerve stimulation (TENS) machine.

Problems with thinking, learning and memory

If you experience problems with thinking and memory, you may be referred to a neuropsychologist and an occupational therapist, who can help assess your problems and suggest ways to manage them.

Emotional problems

If you experience emotional outbursts, such as laughing or crying for no apparent reason, you should be assessed by a specialist like a clinical psychologist. They may suggest treatment with an antidepressant. Please consult your neurologist because these medicines could be habit forming.

Safety Tips

In addition to improving your steadiness, there are some other things you can do to reduce your risk of falling.

Proper clothing and shoes can help you avoid tripping. Either wear shorts or close-fitting trousers, and consider wearing supportive shoes with soles that don't flare too much.

To reduce the risk of tripping around your home, remove small rugs or mats and secure them with double-sided tape to keep them from moving. You can also install night lights if you need to get up at night to use the toilet.

Install sturdy grab bars beside toilets and baths and inside showers. Non- slip mats or adhesive strips in showers and baths can also help.

Why Walking Steadiness Goes Down

When walking steadiness drops quickly, it's usually due to MS. But when it declines over months or years, there could be many reasons and the exact cause may be more difficult to uncover.

Sometimes it may simply be due to the effects of ageing on our strength and ability to move. Age can also have an impact on the system in your inner ears that controls balance. It may even be due to the underlying condition, medication, vision loss or other factor. A doctor may be able to help if you can't identify an obvious cause.

Why You Should Pay Attention

Walking steadiness has a direct relationship with fall risk. As steadiness goes down, fall risk goes up. As MS increases, our chances of being injured in a fall increase dramatically and falls are the leading cause of traumatic brain injury and fractures in older adults.

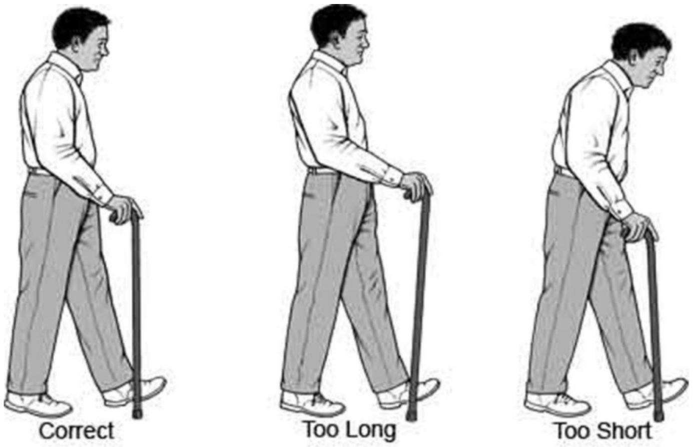
By tracking your walking steadiness and monitoring changes over time, you're able to see changes before they become pronounced. And the sooner you notice a problem, the sooner you can take steps to correct it.

Exercises That May Help

If your walking steadiness is OK, exercises that improve strength, balance and flexibility can help you maintain or improve your steadiness.

Tai Chi or yoga, for example.

If your walking steadiness is low or very low and you'd like to improve it, talk to your doctor, who may provide you with a set of strength and balance exercises tailored to you or refer you to an exercise programme shown to reduce fall risk. You may also receive guidance on how often you should do the exercises.



#MyMSStory-Ritu Batra

My name is Ritu - appropriately named by my wonderful parents, as I have been constantly changing like the seasons !

I had an exciting and loving childhood , somewhat spoilt by my parents.. I think it must have been because I was a really cute kid ?

I grew up in the cold and beautiful North Eastern state Arunachal where my dad was posted as an engineer with a government department. My mother used to dress me very nicely and I believe I was even picked up by our late Prime Minister Smt Indira Gandhi as a baby doll !

After my father was transferred back to New Delhi , I soon had company with a younger sister who was very different from me.I was calm and composed and she was very naughty.

I was a meritorious student , studying at prestigious schools of Delhi.

The years passed by fast - but it was actually a real fun time . We used to walk down to school as it was just a kilometer away, summer, winters rains with the raincoat and umbrella at times - we loved to splash in the puddles.

I enjoyed the competition with my cousin and my neighbour who were also in the same grade, there was a competition between three of us , but we were soon transferred to Ahmedabad. Life was very different there, My life went bizarre which made me feel as to what foreign land my parents have brought me to ! But it had a positive effect, and with slight boredom in my surroundings my interest in studies increased and competition with my neighbour continued.....School life was ok, we had friends from different backgrounds, more so army background. I secured a good percentage in boards and opted for Science as I wanted to become a doctor Unfortunately I could not crack the entrance exam as I feel now I just did not put in that much effort !

The result of senior secondary came in and the decision had to be made on which stream to pursue, I sure was not interested in doing simple physics or biology, medical had not happened, made me do a lot of thinking . Finally a friend advised me to take home science which had community resource management and extension as a major. I took her advice and believe you me , it was one of the best decisions I had made. Lots of different and interesting subjects which were fun to do.

With the start of my college life, I was a changed individual. Style had crept in, a variety of dresses matching shoes and purse had become my style. I in fact got a title of Ms Hot Shot, and college life was cool.

After doing my graduation I expressed the desire to do post graduation as well. There were restricted seats in Delhi.

God was kind and I worked hard , I got a seat on merit at Lady Irwin, Delhi University itself.

Life was fun, I studied a range of subjects from farm food production, psychology to child development I majored in resource management and extension, did my dissertation on assessing the water and sanitation status of four villages in Haryana. It was a thrilling experience, talking and sharing with villagers was a different experience altogether.

My first job was with a conglomerate of Australian Universities where I worked very hard and prove my mettle and then there was no looking back.

I soon got married to an entrepreneur , life was cool and cozy and years just flew. I was blessed with a cute baby boy Shivansh- He was a really cute & naughty fellow-I also managed to bag advertisements for him.

He advertised for Horlicks and a couple of other products. .
Life got very busy with the advent of a little one in my life - full time baby duties and of course family responsibilities. Days passed by and it was so nice to see the little one growing up. The responsibilities increased multi fold at the work front also.
Getting up by 7 am , handling the home, kids & the job was tough but I enjoyed every moment of it. Time passed and I became all the more settled in life, family chores, office. By the time Shivansh turned 4 and joined " big school", I was once again blessed with another little baby boy-and the previous routine started again.
This time I was experienced and more mature so was able to cope better with the varied demands on my time. ...

When my second child was 5, one day I had a tingling sensation on my left cheek which stayed for 2 days. It was a very irritating sensation, so when I went to a GP who referred me to a neurologist. This Doctor asked me to get an MRI done, it was then I found that I have some autoimmune disorder called multiple sclerosis. This was in 2008-yet none of us knew anything about it or had even heard of it before, I went to a neurologist who gave me medication and I was perfectly fine within 15 days.

Life moved on and I shuttled between my office home and my kids' school. It all felt like smooth sailing. I offer my gratitude to the Almighty that He gave me time till my kids were almost out of school.

I still remember it was in 2015 I got my next attack-my first optic neuritis attack. I was admitted for 5 days on intravenous steroids and then back to my battlefield of home & work. But this time things were not so simple- now doctors' visits and stories of medication started.
There would not have been a single alternate therapy I have left out. Magnets, acupuncture ,acupressure-Even went to Pandits and all , since I was now facing walking problems, Googled left right and centre and finally came to the conclusion that ultimately it is your own positive energy, yoga and meditation that can be of some help .

I just have one disappointment-When our country is working and leading on so many fronts, the one thing I fail to understand is why people like us facing some disabilities do not have jobs in the corporate sector.
Multiple Sclerosis may have its own pattern of physical limitations & disability, but the brain keeps ticking. I am confident that given an opportunity we can work very efficiently and contribute not only to the growth of our economy, but the confidence and joy of working really helps us live with dignity, face the world with confidence and self esteem.

Why can’t there be some reserved seats in the Government sector for Multiple Sclerosis persons?
Corporate social responsibility (CSR) is talked about, but where is it when it comes to jobs? Organisations feel by giving a small donation of a few lakhs a year to NGOs they can fulfill their CSR obligations !
I am a post graduate with over 15 years of corporate experience, but today I sometimes feel dejected and depressed . I am just awaiting some policy where I can get re-inducted in the job stream, that will keep me busy and divert me from thinking about my disorder.

I want to live a quality life and not brood over my condition! I think I deserve it .. don't you ?

Ritu Batra
PwMS - Delhi Chapter

MEETINGS & AGM 2023-24

SEMINARS & MEETINGS

WINNING ACCOLADES - CREATING AWARENESS

TOUCHING LIVES WITH OUR PROJECTS

In the treatment of RRMS

℞ **Deno**

Teriflunomide 14 mg Tablets

Designed

Teriflunomide vs IFN

ARR

34% **in treatment naive patients**

34% **in previously treated patients**

41% **in recently treated patients**

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

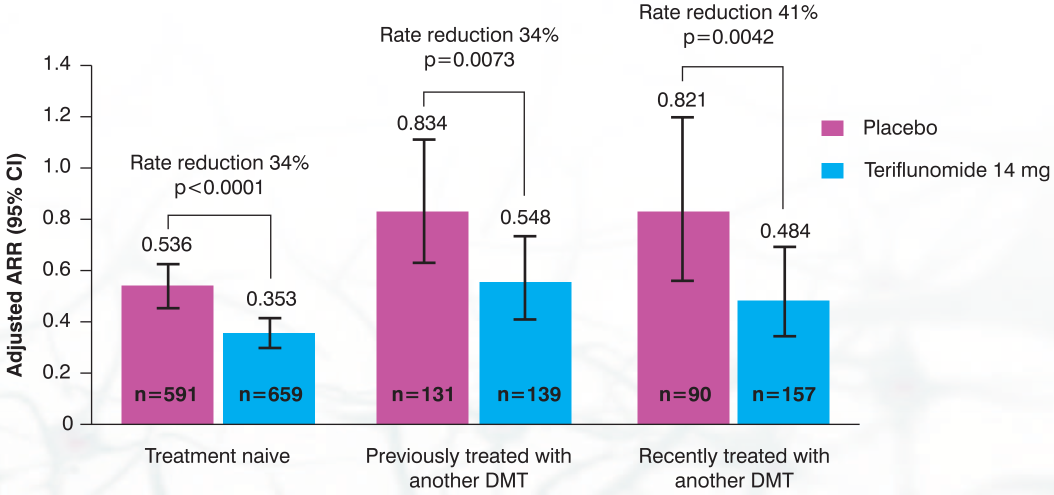
psy

to Quiescent MS

ESTABLISHED ★ ★ BIO-EQUIVALENCE*

B-1a, IFNB-1b & GA

Adjusted ARR with teriflunomide 14 mg or placebo



Orally Once Daily with or without food

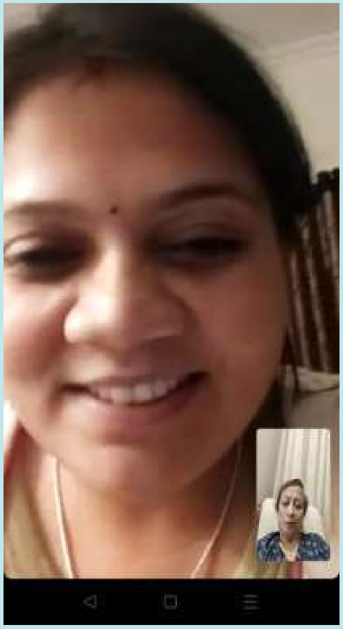
NATCO

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

ADVOCACY - CREATING AWARENESS

TOUCHING LIVES- HOME VISITS

Video Counseling & Birthday Greetings, Connect Groups



MULTIPLE SCLEROSIS DIET: FOODS TO EAT AND AVOID

Multiple sclerosis leads to symptoms such as fatigue, depression, muscle spasms, and difficulty regulating the bladder and bowels.

Lifestyle habits, including diet and exercise, influence how the disease progresses over time. But these risk factors are modifiable-unlike genetic or some demographic factors-and adopting a healthier lifestyle can improve the outcomes of MS patients.

Does diet affect MS?

Diet has a wide range of effects on an individual's health-it impacts a person's weight, and can alter the risk of heart disease, bone problems, and other health issues. Diet also can change the activity of the microbes that live in the digestive tract, and some substances consumed in the diet and/or made by these microbes can alter inflammation and brain activity.

There is no evidence that any one dietary strategy is best for people with MS. Generally, it's recommended that patients eat a varied and well-balanced diet along the lines of what is typically recommended in the general population-lots of plant-derived foods like fruits, vegetables, and whole grains, and fewer foods that are processed or high in refined sugars and fats.

People with MS are advised a dietary plan that makes sense for them, and that's realistic given factors including personal preferences, accessibility, affordability, and cultural traditions.

While diet cannot replace treatment with MS disease-modifying therapies, studies suggest eating a balanced diet that provides for all nutritional needs may help patients better manage and control MS. Specifically, a good diet can help in:

reducing the likelihood of flare-ups;
lessening the chances of disability progression; and
improving both physical and mental health-related quality of life.
Diet also can help to ease some symptoms of the disease. For example, being obese or overweight is linked with worse severity of some MS symptoms, such as fatigue and pain. Changes to diet that help patients lose weight may ease these types of symptoms.

Dietary modifications also may be helpful for managing other specific symptoms of MS.

Bladder problems:

Drinking enough fluids to stay hydrated and avoiding spicy foods, alcohol, caffeine, and fruit juices can help with issues like frequent urination and urinary tract infections.
Bowel problems: Eating enough fiber and drinking enough fluids can help ease constipation.
MS fatigue: Problems related to fatigue may be worse if a person's diet isn't providing enough energy for the body to function effectively; changes in eating habits may increase vitality.

Emotional challenges: a varied and balanced diet that avoids alcohol and caffeine (excess tea & coffee) may help to ease depression.
What nutrients should an MS-friendly diet include?
Broadly speaking, it's recommended the diet for individuals with MS should be varied and well-balanced to provide all the nutrients the body needs to function. Components of a healthy diet generally include:

- carbohydrates (sugars and starches), which are used for energy in the body;
- proteins, used for growth and to repair damaged tissue;
- fats, which serve as an energy source and are important for absorbing other nutrients;
- vitamins and minerals, a broad group of essential nutrients needed for a range of bodily functions; and fiber, an undigestible plant matter that helps food pass through the intestines.

Some specific nutrients of particular relevance to MS include:

Vitamin B12: This vitamin is used to make myelin, the fatty wrapping around nerve fibers that becomes damaged in MS. While a deficiency in this vitamin may result in MS-like symptoms, there is no evidence that B12 supplements benefit MS patients with normal levels of the vitamin.

Vitamin D: Affecting a number of biological functions, this vitamin is known to impact immune activity. Low vitamin D levels have been linked with an increased risk of MS and more severe disease activity.

Calcium: This mineral is needed to maintain healthy bones. Calcium supplements may be given to MS patients at risk of bone problems-for example, individuals who have limited mobility or are taking steroid medications.

Essential fatty acids (EFAs): EFAs are a class of polyunsaturated fats that cannot be synthesized in the body and must be acquired through diet. They are needed to repair damaged nerve cells and to produce certain signaling molecules that control inflammation.

Antioxidants: Oxidative stress is a type of cell damage that contributes to inflammation in MS. Antioxidants, as their name suggests, are molecules that can lessen oxidative stress, thereby helping to reduce inflammation and neuronal damage. Common antioxidants include vitamins A, C, and E, as well as compounds such as flavonoids and beta-carotenes.

FOODS TO EAT

Fruits and vegetables

Most fruits and vegetables are a good source of carbohydrates, vitamins, minerals, antioxidants, and fiber. A higher intake of fruits and veggies has been linked with less disease activity and disability among MS patients.

Whole grains

Whole grains and unpolished cereals are a good source of complex carbohydrates and fiber. Research has linked more whole grain intake with less severe MS-related disability.

Lean protein

Skinless chicken, fish, and plant-based proteins such as beans (rajmah) , peas, lentils (daals), and soy products, are different kinds of lean proteins. All are considered good foods to eat to get protein without consuming a lot of saturated fats, which have been linked to more severe disease among MS patients.

Unsaturated fats

Unsaturated fats, particularly polyunsaturated fatty acids or PUFAs-which include EFAs -have been shown to have anti-inflammatory and nerve-protecting properties in animal studies. Of note, studies of PUFA intake in MS patients have shown inconsistent results. Foods rich in PUFAs and EFAs include oily fish like salmon and mackerel, and some nuts and seeds like walnuts, soybeans, and flax seed (alsi).

Water

Staying hydrated is critical for maintaining health, and regularly drinking enough water can help to ease constipation and avoid bladder infections.

FOODS TO AVOID !

Saturated fats

Considered unhealthy fats, saturated fats have been linked to an increased risk of heart disease; they also have pro-inflammatory effects. In animal models of MS, eating a diet high in saturated fat leads to more inflammation, and higher saturated fat intake has been linked with increased relapse risk and more disability among MS patients. Saturated fats are mainly found in animal-based foods such as whole milk, high-fat cheese, pastries, paratha, poori, processed meats, and fatty cuts of meat. Some plant-based foods such as coconut oil, palm oils, and cocoa butter also are high in saturated fat .

Trans fats

Trans fats are strongly associated with an increased risk of heart disease, so most experts recommend limiting the amount included in the diet. Fried foods, commercial baked goods, frozen fries, pizza, chips , wafers & fried snacks like bhujiya and namkeens, and processed foods commonly have a high trans fat content.

Refined sugar

The effects of a high-sugar diet-containing a lot of sweetened beverages and cereals, cookies, and cakes-have not been confirmed in studies of people with MS. But a high sugar intake can promote inflammation and lead to more aggressive disease in MS . A small study found that MS patients who drink more sugar-sweetened beverages like soft drinks & colas tend to have more severe disease. High sugar intake also is linked with a higher risk of other conditions, like diabetes and heart disease, weight gain that may increase the symptoms of MS.

Alcohol

Evidence suggests the overall severity of MS is not affected by alcohol intake. However, especially in large quantities, alcohol's effects on the body can cause worsening of numerous MS symptoms, including coordination difficulties, bladder problems, and depression. Alcohol also may interact with medications. Consequently, it's generally recommended that people with MS should practice moderation in their alcohol intake, and should discuss how much alcohol it is safe to consume with their healthcare teams.

MORE RESEARCH NEEDED IN THE FOLLOWING

Dairy

It remains unclear whether consuming dairy products affects the course of MS. Some studies have found MS patients who consume more dairy tend to have more severe disease, but other studies have reported the exact opposite trend, with more dairy consumption linked to less severe MS. Full-fat dairy products are often high in saturated fats, but dairy also can be a good source of protein, calcium, and vitamin D. Some experts recommend MS patients stick with low-fat dairy options or dairy alternatives, which include products made from nuts, soy, and oats. There is experimental evidence that an immune system attack against a protein found in cow's milk can lead to MS-like autoimmunity in the nervous system, but the clinical relevance of these findings for people with MS is unclear.

Salt

Some research has suggested a link between higher salt (sodium) intake and more severe MS, but other studies have shown no connection between salt consumption and MS severity. A high-salt diet can increase the risk of other health problems like high blood pressure, so it's generally recommended that salt in the diet be moderated.

Gluten

A few studies have explored whether gluten intake may influence MS, but there is not enough evidence to make any conclusions one way or another. Available evidence suggests the rate of gluten intolerance, known as celiac disease, is no higher among MS patients than in the general population.

Vitamin D

Vitamin D is mostly produced in the skin upon sun exposure but also can be obtained in the diet through food or supplements. This vitamin is important for maintaining bone health, and also can modulate the activity of the immune and nervous systems.

A deficiency in vitamin D has been linked with an increased risk of MS, and patients commonly have lower-than-normal levels of this vitamin. In MS patients with low vitamin D levels, supplements or other interventions that aim to normalize vitamin D levels are generally recommended.

Some studies have tested whether additional vitamin D supplementation may provide benefits to MS patients. So far, however, the data have not shown any clear benefit of vitamin D supplements beyond maintaining normal levels. Clinical trials in MS patients also suggest that high doses of vitamin D supplementation bring no added benefit over lower doses.

Special diets for MS

What is good & healthy for the rest of the world is good & healthy for you !

There is no single diet universally recommended for people with MS. Still, several dietary strategies have been developed for multiple sclerosis, which generally aim to provide for the body's nutritional needs while avoiding foods that could worsen inflammation.

Some of these diets have been explored in clinical trials, but studies are generally small, lack comparison groups, and often have high dropout rates. These factors can make it hard to determine how meaningful the results are.

It's also important to keep in mind that researching the impacts of diet among people is necessarily complicated, given the other factors at play-from genetics to lifestyle, and even whether or not someone chooses to participate in clinical research-that may affect the results.

SOME POPULAR DIETS ..

NOTE : These are various diets tried by small numbers of people , but no one diet has been proven to reverse MS. It may work for some and not for others. If we go into the details of each diet, you will notice a few common factors: they avoid excess fats & sugars; they advocate lean proteins ; recommend fibre rich, fresh plant based foods and include light exercise. That really is the key.

Best Bet Diet

The Best Bet diet is based on the idea that molecules in certain foods may leak out of the intestines and worsen the inflammatory attack that drives MS. It is a strict exclusion diet that recommends cutting out all dairy, grains, legumes, sugar-rich foods, and any foods that may cause an allergic reaction, such as eggs and yeast. It also recommends reducing the intake of saturated and polyunsaturated fats, salt, and alcohol.

Developed by Ashton Embry, a geologist whose son has MS, the diet consists mainly of fish and lean meats, lots of fruits and vegetables, and olive oil. It also recommends a number of nutritional supplements, such as vitamin D, calcium, magnesium, and omega 3 fatty acids.

While some people with MS report feeling better on this diet, there is no research showing benefit for MS patients. Because the diet cuts out many food groups, it's important that any MS patients following it should take precautions to ensure they get all needed nutrients.

Ketogenic Diet

A ketogenic or "keto" diet is one that is low in carbohydrates and high in fats, leading the body to use fats as its main energy source — a process called ketosis. The diet was originally developed to help manage certain seizure-causing disorders.

A few small studies have indicated that following a keto diet may help to ease fatigue and depression, and improve quality of life in people with MS. However, the diet also may have negative effects, like vitamin deficiencies or digestive upset. In rare cases, it can cause serious problems with the pancreas and liver.

McDougall diet

The McDougall diet is a low-fat, plant-based diet rich in complex carbohydrates, whole grains, fruits, and vegetables. It completely cuts out meat, dairy, oils, and all other foods that come from animals, and only allows small amounts of sugar and salt.

In studies, the McDougall diet has not shown any effect on measures of MS progression, such as relapse rates or inflammatory activity on MRI scans. But some research suggests the diet may help ease fatigue in MS patients.

Mediterranean diet

As its name suggests, the Mediterranean diet is based on the foods that are commonly eaten in cultures surrounding the Mediterranean Sea. The diet includes plenty of fruits and veggies, whole grains, and olive oil, and recommends a moderate amount of low-fat dairy products, fish, poultry, and red wine. Only limited amounts of red meat, sweets, and animal fats are included in this diet.

There is not much research specifically evaluating the Mediterranean diet in MS, though the plan is generally considered well-balanced and nutritionally complete. Some small studies suggest it could help ease fatigue, as well as reduce the impact of MS symptoms and delay disability progression.

Overcoming MS diet

The overcoming MS (OMS) diet is a plant-based diet that also includes fish and seafood, but cuts out all processed foods, eggs, meat, dairy, and saturated fats. The diet usually includes daily supplements of flaxseed oil or fish oil. Additional supplements or dietary modifications may be needed to ensure patients get enough nutrients, like protein, iron, and calcium.

The diet was developed by George Jelinek, MD, an Australian doctor who was diagnosed with MS in the late 1990s, as part of a lifestyle program that includes diet, exercise, and meditation, alongside medical treatment.

A few small studies have reported that this diet or lifestyle intervention is associated with increased mental and physical quality of life, and a columnist with Multiple Sclerosis News Today also reported feeling better just a few weeks into the diet. But the studies usually lack a comparison group so it's difficult to draw firm conclusions.

Paleo diet and the Wahls protocol

The paleolithic or Paleo diet involves eating foods that are thought to be similar to what ancient humans ate before the advent of farming and agriculture. The diet mainly includes meats, fish, nuts, vegetables, and fruits, while it excludes processed foods, grains and beans, potatoes, cereals, dairy, and eggs.

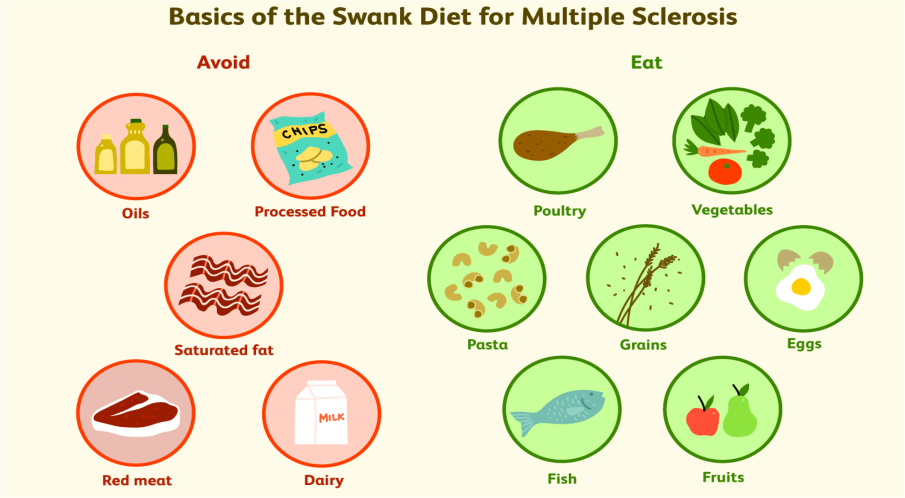
The Wahls protocol is a lifestyle intervention that combines a Paleo-inspired diet with vitamins, meditation, and exercise. The protocol is named for Terry Wahls, MD, an American doctor with MS who promoted it.

There is some evidence that a Paleo or Wahls diet can help to ease fatigue and improve quality of life in people with MS. However, because the diet cuts out many large groups of food, it may increase the risk of nutritional insufficiencies, so it's important that patients work with their care team to ensure that their nutritional needs are being adequately met.

Swank diet

The Swank diet mainly advocates strictly limiting fat intake, emphasizing low-fat dairy products, whole-grain starches, fruits, and veggies, and cutting out red meats and oily fish. Proposed in 1948 by neurologist Roy Swank, MD, PhD, the diet also recommends cod liver oil and vitamin supplements to ensure patients meet all their nutritional requirements.

A study conducted by Swank more than 30 years ago suggested that people who followed the diet had lower risk of relapse, disability, and mortality than those who didn't. But the study did not include a control group or a scoring system for MS disability, so the meaningfulness of these results is debatable. More recently, a small 2021 clinical trial suggested the Swank diet may ease fatigue and improve physical quality of life in MS patients.



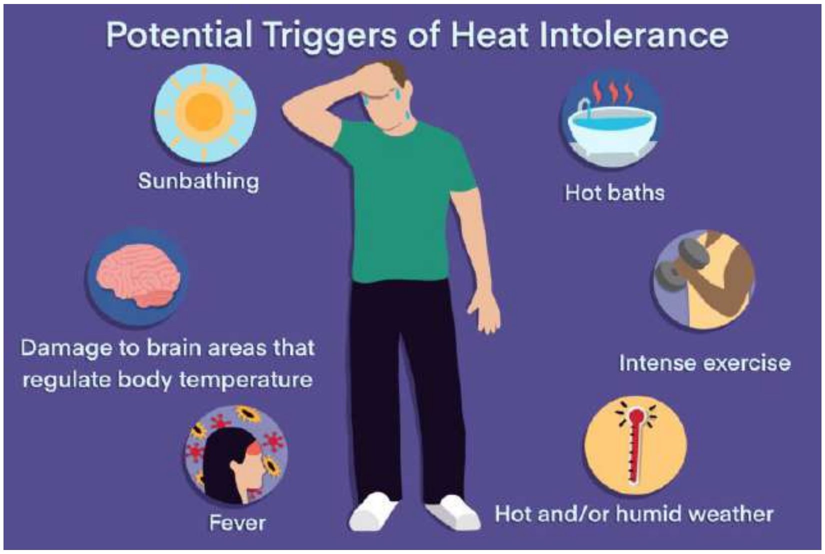
Intermittent fasting and calorie-restricted diets

Calorie restriction, as the term suggests, is a dietary strategy that involves limiting the amount of calories (units of energy derived from food) one consumes. It commonly involves cutting out high-calorie foods that contain a lot of fats and sugars.

Intermittent fasting is a form of calorie restriction in which the amount a person eats is strictly limited or prohibited at certain times, while the rest of the time the person eats according to their normal habits, without cutting out any specific food type.

Research has indicated that a low-calorie diet can help to reduce markers of inflammation, and some small studies reported MS patients have better emotional health (e.g., better well-being and less severe depression) after following these diets. However, this type of diet may not meet all of a person's nutritional needs so it can lead to substantial weight loss. Other negative effects may include poorer bone health, reduced sex drive, and irregular menstrual periods

HOT AND BOTHERED: HOW HEAT MAKES MS SYMPTOMS WORSE



Around three quarters of people with MS find that their symptoms get worse when they are hot. This might be when the summer weather arrives, during exercise, when the central heating is too high or if you are in public spaces which can be overheated.

Which symptoms get worse?
Any symptoms can flare up, but it is common to experience increased:

fatigue, blurred vision, poor balance, trouble with concentration or memory
The effect is temporary and symptoms should calm down once you are cool again.

What causes heat sensitivity?
There are several possible reasons. In many people with MS, getting hot slows down the messages passing along nerves which have already been damaged by MS and this gives rise to increased symptoms. In some cases, there is a lesion in a part of the brain that controls temperature regulation in the body. Other people might have a lesion in a brain area that should respond to increased temperature, for example, by initiating sweating or sending more blood to the skin so you cool down again. In both cases, the poor response means that body temperature rises.

Colds, flu and other infections
Many infections cause the body's temperature to rise. You may realise that you have a fever or you could just feel unwell. Either way, MS symptoms can flare up and you may even feel like you are having a relapse. However, as you recover from the infection, the symptoms will subside.

Keeping your cool
If you are heat sensitive, there are a range of things you can do.

In hot weather, you might go out earlier or later in the day when it's cooler or keep to the shady side of the street. You could avoid sitting in the sunshine for too long, wear layers of clothes that you can peel off, take a broad brimmed hat or a sunshade.
If the family likes to have the heater up high, you might negotiate turning it down and encourage them to wear an extra layer. This might be popular with the bill payer too. ?? Some people think that, if you aren't well, it's a good idea to keep warm. You might like to explain that the opposite is true with MS.

If you get too hot during exercise or everyday activity, you could opt to go out at the coolest time of day. You can precool yourself by having cold drinks, sucking ice cubes, taking a cold shower or spraying yourself with cool water.
If you are sitting still, you could organise a fan or an air conditioner to provide cooler air.

HEAT & MS

People with MS can be sensitive to extremes of temperature, and may find that either heat or cold makes their MS symptoms worsen. Some people can find they experience problems with both extremes of temperature. This can be hard to explain to people around you, as different symptoms may be affected by heat and cold. You may find you need to monitor the temperature and situation around you and take steps to keep yourself at a comfortable temperature.

What causes temperature sensitivity in MS?

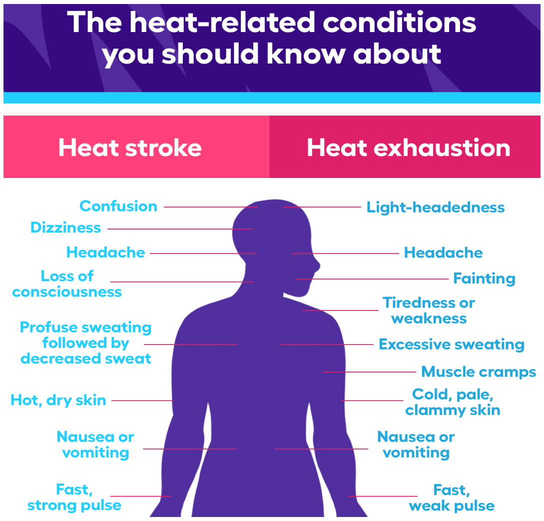
Temperature sensitivity could be caused in a number of ways. Extremes of heat and cold may affect the speed at which nerve impulses can travel along your nerves, particularly where there has been demyelination or nerve damage. Alternatively, MS may have caused a lesion in the part of the brain that controls or responds to body temperature. Your brain may not trigger sweating or shivering responses that keep your body at the best temperature for comfort. Although unpleasant, the effects of heat and cold are temporary and do not cause any permanent damage to your nerves. Your symptoms are generally quickly reversed when body temperature returns to normal. If they do not, then discuss it with your doctor or MS team.

Heat sensitivity

Between 60% and 80% of people with MS find that heat can cause their symptoms to worsen. This might involve a build up of fatigue, blurred vision, loss of balance or a worsening of cognitive symptoms such as concentration or memory. The effect of temperature changes can affect your visual symptoms as well. Summer weather, excessive central heating, vigorous exercise or having a fever can all raise your core body temperature. You might also find environments with lots of people crowded together uncomfortable. If you have MS, just a small rise in core body temperature can make a huge difference to how you might feel. Being heat sensitive may affect the activities you choose to do. If you are sensitive to heat, you could opt for strength or resistance exercise rather than endurance exercise, as this tends not to raise your core temperature so much.

Dealing with the heat

Have regular cold drinks or suck an ice cube or frozen pineapple chunks. Spray your face and wrists with a spray bottle filled with iced tap water There are also commercially available sprays available that will stay cool throughout the day. Keep a wet towel handy when exercising & wipe your face , neck & arms. Some people find eating makes them warmer, and so it may be an idea to choose salads and sip iced water while eating. A cooling dessert can help. When you take a bath or shower, start with warm water and reduce the heat gradually. Avoid steamy hot baths. A floor or desk fan can help to keep the temperature down and the air flowing in a room. A hand held fan can be useful when moving around. When going out, make sure you do your outdoor activities in the cooler parts of the day. In summer, park your car in the shade. Try to avoid sitting in an overheated car. open the doors & windows, let out the heat, start the AC before you sit in it.



Useful equipment to keep cool

There are many different options for cooling equipment. Wearable options include hats, scarves, ties and wrist bands that can be worn during day to day activities and are relatively inexpensive. These contain a gel or other substance that can be pre-cooled before wearing, usually by soaking in water. Depending on the product, the cooling effect can last from a few hours to several days.

A Letter to MS

Dear Multiple Sclerosis,
I get confused,
I get emotional,
I cry, I laugh
I have mood swings
And issues of anger.
I have pain sometimes severe.
I get MS hugs,
I am in pain,
Taking Tylenol goes vain.
Doses of IV and Tecfidera
have drained me
You have strained me.
I forget things
And cannot into my brain log,
Because of brain fog.
I fall
And due to disabled gait,
I banged my head against the wall.
My relapses are unforgettable,
I suffer from insomnia
I have weakness
I have depression
I have numbness
At times I feel hopeless.
I know you live inside me
I know you have taken
control of me
You worsen my immune system,
You increase my everyday struggle,
that a normal person cannot even boggle.
You make me weak
You may want to bring me down
But you cannot break me
I have support of my kith and kin
I will not let you win
because Krishna is with me
And he has a plan!!

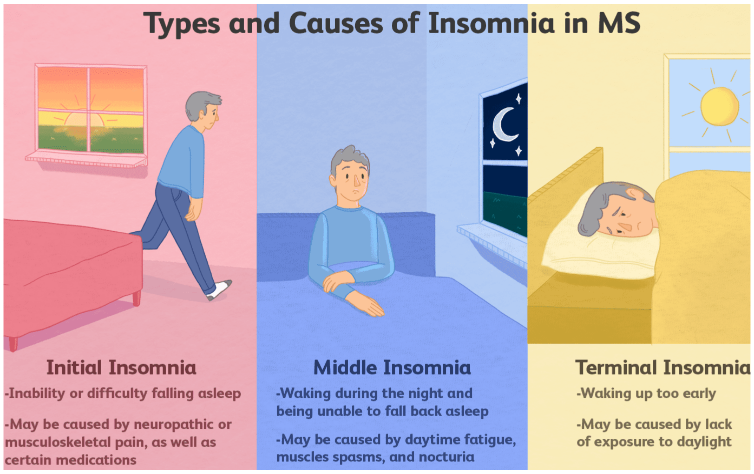
- Garvita
PwMS, MSSI, Delhi

NIGHT SYMPTOMS AND MS

If your MS symptoms feel worse at night, you are not alone. Many people find their MS is worse or harder to cope with at night time. It can disrupt your sleep and play havoc with your energy levels, concentration and emotions the next day. The good news is that many of these MS symptoms can be improved. Talking to a heath professional or making some small changes to your routine could make all the difference. Read on for ideas for managing some common night symptoms.

Getting up to pee

Getting up often in the night to pee is called nocturia. It can seriously interrupt your sleep schedule, leaving you feeling overtired the next day. It's normal to get up once or twice at night, but someone with nocturia might need to get up five or six times a night. Around seven out of ten people with MS have reported this happens to them. If you need to wee a lot through the day, this can continue at night as well. Your bladder and brain need to co-ordinate when your bladder empties based on how full it is and whether a toilet is handy. MS can scramble these messages and make it harder to tell when you really need to go. It can also stop the flow when your bladder has not fully emptied. Sometimes nocturia is caused by an untreated infection (urinary tract infection, or UTI), or affected by other medical conditions, your age or pregnancy. If your sleep is disturbed for another reason, then you might find you need to get up to wee as well. Bladder problems like nocturia are often treatable, so first speak to your doctor about it Although staying hydrated (drinking adequate water) is important, think about the timing of drinks through the day. Try having your last drink before 8pm, and see whether limiting your tea/coffee or liquid intake makes a difference. Caffeinated drinks can irritate your bladder and alcohol can affect your sleep patterns.



Restless legs

Restless legs syndrome causes an overwhelming urge to move your legs, and can feel like your legs are crawling or twitching. It can be intensely irritating and is often worse in the evenings and at night. People with MS are more likely to have restless legs syndrome than other people. Restless legs syndrome can be associated with iron deficiency, kidney issues or with pregnancy. Some neurologists believe that the underlying cause could be down to how your body processes a signalling chemical called dopamine. For many people with restless legs syndrome, there is no obvious cause. Some drugs prescribed for MS symptoms may make restless legs syndrome worse. For mild cases, you might find that small lifestyle changes can help. These include exercising during the day, developing a regular sleep schedule, and avoiding caffeine and alcohol late in the evening. Some people find that magnesium spray on the legs can help. For more persistent cases, speak to your doctor. They can investigate whether you have any nutritional deficiencies or other causes and review your medication.

Muscle spasms

If you experience muscle spasms or stiff muscles (spasticity), you'll know that getting comfortable enough to sleep can be tricky. Your body or limbs might twist or jerk, which can affect your bed partner's sleep too. Spasms and spasticity can cause pain and make it difficult to move yourself in bed. With less distractions, you can become acutely aware of these problems during the night. If this is an issue for you, then it could be worth reviewing your sleeping position and checking that your mattress is comfortable. By using pillows or foam wedges for support, you can get your body into a position where your muscles are less likely to stiffen up or spasm. Sleeping with a pillow under your knees, or resting on one side may make a difference. An occupational therapist may be able to help. If you take medication for your muscle stiffness or spasms, then try to take it around 30 minutes before you go to sleep, so that it is working best when you need it to.

Pain

A bad night's sleep can make pain feel harder to cope with, but pain can also make it harder to sleep well. This vicious cycle can be hard to escape. Pain in MS can have many different causes, from problems with your posture to altered nerve sensations. Ask your doctor whether there are options to help you manage your pain. They could review your medication, refer you to a pain management clinic, or support you to use complementary (alternate) therapies to improve your situation.

Medication side effects

Some drugs used in MS can affect your sleep. People taking the beta interferon disease modifying drugs (Rebif, Avonex, Plegridy and Betaferon) sometimes report that taking these drugs can make it harder to get to sleep and stay asleep. These drugs may have side effects including headaches or fever and so people are advised to take them in the evening so they can sleep through the side-effects. If you are taking a beta interferon drug, and you find the other side effects are tolerable, you may prefer to take the drug earlier in the day, so your sleep is less affected. There is little recent research data on the impact of other disease modifying drugs on sleep, although people taking natalizumab (Tysabri) sometimes report that it improves their sleep patterns. Some drugs for treating pain or spasticity in MS, such as gabapentin or cannabis-based medicines, can promote better sleep because they reduce the symptoms that might get in the way of a restful night.

Stress

Worry can keep you awake, and living with stress can affect your sleep. If you are able to resolve the stressful situations, you should find it easier to sleep again. However, when stressful circumstances are beyond your control, mindfulness or relaxation exercises can help you put this in context. So can talking things over with a trusted friend, relative or mental health professional. They may help you spot issues that you can resolve or encourage you to think about things in a different way. If your head is racing with things you don't want to forget, consider keeping a notepad by the bed and writing down your thoughts. Then you'll know they are safe there for the morning when you can deal with them more easily.

Coping with insomnia

Of course, you may well experience more than one of the issues above. They can all interact with each other, and untangling them can take some time and patience. If you're kept awake by spasms or pain, or woken up by nocturia, you would not be surprised to be tired or fatigued the next day. As a result, you might have less energy for tasks, socialising or exercise. It doesn't take much for this to become overwhelming or to bring your mood down.

Many night symptoms can be improved with support from your health professionals, so don't be afraid to let them know. Your GP or MS team can review your medication and help you manage other MS symptoms that are interfering with your sleep.

BRAIN TICK TOCK

So there is lots you can do to keep your brain active, from the very ambitious to just doing your everyday chores. What do you do to keep your mind active?

There is a lot of talk about brain health and how to keep your brain as healthy and fit as possible. But what does this really entail? In this blog Helena from the MS Trust information and engagement team explores some ideas on how to improve your brain health.

Have you heard people talking about brain health in MS and wondered what they actually mean? In MS the immune system mistakenly attacks and damages tissue in the brain and spinal cord, this can result in lesions (scars) that can be seen on a MRI scan. As the brain is a clever organ, it can compensate for some of this damage by rerouting signals or adapting healthy areas of the brain to take on new functions. This capacity is known as 'neurological reserve' or 'brain health'.

Last year a new report called Brain Health: Time Matters in Multiple Sclerosis came out, this was an international report written by a multidisciplinary group and chaired by neurologist Professor Gavin Giovannoni from the UK. The report made the case for a new strategy for treating MS, and the main focus was on brain health and how it could help people with MS.

So knowing this, it makes sense for us to keep our brains as healthy and fit as we possibly can. But how can you achieve this if you have MS?

MSSI Delhi MULTIPLE SCLEROSIS SOCIETY OF INDIA

Interview on Doordarshan Health Channel

featuring

PadmaShri Dr. Kameshwar Prasad

Director Neurology Fortis Hospitals, Former HoD Neurology ,AIIMS

Broadcast throughout the day on 4th February 2024

On the occasion of India MS Day 2024

IndiaMSDay #InsureMyMS

MSSI Delhi MULTIPLE SCLEROSIS SOCIETY OF INDIA

Interview on AIR FM Gold

featuring

Prof. Manjari Tripathi, HoD Neurology AIIMS New Delhi

Dr Vinay Goyal, Director Neurology, Medanta Hospitals

Ms Bipasha Gupta, Chairperson MSSI Delhi

On the occasion of India MS Day 2024

IndiaMSDay #InsureMyMS

MSSI Delhi MULTIPLE SCLEROSIS SOCIETY OF INDIA

Interview on AIR FM GOLD and Big FM 92.7

featuring

Dr. Dheeraj Khurana, Prof of Neurology PGI-Chandigarh

Broadcast throughout the day on 4th February 2024

On the occasion of India MS Day 2024

IndiaMSDay #InsureMyMS

The main points from the Brain health report were:

- Keeping as fit and active as you can through regular exercise
- Maintaining a healthy weight
- Keeping your mind active
- Avoiding smoking
- Limiting how much alcohol you drink
- Continuing to take any other medicines that your doctor has prescribed.

Some of these are fairly straight forward, such as avoiding smoking, limiting alcohol and continuing to take other medicines you have been prescribed. But how to keep your mind healthy and active is perhaps less obvious. We asked MS nurse adviser Vicki Matthews and the people in our MS Trust Facebook group for their tips on the best ways to keep your mind active, this is what they said.

Keeping your mind active and healthy

Vicki Matthews has some good suggestions on what you can do to maintain brain health through keeping your mind active. She compares the brain to any other muscle of the body, it needs both exercise and rest. It is important not to forget the rest element, try to recognise when you are getting cognitive fatigue and let your brain have a rest then, perhaps turn your mobile off and do nothing for a little while. Vicki also says it is important to get a good night's sleep for the brain to get a proper rest.

When it comes to the part about keeping the mind active, it can be as easy, or as complicated, as you like. Games are a good way to exercise the brain and thought processes, especially puzzle games like sudoku for example, which are easily found in magazines, shops and online. Jigsaws. Now I can't manage them on a table - so I do them on my iPad.

Charu, MSSI Facebook group

One thing that really gets the brain going is learning a new skill. This could be something ambitious like a new language or perhaps something a little less taxing like learning a new exercise. Other ideas could be learning to sing, draw or dance!

I often share ideas about the benefits of learning a new skill to keep the mind active. In fact I myself make a point of learning something new each year, last year it was painting.

Meera, MS Member

What's relaxing for me is playing the guitar. As my teacher told me, playing the guitar requires both parts of the brain to work.

Murtaza , MSSI Facebook group

Be kind to your mind

Mindfulness is another way to be kind to your mind. If you are not familiar with it, mindfulness is a meditative technique that involves learning to focus attention on emotions, sensations and thoughts in an accepting and non-judgemental way. By focusing fully on the present moment, rather than on regret for the past or worries about the future, mindfulness can help to break the cycle of negative thoughts and emotions. Some of our Facebook group members had even tried a combination of learning a new skill and mindfulness together.

I go to a mindfulness art class once a week, not only is it fun but I have three hours of not worrying about MS. It takes part in the local community centre of our housing Society. We tend to do arts and crafts, a cup of tea and biscuits and a general chitchat . Sometime we invite special speakers and anyone can discuss problem's and any difficulties caused by any ongoing illness or mental health issues. It's great fun, with interesting people.

Samridh, MS Facebook group

Several people told us they really enjoy knitting or crocheting and painting. It requires you to follow a pattern and also to keep your fingers busy, whilst the body can relax. If you don't want to sit and do it alone or if you'd like to learn how to do it, most places have local knitting, stitching or crochet groups, where people can meet up have a chat and do their handicraft.

I love relaxing in front of a good movie with some knitting. Pick a complicated pattern and there's plenty of brain work involved!

Pia, MS Facebook group

We had lots of other great suggestions in the Facebook group from people and what really came through was that it didn't need to be complicated or expensive to keep your mind active.

Cooking. It needs a sequence of actions. If I forget one part I sit and think rather than get frustrated. Then there is writing and chilling with friends over cricket scores & statistics !

MSSI DELHI
wishes to thank you all

*** Justice Rohinton F. Nariman**

*** SLMTT**

*** Fena Foundation**

Baljit Kaur Dhupia
Pran K Murgai
Hemant Kumar
ACTL
Kotak Mahindra Bank Ltd
Gyanendra Pratap Singh
Nalini Sehgal
Ragini Mathur
Ramesh Agarwal
V.N. Kutty
Divya Rawal & Sons
Indira Rai
EMU Lines- Anil Mohindru
Bani Jagtiani Trust
Ankit
SwarnLata Motherson Trust
Santosh Bhasin
Velocis Systems P Ltd
Ms. Rupa Nandy
KSN Impex Pvt. Ltd
Live it for Everyone Foundation
Neterwala & Aibara Interior Architects
Ameeta Gupta
Sarita Mehra
Brij Mohan Ahuja Charitable Trust

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


Healthcare Tech Supplement | No. 1 | Jan-Dec 2024 | Rs. 200
HealthTekPak
www.healthtekpak.com
RFID for unit-level traceability in Pharma
Avery Dennison at Pharmapack 2024
MEDICA

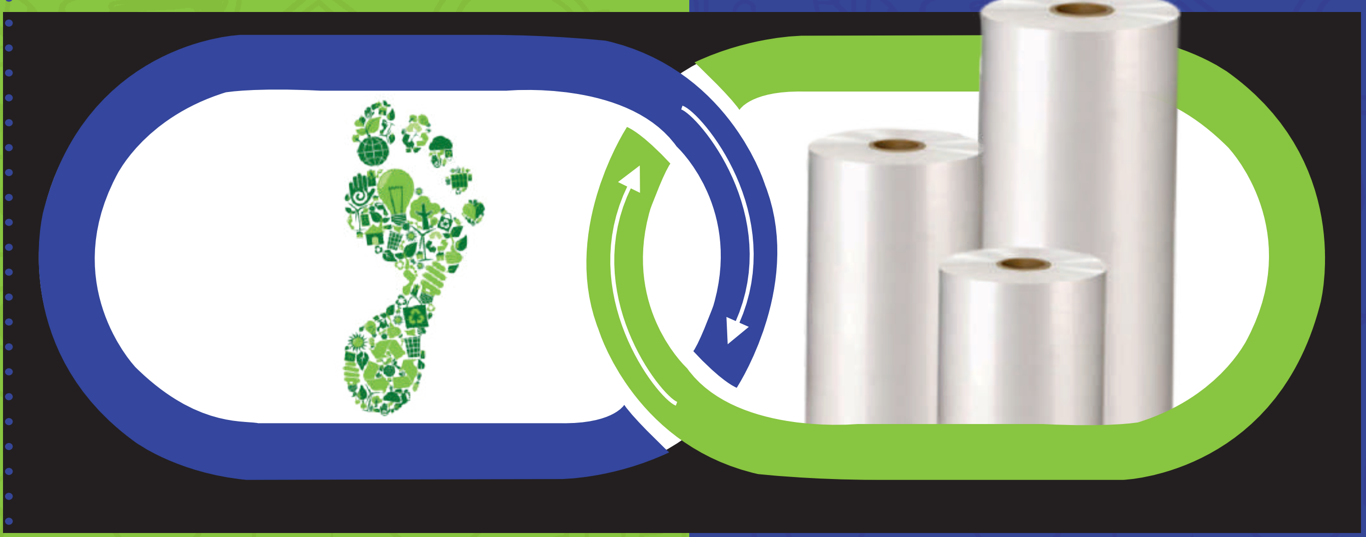

KOMPACT
KOMPACT
Chocolate
Vanilla

POLYPLEX

INDIA | THAILAND | TURKEY | USA | INDONESIA

Committed to Sustainability!

Polyplex has the fifth-largest capacity of polyester (PET) film globally.
With Global presence, we supply to 1900 customers in over 80 countries.
At Polyplex, We strive for continuous Growth and sustainability.



- IN-HOUSE DEVELOPED CHEMICAL RECYCLING FOR POST CONSUMER REYCLE BOTTLE FLAKES
- USE OF BIO-BASED RENEWABLE RAW MATERIALS & ENERGY SOURCES FOR MANUFACTURING
- BIODEGRADABLE FILMS – UNDER TESTING & VALIDATION AS PER ASTM D5511 STANDARDS
- ADDED IN-HOUSE CAPACITY IN THAILAND FOR RECYCLING & SOURCED PLASTIC WASTE
- FURTHER INVESTING IN NEW POST CONSUMER BOTTLE RECYCLING PROJECTS

POLYPLEX CORPORATION LTD.
B - 37, Sector - 1, Gautam Budh Nagar, Noida - 201301, (U.P.) India
Tel : +91 120 2443716 to 19 | Fax : +91 120 2443723 / 24