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#### Acknowledgments

**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.



MSSI Delhi is proud to present the 16<sup>th</sup> issue of our Annual Handbook. This publication is specially designed in context to the Indian environment. Indian medical research outcomes have been blended with international material and

combined with personal experiences of our MS members to put together a very personalized and topical collection of articles. This year has been a unique challenge for everyone, with Covid19 taking over the world. It has created a "double whammy" for people with MS. We have however taken the opportunity to include some information which will help you live with Corona , till such time as a vaccine or cure is found.

Our Annual Handbook remains the only publication of its kind which addresses the questions and dilemmas of PwMS compassionately and in a reader friendly format.

This issue onward we will also be available on the MSSI website so that not only all members from across our 8 Chapters, but all visitors to our site will be able to access it.

I wish to thank my colleagues Meenakshi Bhujwala & Mridula Murgai for their inputs and assistance in putting this issue together.

#### **Bipasha Gupta**

Hony. Chairperson-MSSI Delhi

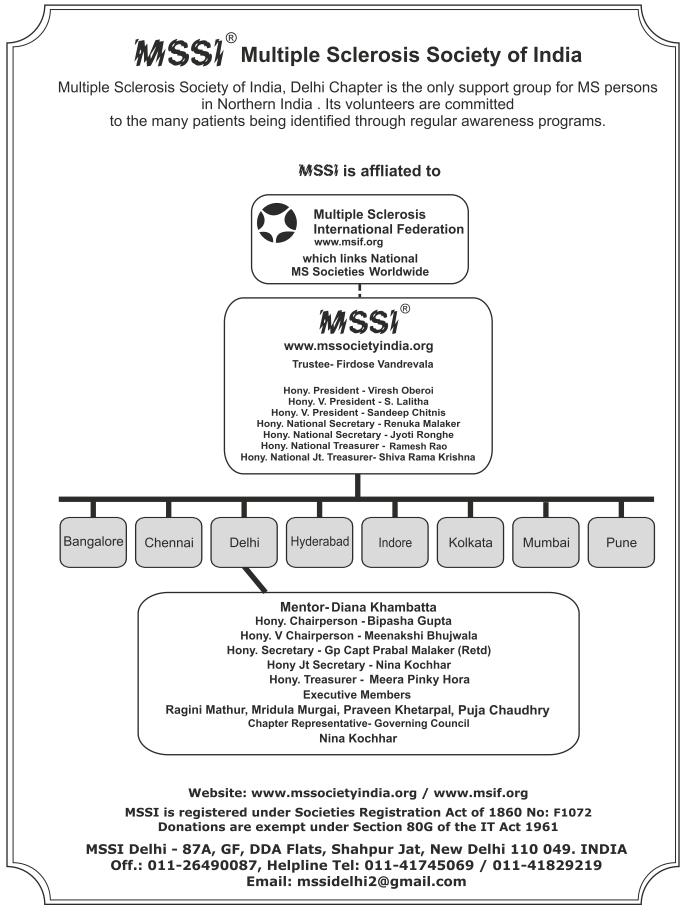
**Cover** : Acrylic on canvas. Painting by Arun Srinivasan , multimedia artist & person with MS.

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#### **MSSI DELHI AND ITS MEMBERS** A very special relationship!



All of you must be familiar with the MSSI – Delhi Chapter, after all you are right now going through our 16th Handbook!

MSSI Delhi is deeply committed to working with its members and helping them in any and every way possible. We are all volunteers, except for our two indispensable office assistants – Rajkumar and Shashi, who all of our MSP's must be familiar with!

At the time of printing, we have a database of over 750 PwMS members registered with us. These MS persons are spread over all of North India - Delhi NCR, and neighbouring states of UP, Haryana & Rajasthan. We also have members from Punjab,Himachal, Uttarakhand , J&K, and some from even as far as Bihar, MP & Jharkhand. It remains our mission to get to know each and every one of them & keep in touch with them through phone, Email & letters. We interact with our PwMS's in so many ways, we touch their lives in so many aspects and realise that they are so much a part of our daily lives as well ! A lot of MSps who first get in touch with us always ask one question-"What does MSSI do ? How can you help me?"

# Do you really know what all MSSI Delhi does?

Today, let us welcome you into our world and introduce you to our various activities. We are always looking for ways to interact with our members-whether it is through Home Visits, or Day Care events or medical camps.

We also organise trained physio therapists visits in the comfort of their own homes, visits by an attendant for helping with daily care bath etc of our female patients.



MSSI Delhi distributes medical & mobility aids, organises doctor appointments on priority, interacts with them on various WhatsApp chat groups dedicated to MS persons.

#### Our Fun-filled MSSI Events....We love organising them!



Every year we look for new and interesting events for our MSP's. A lot of planning goes into preparing for these events. Not only do we have to make sure that the venue is easily accessible to all those who come, but we also try to make transport arrangements for many of our participants who are housebound & dependent. We also must take into consideration the fact that fatigue is a major part of their lives, so the events should not last too long and should be in an air-conditioned environment. Our volunteers work very hard to make these events go smoothly and make sure that every one of our special guests has a great time.

#### **Day Care Events:**

These are our most popular events. These are regular programmes which are educational, social or merely fun activities. They include medical seminars, talks by doctors and motivational speakers, entertainers, celebrations of festivals, music & laughter.

Frequently, we organise an event where our MSP's and their caretakers are invited to watch a movie, spend a fun day at the Mall and play games, along with a meal served by us. On these occasions we get a chance to spend some relaxed time with each other,

interact with the caretakers and other MSps and families.

#### A Day at the Mall

Select City Walk has been one of our most generous patrons for many years. Once again on 15 September 2019 they organised a movie show for our MSP's and a sumptuous lunch for them.We gathered in their Training Centre at the Mall, where we danced and sang and told jokes.

The MSP's also played Tambola, they also got a chance to have their caricatures drawn by a caricature artist who was really the star of that event! This was followed by a lunch and the very thought provoking movie **Article 375**.



PVR Audi 5 in Select City Walk has accessible seats which fulfil the disability barrier free criteria., and their staff is most helpful & makes sure that our MSP's move around and sit in comfort. We never have enough words to thank them, and we are sure they will keep doing these special events for our members again and again.



#### **Diwali Festivities:**

The Sunday before Diwali, every year, we invite our members to Panchshila Club to spend an afternoon with us. Once again, this year, on a beautiful October afternoon we gathered at the Club lawns to share our joy.

There were gifts for all, there was great food, jokes and laughter and a festive atmosphere.

The Rehnuma band, consisting of Karan on the guitar and Ashu on the vocals were really, good! Dr. Vinay Goyal of AIIMS was our special invitee, and he was most cooperative and patiently answered all the queries of the MSP's. Along with our volunteers, we were almost 100 people and we truly had an evening to remember.

#### **Beyond Limits Art Exhibition**:

At Arpana Art Gallery, Academy of Fine Arts & Literature. This is a very special Annual Art Exhibition-organised by the Family of Disabled Organisation it features upcoming talented artists. This year, our very own PwMS Arun Srinivasan participated. We felt so proud when his paintings were appreciated by many who came to visit the venue. Three

of his paintings were selected for the exhibition after a very strict screening process and he managed to sell one. Next year we hope to get more of our members to participate.

Like each year we also had several programmes throughout the year which included, **a Seminar on World MS Day held at ISIC**, which saw a large participation with MS specialists from leading Institutes across North India sharing their knowledge & taking questions from the audience.

We also had active participation under our **Swayam** project by PwMS at popular **Charity Bazaars & Melas** at Australian High Commission, British High Commission, Lajpat Bhawan Mela, Diya Fest & Valentine Day Fair at **Select City Walk** among others.



#### Home Visits by MSSI Volunteers:

Most of our MSP's are familiar with Home Visits by our team which started in 2003. We organise visits by rotation wherein two of our team members go to the homes of our MS members almost every month. Over the years we have covered not only the Delhi NCR region, but visited several cities in UP, Haryana Punjab & Rajasthan. These visits not only cheer up the MS person & families, but they also teach us lessons in patience & forbearance.

We also get to know the MS person's entire family, their home environment, their challenges & share their joys & difficulties as well.





#### How do we prepare for them:

- We plan the itinerary by choosing MSP's who live within the same area.
- Appointments are made after calls to all the chosen homes.
- We plan a full day's round-choosing between 5 to 7 MSP's, making sure that we have at least 30 to 45 minutes with them.
- Hire a car for the entire duration

#### Why do we organise these Home Visits:

- These visits give us a chance to interact with our members and their caregivers in their home surroundings.
- We get a first-hand glimpse of the circumstances and surroundings they live in.
- We often counsel the MSP's and families about the emotional & social problems they face.
- We update our records about the medications they are taking and the latest condition of their personal health issues.
- It cheers them up because they realise that we care and we do like to keep in regular touch with them. They just talk to us for a few minutes, and most often, they become our friends for ever very soon.







#### What have we learnt from these visits:

- We are amazed at the resilience and fortitude of our MSP's. They are coping with life in amazing ways and we feel proud of them. Their never-say-die attitude astonishes us and makes us feel proud of them.
- Some of them are lonely and depressed-and all they need is a kind word, or someone to say we care. Our guidance for the caregivers helps many a family to deal with day to day issues of living with MS.
- We also make an effort to understand and appreciate the love & dedication which the caregivers are showering on their loved ones.
- It is important to be in constant touch with our members, they need to know that we are there for guidance and also provide all assistance and information that is possible.

#### The problems we face:

- Often MSP's forget that we are coming and are not at home. Or just change their mind at the last minute ...This puts our entire schedule out of gear. This actually also results in some other family missing out on a visit that they were really keen on.. which is a bit unfair, don't you think ?
- Occasionally an MSP may be having an emotional issue and may refuse to meet us. It takes a lot of patience to get them to agree to just talk to us for a few minutes. Often, they agree and open up to us.
- Some expect us to provide them with solutions to family issues, legal help, disability certificates or solve their money problems. Once again, we must patiently inform them that we are volunteers and there are limitations to what we can do.

But all said and done, we enjoy these visits. We are greeted with immense enthusiasm, we are plied with food and snacks and often the whole family gathers around us and chats with us, making us feel so welcome.

We promise to continue making these visits and if you would like us to visit you sometime soon do inform our office staff.



#### **Home Physiotherapy Services:**

We have nine physiotherapists on our rolls, and we are constantly looking for new ones to join us. These physiotherapists have all been trained specially to work with MS patients. At various sessions held by AIIMS doctors they are taught about the unique needs of MS patients and the special exercises they need to concentrate upon. Over 60 MSP's are covered under this scheme and almost 600 sessions are held in the year in the comfort of their own homes.

On 7<sup>th</sup> July, 2019, Dr. Jasmine Anandabhai, previously Head of Physiotherapy at Max Hospital and now Asst. Prof. Subharati Hospital and Physiotherapy College in Meerut is our Physio therapy Project trainer. She held yet another special session with 8 of our physio therapists. They were taught how to change the mode of exercises by using techniques such as relaxation, yoga, and breathing exercises and how to follow a holistic approach by treating the body as a whole and involving the patient in their care.

MSSI Delhi Chapter covers part of the costs through funds raised specially for this flagship project. Here the MSP's pay a subsidised amount for this excellent and essential well being programme, while the balance is covered by MSSI to ensure that the Physiotherapists get a fair market rate for their services. These physiotherapists are now MS experts due to their years of experience in this field and often they are greeted as friends or family members by the Msps.

#### Home Care Attendant:



Among our female patients, **Shagufta** is a popular visitor. She washes their hair, bathes or sponges them, takes care of their hygiene needs, gives them head or back massages, sometimes just gives them a mini manicure or combs their hair in new hairstyles to make them feel better. She also chats with them while she is doing all this and they get a chance to be pampered and bring out their inner glow.

**Scholarships, Mobility Aids and Health Supplements** There are some ways in which we help our MSP's and their families with materials or indirect monetary aid.



**Scholarships:** Presently MSSI Delhi is supporting the education of 28 children of MSP's, who receive partial scholarships. Every quarter we give scholarships worth over 1 lakh Rupees to these young students. There are several donors who have sponsored some of the senior students and all others are supported by funds raised by MSSI Delhi Chapter.

**Mobility Aids & other :** We also distribute wheelchairs, walkers, tripod sticks, air mattresses etc to our MSP's who are from disadvantaged sections of society. Bed bound MSPs are also given diapers & other products as per their needs. Some of these are purchased specially by MSSI while others are donated by our very generous donors on special request.



#### Health Supplements:

**Morepen Labs Ltd** has very generously been giving us regular supplies of protein powders and well-being and medicinal supplements. The beneficiaries of these products are carefully chosen based on their health needs & financial condition. These medicines are then couriered to them at regular intervals. These products have been very well received and our PwMS keep requesting for more & more.

# If there are any activities that you have missed out on and would like to be part of, do contact our Office staff and register your names with us.



### **VISION PROBLEMS**

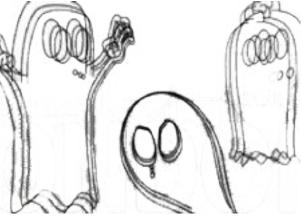
People with MS commonly experience some form of vision loss as the disorder progresses. A problem with vision is one of the most common symptoms of MS, and often one of the first that people with MS notice. The symptoms can include blurred vision, double vision (diplopia), optic neuritis, involuntary rapid eye movement and occasionally, a total loss of sight. Vision problems usually affect one eye, and they tend to get worse before getting better. Anyone experiencing these symptoms should contact their doctor immediately, as in some cases, treatment options are available.

Although complete vision loss is possible, it is not as common as other symptoms, such as:

- blurred vision
- loss of colour or greying vision
- pain as the eyes move
- partial or total blindness in one eye that gets worse during an attack
- trouble seeing to the side
- dull pain behind the eyes
- Eye movement problems

People with MS may experience uncontrollable eye movements called **nystagmus.** 

Nystagmus will not always present the same way, but it often causes one or both eyes to move back and forth repetitively. The person may lose control of how their eye moves in a certain direction. They may also feel as though things are moving when they are not. The severity of nystagmus can also vary. Some people may experience mild symptoms, while others experience movements that are severe enough to disrupt their vision.



#### **DOUBLE VISION**

Some people with MS may also experience

double vision, or diplopia. Diplopia occurs when the muscles in the eyes are out of sync because one is not working correctly. As a result, the brain struggles to put together a clear image.

In someone with MS, this occurs when the disorder affects the nerves controlling these muscles.

#### BLINDNESS

In the advanced stages, MS may destroy the protective coating around the nerves, leading to permanent changes in eyesight. In a person who regularly experiences vision issues during flare-ups, this may lead to partial or total blindness in one or both eyes.

MS affects each person differently, so there is no guarantee exactly how long symptoms will last.

Symptoms should subside as the inflammation in the nerve cells goes away. For many people, this is as little as a few weeks. Others may experience symptoms that last up to a year or more.



Some people may find that their symptoms get worse with heat, for example, after a hot shower or on particularly hot days. A high body temperature from exercise or the flu can also increase symptoms in some people. Symptoms may also worsen as the person uses or strains their eyes all through the day, like working long hours on a computer. Anyone experiencing eye symptoms should take regular breaks throughout the day to rest their eyes and avoid unnecessary strain.

#### **Optic neuritis**

A common visual symptom of MS is optic neuritisinflammation of the optic (vision) nerve. Optic neuritis usually occurs in one eye and may cause aching pain with eye movement, blurred vision, dim vision, or loss of colour vision. For example, red may appear washed out or grey. Vision may be lost completely in the affected eye. A blurred or dim spot (scotoma) may occur in the centre of the visual field, with peripheral vision unaffected. Optic neuritis usually occurs in one eye only. It is possible that after experiencing optic neuritis in one eye, you may experience it in the other eye at some time in the future-although this does not always occur.

Optic neuritis, with a loss of vision can be a frightening symptom, but in most cases, vision returns. Residual symptoms are possible, and you may notice a dimming or blurring of vision if you are very fatigued or overheated. Rest and cooling generally help vision return. **10** 

#### Causes

Eye symptoms arise when the immune system attacks the myelin sheath of the nerves that control various aspects of the eye. The type of symptoms that a person experiences will vary depending on which nerves sustain damage.

MS is not the only cause of optic neuritis. Other factors that may cause inflammation in the eyes and result in symptoms include:

- Some medications
- Viral or bacterial infections, such as Lyme disease, mumps, or measles
- Other auto immune conditions, including lupus or sarcoidosis
- Diagnosis
- To properly diagnose MS-related eye problems, doctors will need to rule out other conditions. To do so, they may order tests to check for MS or other issues. These tests may include:
- A vision test with an ophthalmologist
- Blood tests
- Ophthalmoscopy
- Imaging tests, such as MRI scans
- A visual evoked response test
- A lumbar puncture

Even if the person already knows that they have MS, a thorough diagnosis is important to avoid misdiagnosing another underlying issue.

#### Treatment

Most vision problems that occur due to MS eventually improve on their own, but people can still find these symptoms difficult to manage. Continuing to take medication to relieve MS symptoms will help. Doctors may recommend additional treatments if a person is experiencing very severe symptoms. For instance, if a person has severe vision loss, a doctor may recommend treatments that they would otherwise avoid, such as intravenous steroids.

In other cases, simple methods may help. For instance, doctors may give a person with double vision a temporary eye patch. The patch will block out input from one of the eyes, which should correct the double vision. Some medications may also help reduce the side effects of vision problems until the flare-up subsides.

#### Prevention

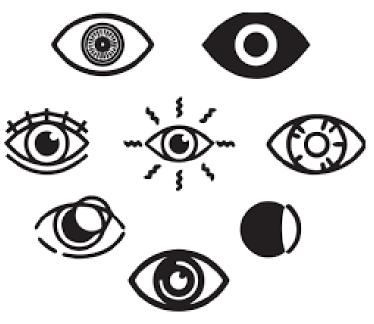
It is not possible to completely prevent MS damage to the eyes, but people can take steps to reduce the likelihood of it occurring.

People who are prone to flare-ups in their eyes should rest their eyes regularly throughout the day. Doctors may also recommend that people wear glasses with specific prisms in them that help control disturbances in the eye and reduce symptoms.

There may also be a link between vitamin D levels and the severity of flare-ups. A study in one of the journals found that there was an association between vitamin D levels and the severity of optic neuritis.

However, this does not necessarily mean that taking vitamin D will result in a person having less severe attacks. Researchers are performing more comprehensive research, but in the meantime, some doctors recommend that their MS patients take vitamin-D supplements to support their body.

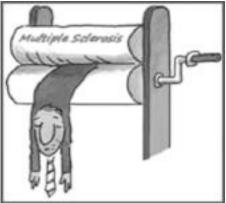
Anyone who notices new symptoms or whose symptoms begin to get worse should speak to a doctor who can advise on ways to treat or reduce the effect of symptoms.



#### Summary

MS-related vision problems are common, but the condition will not affect everyone in the same way. Many symptoms will go away on their own without treatment, and the overall prognosis is good.

Early diagnosis and treatment are important to help reduce symptom severity.



# WEAKNESS & FATIGUE IN MS

#### MS Fatigue: What to Know

While most people associate multiple sclerosis (MS) with muscle weakness, numbness, and pain, fatigue is the most common symptom of the condition. Nearly 80 percent of people diagnosed with MS experience fatigue at some point. In India, every MS person complains of deep fatigue. Fatigue is defined as extreme tiredness or unrelenting exhaustion. The fatigue associated with MS can be difficult to cope with and is also difficult to explain

to other people. Although it's an invisible symptom, fatigue is very real for those living with the condition.

The good news is that it's possible to manage fatigue with the right combination of medications, lifestyle changes, and energy-saving tips.

#### What causes MS fatigue?

Scientists currently don't fully understand the exact cause of MS-related fatigue. Some think that fatigue may be related to the constant activation of the immune system, sort of like having the flu virus always.

Others theorize that fatigue is related to the need for the brain to work harder in people with MS.

Fatigue may also be a result of nerve damage caused by MS. Sleep problems, depression, and medication side effects could also be part of the problem.

MRI scans have shown that people with MS fatigue use a larger area of the brain to perform tasks than people without fatigue. In response to nerve damage, the brain of a person with MS may be finding new routes for sending messages. This is thought to take more energy.

The feeling of fatigue may also be a result of the muscle weakness associated with MS.

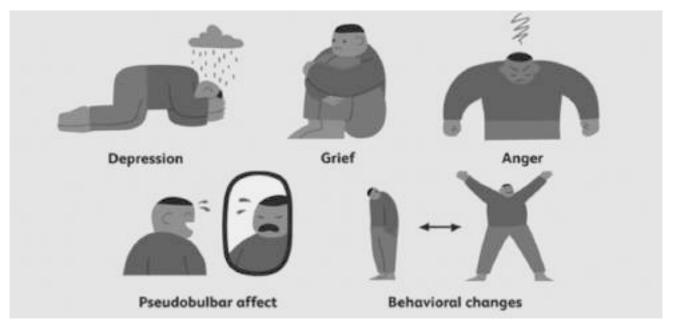
Certain complications of MS can also induce fatigue. This may be referred to as a secondary cause. Complications of MS that may also cause fatigue symptoms include:

- Chronic pain.
- Emotional disorders, such as anxiety and depression.
- Anaemia.
- Reduced physical fitness.
- Being overweight or obese.
- Reduced thyroid function.
- Diabetes.
- Infections.
- Sleeping issues, such as insomnia, sleep apnea, or restless leg syndrome.

Fatigue can also be a side effect of certain medications, such as those used to treat spasticity, pain, and bladder dysfunction.



## **Psychological Symptoms of Multiple Sclerosis**



#### What does it feel like?

Not everyone experiences fatigue the same way, and the feeling can be difficult to explain to others. In general, there are two types of MS fatigue: a general feeling of extreme tiredness and muscular fatigue.

MS fatigue is different from regular tiredness. Some people with MS describe the fatigue as feeling like you're weighed down and like every movement is difficult or clumsy. Others may describe it as an extreme jet lag or a hangover that won't. For others, fatigue is more mental. The brain goes fuzzy, and it becomes difficult to think clearly. Fatigue may affect the eyesight, as well as your ability to speak without slurring your words.

#### MS fatigue is also distinguished by the following characteristics:

- Occurs daily.
- Often occurs in the morning even after a good night of sleep.
- Tends to worsen as the day progresses.
- Is aggravated by heat and humidity.
- May come on suddenly.
- Interferes with daily tasks, such as work.



#### How to treat it:

If you're experiencing fatigue, make an appointment with your doctor to discuss possible treatment options. A doctor will likely want to run some tests to find out more about what may be causing your fatigue.

Based on the results of these tests, your doctor may prescribe medications or recommend counselling, physical therapy, and occupational therapy.

#### **Medications:**

Depending on what's causing your MS fatigue, a doctor may prescribe any one or a couple of these medications:

- Anti-inflammatory pain medications.
- Antiviral drugs that may help with MS fatigue.
- Iron supplements to treat anaemia.
- Sleeping pills to treat insomnia.
- Multivitamins to treat nutritional deficiencies caused by poor diet.
- Antidepressants to help with leg spasticity.
- Medications for urinary dysfunction, if the need to use the bathroom is keeping you up at night.

#### If you think one of your current medications may be causing your fatigue, ask your doctor about the possibility of changing your medication or adjusting the dosage. Don't stop taking your medication without consulting your doctor first.

#### Lifestyle tips:

- People with MS fatigue may need to recharge their batteries with frequent rest and a short daily nap, but it's also possible to plan and schedule your daily activities to help conserve energy.
- To conserve energy, try these tips:
- Divide large projects into smaller parts.
- Gather supplies in advance of an activity, like cooking or cleaning, so you won't have to run around to find supplies while you complete the task.
- Plan your shopping list in advance.
- Have your groceries delivered.
- Organize your house so that frequently used items are stored in easy-to-reach places.
- Make sure you have good lighting in your home so you're not straining to see things clearly.
- Consider using adaptive devices for dressing, bathing, and household chores.
- Keep your house cool if your fatigue tends to get worse when it's warm.
- While conserving energy is important, too much rest can be counterproductive. Exercising daily is essential for maintaining muscle strength and building endurance.
- There are several other lifestyle changes and remedies that can help you battle fatigue. These include:
- Going to physical therapy to learn about ways to conserve your energy and to establish an exercise routine.
- Practising good sleep hygiene.
- Seeking psychological counselling if you're depressed or anxious.
- Reducing alcohol consumption.
- Eating a healthy diet high in fruits, vegetables, whole grains, healthy fats, & lean protein.
- Eating a vegetarian diet. A study found that people with MS who followed a very-low fat, plant-based diet had a significant improvement in fatigue after 12 months.
- Reducing stress. Yoga, and meditation, are excellent ways to reduce stress and engage in physical activity.

#### The bottom line:

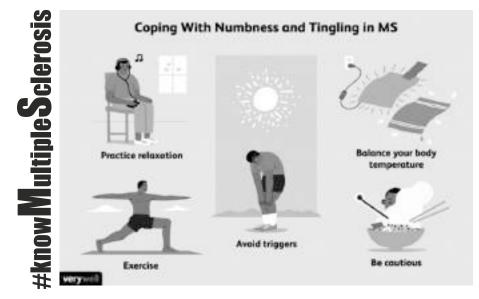
Fatigue is a very common symptom of MS and may be one of the most troublesome. If fatigue is affecting your work or daily life, talk with your doctor to find out if there are any medications you need to be taking or if your current medications need to be adjusted. You can overcome fatigue with the right combination of medications and lifestyle changes.

### NUMBNESS AND TINGLING IN MULTIPLE SCLEROSIS

#### What Is Multiple Sclerosis

Multiple Sclerosis (MS) is one of the most prevalent diseases of the central nervous system. It affects men & women in the prime of their lives. It occurs as a result of immune damage to the myelin sheath which insulates the central nervous system's nerve fibres. This damage blocks the passage of nerve impulses from the brain to other parts of the body.

Symptoms vary widely and include blurred vision, weak limbs, tingling sensations, unsteadiness, incontinence and fatigue. Some people may feel and seem healthy for many years after diagnosis, while others may be severely debilitated very quickly. It occurs without any known cause and is incurable despite intensive research worldwide. However its progress and consequences can be treated in order to improve the quality of life of the sufferers and their caretakers.

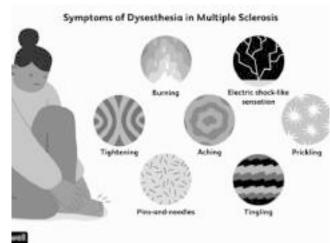


#### Why It Happens, How It Affects You, and Ways to Cope

Most MS Person's tell us that their first intimation that something is not right is when they began to feel frequent bouts of numbness in their hands and feet or on their face. The tingling sensations on the fingers and feet are also a part of theses phenomenon. Numbness and tingling are two of the most common symptoms of multiple sclerosis (MS). Often, they recur while the MS is static, and MSP's fear that they are the indication of a relapse. It is helpful to know that this is not always the case. While numbness and tingling can be frightening, they're usually not as disabling as motor symptoms.

#### Overview

Numbness is loss, reduced or altered sensation. You may notice that you have less feeling when touching something with your hand or notice the sensation in one leg is different than the other. You may feel the sensation of your limb being "asleep" with a pins and needles sensation. Numbness of the face, body or extremities (arms and legs) is one of the most common symptoms of MS. The numbness may be mild or so severe that it interferes with your ability to use the affected body part. For example, if you have very numb feet, and cannot feel the floor, you may have difficulty walking... you feel you are walking on a soft uneven surface. In India, numb feet can prevent you from realising the floors are very hot or cold due to extreme summer and winter. Numb hands may make it difficult for you to get dressed or hold anything.



Numbness and tingling can be separated into four categories:

• **Paresthesia:** The feeling of pins and needles, or a crawling sensation.

• **Dysesthesia:** A burning sensation along the nerve that may change how you feel pressure

• **Hyperpathia:** An increased sensitivity to pain

• **Anaesthesia:** A complete loss of any sensation

The first three types of numbness are more common in people with MS and may vary in timing and severity. The fourth type, anaesthesia, is less common in MS. While everyone's experience is different, these sensations are often temporary and resolve on their own.

#### How It Can Feel

Many of you will have experienced the sensation of an extremity "falling asleep." The sensation is similar in MS, except that it's chronic, it can last much longer, and it may occur in other places besides your arms, legs, hands, and feet.

Commonly referred to as "numbness" or "tingling," these are two of the most frequent MS symptoms for which people seek help. They're part of a group of sensory symptoms called "paraesthesia", abnormal sensations that cause discomfort but not pain.

Though numbress and tingling are most often the terms used to describe these sensations, other "paraesthesia" characteristics can include:

Pins and Needles	Buzzing
Burning	Vibrating
Tickling	Throbbing
Prickling	Itching
The affected area feeling cold	Difficulty using the affected area

When a sensation is painful, it's called a "dysesthesia", another type of sensory symptom. An example is feeling like your feet are burning.

Some people with MS also experience another sensory symptom called "allodynia", which is feeling pain when you're touched with things that don't normally cause pain, such as your clothes or a friendly stroke of your arm. Each person has his or her own individual pattern of sensory disturbances in MS that can include any of these symptoms.

Sensory symptoms can be transient (lasting for just a little while) or they can last for a long time. In addition, while some sensory symptoms cause only mild discomfort or are simply annoying, as in the case of paraesthesia, others may be quite painful.

#### **Location and Effects**

Numbness and tingling in MS can occur anywhere in your body, which may present a variety of problems depending on their location. For example, if your feet are affected, you may experience problems walking because you feel pain when you put pressure on your feet, your coordination and balance are impaired, and your ability to sense where you are, is impaired. When your hands are affected, you may experience problems with writing, fine-motor movements, or holding things.

#### Causes

Sensory issues in the genitalia, especially numbness, can cause sexual dysfunction. Paraesthesia's of your tongue or face may make it difficult for you to speak, eat, drink, or to detect the temperature of your food.

Sensory disturbances, including numbness and tingling, tend to be worse at night and when you're hot. A good rule of thumb is to ensure your bedroom is cool, as this may help ease your symptoms. In India, during our very hot summers many of these symptoms get exacerbated. Often these symptoms affect the sleep patterns, and an occasional sleeping medicine may be needed.

# Here are some things to keep in mind if you are experiencing numbness or tingling:



#### Communicate with doctor and family members

Although numbness and tingling may be mild in many cases, it's important to let your caregivers and doctors know what you're feeling. Your medical team may discuss different options to address this symptom if it is severe. If you find it difficult to do physical activities, such as writing, dressing, or walking, seek help from your family members and caregivers as they may

be able to assist you.



#### Be careful while eating

If your face is numb, be cautious when you're eating. Try to take slow bites and monitor your chewing. This may help you avoid biting your cheeks, tongue, or lips.



#### Use caution around hot objects

Whether you have MS or not, you should always handle hot objects with caution. If you are experiencing numbness, you should be particularly careful, as you may not feel a burn. Be careful around fires, hot water, stoves, and other hot items.



#### Consider assistive walking devices

Some people with MS experience numbness and tingling in their feet or legs. This may make walking difficult. Consider using a cane or walker to help keep your balance if you have difficulty walking. Remember, roads in India are very uneven and the pavements are frequently broken and uneven. Hence, we need to extra care in India!

Remember, even though these symptoms are often temporary, you should always take extra steps of caution and let others know how you are feeling.

## Treatment

While there are no medications to treat numbness and tingling specifically, there are some options you can try that may help these symptoms.

#### **Complementary and Alternative Medicine**

Some people find relief from their sensory symptoms by using complementary and alternative medicine (CAM) approaches, such as:



**Reflexology:** With this therapeutic technique, a practitioner presses on certain points on your hands and feet to promote healing.



**Acupuncture:** This treatment involves pricking your skin with needles to relieve pain. Since acupuncture can stimulate your immune system (an undesirable outcome since MS is thought to be an autoimmune disease), talk to your doctor before you try this.



**Homeopathy:** There are many homeopathy medicines which may help relieve your symptoms. They do not work against your basic medicines, but in co-ordination with them, and may be a good alternative medicine.



**A new diet:** It's possible that certain foods trigger your symptoms, though this is a controversial topic. Work with a dietitian to strategically pinpoint the foods that exacerbate your symptoms and a design plan to minimize your intake of them. Spicy food should be avoided, and of course, oil intake should be reduced.



**Supplements:** Low levels of vitamin B12, a deficiency that's more common in people with MS, could cause sensory symptoms. However, research regarding the link between vitamin B12 and MS is still inconclusive. Look into getting your B12 level checked, just to be sure, and ask your doctor whether it's a good idea to take a supplement.



Coping:

There are also some management techniques you can try that may reduce or even prevent numbness and tingling, as well as help you deal with them when they do occur.

#### **Be Cautious**

Make sure you're taking appropriate precautions when you feel numbness and tingling in areas of your body that could create safety issues. For instance, if you have facial numbness, be cautious when you're chewing food and drinking hot beverages, so you don't bite the inside of your mouth or tongue or burn yourself.

If you're feeling paraesthesia in your hands or feet, be careful not to engage in any activity in which you might lose your grip or fall and injure yourself. If possible, try to relax until the sensations pass.

### Relax

Your sensory symptoms may get worse when you're stressed. In fact, just thinking about a stressful situation can be enough to ratchet up tingling in your feet.

Try taking a break from your stress and relaxing. If you can find time to turn off that part of your brain that has you worried about finances, wondering how you're going to get everything done, or replaying an angry conversation, for example, your symptoms may back down a little. It's not easy, but it can be done.

One strategy is doing a mini meditation. This is not an in-depth meditation; it involves taking one or two minutes in the middle of a stressful period to close your eyes, take a few deep breaths, and focus your thoughts on your breathing.

Alternatively, do something that you love for at least a couple of minutes. Listen to your favourite song. Read a couple of pages in a fun novel. Have a cup of tea. Go for a walk around the block. Carving out a little time for self-care every day can help you manage your anxiety and can help raise your self-esteem.



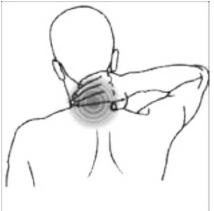


#### Warm Up or Cool Down

Sometimes your feet can get either very hot or very cold, especially at night, and these temperature extremes are often accompanied by a burning or tingling sensation.

To warm up your feet, try a wrap that's filled with rice or beans that can be heated up in the microwave and put on any body part that's chilly. You can put one on your feet and one over your shoulders. You can also use a hot-water bottle to warm up your feet or you can soak them in hot water. Wearing thick socks to bed helps too.

Cooling down burning feet is a little trickier. The solution can be something simple, like sticking your feet outside the sheets when you're in bed, standing on cool bathroom tiles, or putting a cold, wet washcloth on them.



### PAIN & SPASMS IN MS:

Pain is a common symptom in MS, with up to two-thirds of people with MS in India reporting pain. Those who experience pain may find it affects their daily life activities, such as work and recreation, and their mood and enjoyment of life.

# Why does pain occur in MS and what are the common types?

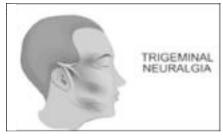
Steady and achy types of pain in MS may be a result of muscles becoming fatigued and stretched when they are used to compensate for muscles that have been weakened by MS. People with MS may also experience more stabbing

types pain, which result from faulty nerve signals emanating from the nerves due to MS lesions in the brain and spinal cord.

The most common pain syndromes experienced by people with MS include:

- Headache (seen more in MS than the general population)
- Continuous burning pain in the extremities
- Back pain
- Painful tonic spasms (a cramping, pulling pain)

Experts usually describe pain caused by MS as musculoskeletal, paroxysmal or chronic neurogenic. Musculoskeletal pain can be due to muscular weakness, spasticity and imbalance. It is most often seen in the hips, legs and arms and particularly when muscles, tendons and ligaments remain immobile for some time. Back pain may occur due to improper seating or incorrect posture while walking. Contractures associated with weakness and spasticity can be painful. Muscular spasms or cramps (called flex or spasms) can be severe and discomfiting. Leg spasms, for example, often occur during sleep. Paroxysmal pains are seen in between five and ten per cent of people with MS.



The most characteristic is the facial pain of trigeminal neuralgia. Number of Indian MS persons complain of this pain.

Neurogenic pain is the most common and distressing of the pain syndromes in MS. This pain is described as constant, boring, burning or tingling intensely. It often occurs in the legs.

Paraesthesia types include pins and needles, tingling, shivering, burning pains, feelings of pressure, and areas of skin with heightened sensitivity to touch. The pains associated with these can be aching, throbbing, stabbing, shooting, gnawing, tingling, tightness and numbress.

Dysesthesia types include burning, aching or girdling around the body. These are neurologic in origin and are sometimes treated with antidepressants. Optic Neuritis (ON) is a common first symptom of MS. Pain commonly occurs or is made worse with eye movement. The pain with ON usually resolves in between seven and ten days.



#### **Muscle Spasms:**

Muscle spasms are defined as sudden, sustained and involuntary contractions of muscles and are common among people with MS.

They emerge as a result of nerve lesions that disrupt the signals between the brain and the muscle, causing the muscle to remain in a contracted state, making it tight or stiff. This muscle stiffness, also called spasticity, makes muscle movement difficult. The most affected muscles are those of the legs, arms, back, and trunk. Muscle spasms in MS may sometimes be accompanied with pain, weakness, and clonus (repetitive, involuntary up and down movements of a muscle). The most common clonus in MS is the tapping movement of the foot on the floor.



## Symptoms:

Though it can occur in any muscle in your body, spasticity tends to most often affect the legs. You may also experience it in your arms, the muscles in your back and trunk, and near or in your joints. Spasticity also tends to be asymmetrical, meaning you may notice that it's worse or happens more often on one side of your body than the other.

The symptoms you may experience when your muscles are spasming include:

#### • Stiffness

• Tightness

- Difficulty moving the affected area
- A feeling of heaviness
- Cramping & Achiness Pain that ranges from mild to severe

Your spasms may be worse when you wake up in the morning or during the night when you're trying to sleep.

#### **Types of Spasms:**

There are several kinds of muscle spasms that can occur in MS, including **Extensor spasms**: These occur when a limb, usually your leg, stiffens and you can't bend the joint, which makes the limb jerk away from your body. These spasms usually affect the quadriceps, the large muscles on the front of your thigh, causing your lower leg to straighten. Spasms of the adductor muscles, located on the inside of the upper leg, are rarer but can cause your legs to close together tightly, making it difficult to separate them.

#### **Spasticity:**

At some point during their disease, many people with multiple sclerosis (MS) experience spasticity, a term that describes an increase in your muscle tone. While that may sound like a good thing if you're looking to tone up, what it really means is that your muscles don't relax as much or as easily as they should, resulting in involuntary muscle spasms. Because of this, spasticity affects your movement, making it a motor symptom rather than a sensory symptom like pain or numbness.



**Flexor spasms:** With these spasms, your limbs bend (contract) towards your body. This type of spasm almost always affects your legs, especially the hamstrings or hip flexors.

**Clonus:** This is the term for what happens when your muscles jerk or twitch repeatedly, like what happens in some types of seizures. The most common forms of clonus are when your foot taps rapidly and repetitively on the floor, or when your knee or ankle jerks repeatedly after stimulation, such as tapping at the joint.

**Stiffness**: This can be thought of as mild spasticity. While not as dramatic as some of the spasms described above, when muscles are slow to relax, it can cause problems walking or using your hands and fingers to perform delicate movements. In some cases, the stiffness may not pose a huge problem. In other cases, it can cause problems with mobility or be painful enough to interfere with your daily life.

#### Causes:

Like most other MS symptoms, spasticity is primarily caused by demyelination, which in this case increases your muscle tone. Because of slow or interrupted nerve impulses, your muscles may respond by not relaxing as quickly as they should, tightening involuntarily, or staying contracted for long periods of time or even constantly.

There are a variety of factors that can aggravate spasticity, acting as a trigger for spasms, like:

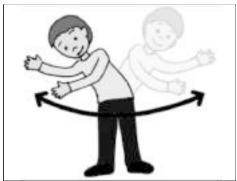
- Infections, such as respiratory, urinary tract, or bladder infections
- Pain
- Sores or skin breakdown
- Quick or sudden movements
- An increase in internal temperature (for example, because of a fever or excessive exercise)
- A full bladder
- Binding, rubbing, or irritating clothes
- Humidity
- Being too hot or too cold
- Constipation
- Problems with posture
- Extreme environmental temperatures
- Stress, worry, or anxiety

#### **Effects:**

For many people, spasticity can be an annoyance or a passing problem that hinders smooth walking one day but is absent the next. It may just be that walking quickly or climbing stairs is harder than it was previously. Others may benefit from mild spasticity or stiffness, as it can counteract some degree of muscle weakness and make it easier to stand or walk.

That said, for some people, severe forms of spasticity or stiffness can cause a problem with mobility, as walking becomes difficult or impossible. For example, some spasms can be aggravated when moving from your bed into a wheelchair.

In addition, some extensor spasms can be so sudden and strong that you can fall out of a chair or bed. Flexor spasms can cause your limbs to be held in painful positions and lead to secondary joint pain.



# **DIZZINESS AND BALANCE**

Dizziness is a common symptom of MS. People with MS may feel off balance or lightheaded. Sometimes they have the sensation that they or their surroundings are spinning-a condition known as vertigo. These symptoms are due to lesions-damaged areas-in the complex pathways of the brain that coordinate visual, spatial and other inputs needed to produce and maintain balance.

#### What does dizziness from MS feel like?

MS can make you feel lightheaded or off-balance, usually when you're standing up and moving around. If you're dizzy and nauseous when you're lying down, or if you stumble to one side, chances are it's a problem with your inner ear, which controls your balance.

#### • Should I go to the hospital for dizziness?

If you experience dizziness following a blow or jolt to your head or body-especially if it comes with weakness, a headache that is getting worse, vomiting, behavioral changes, slurred speech or seizure-seek medical help immediately. It may not be related to MS, but it needs urgent attention.

#### • Is dizziness an MS symptom?

Multiple sclerosis (MS) is an immune system disease that affects the central nervous system. ... Symptoms of MS can include vision problems, numbness of the limbs, and balance issues. Dizziness and vertigo are common symptoms of MS though most people don't have them as their first symptoms. MS can cause a wide range of symptoms that can have an effect on balance, including difficulty with coordination, tremor and muscle weakness, stiffness or spasms.

- When vertigo occurs, the following steps can help you stay safe and feel more comfortable:
- 1. Sit until it passes.
- 2. Avoid moving your head or body position.
- 3. Dim bright lights and don't try to read.
- 4. Avoid stairs.

5. Don't drive until you're sure the vertigo has passed. When you feel better begin moving slowly.

- 6. Drink plenty of fluids, especially water
- 7. Avoid coffee, cigarettes, alcohol and drugs.
- Can you drive with MS?

One of the first questions many people have when they're diagnosed with MS is "Will I still be able to drive?" The good news is that most people with MS continue to drive as normal unless there is lot of spasticity. However, if you have frequent muscle spasms, weakness or numbness in the legs you may need to modify your car for hand controls.

#### What vitamin deficiency can cause dizziness?

Low Vitamin B12 Levels can cause dizziness. Deficiencies in this essential vitamin may lead to a number of neurological problems, including feeling off-balance, and having low blood pressure and decreased blood flow to your brain. You can also get your Thyroid checked.

- Can low calcium cause dizziness ? Fatigue associated with calcium deficiency can also cause lightheadedness, dizziness, and brain fog, which involves lack of focus, forgetfulness, and confusion.
- Don't try to self-treat your bladder problems by drinking less fluid! This can lead to constipation and/or urinary tract infections.



## **BLADDER ISSUES**



There are several symptoms in MS one of which is Bladder dysfunction, a common problem for persons with Multiple Sclerosis.

The severity of symptoms often correlate with the degree of spinal cord involvement and, hence, the MS person's general level of disability. The emphasis of management is now mainly medical and is increasingly offered by urologists. Treatments can be highly

effective, relieving patients of what are otherwise very troublesome symptoms that would compound their neurological disability.

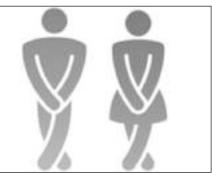
Bowel and bladder issues can be worrying, embarrassing, and painful. One is usually referred by the neurologist to a Urologist. An Indian study reveals approximately 66 % of people with MS will develop bladder dysfunction within three to five years of diagnosis.

The symptom is a result of damage caused by the disease that leads to interrupted signals between the spinal cord and brain, which can affect a wide range of bodily functions, including bladder function.

An overactive bladder is common, where the nerve damage results in frequent, uncontrollable urges to empty, even though the bladder isn't full. Problems emptying the bladder completely are also very common.

#### What bladder issues are associated with MS?

Frequency and/or urgency of urination-Feeling like passing again & again Incontinence (the inability to hold in urine) Hesitancy in starting urination- unable to pass urine although you feel the sensation & bladder is full Frequent nighttime urination- disturbed sleep



#### How does MS affect the urinary system?

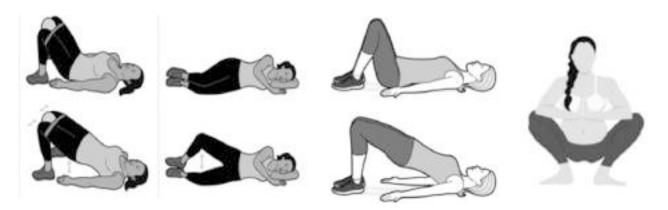
The detrusor muscle which is found in the wall of the bladder should remain relaxed to allow the bladder to store urine and the same muscle contracts during urination to release urine. In MS, this function gets impaired. When the muscle contracts involuntarily, increasing the pressure in the bladder and decreasing the volume of urine the bladder can hold, it causes symptoms of going frequently, urgently, leaking urine, or interfering with a good night's sleep.

Many behaviour modification techniques may be used to manage bladder symptoms. Here are a few suggestions:

- Drink 1.5L-2 L of fluids a day to keep well hydrated. Water is best.
- Drink 200-300ml (1 glass) fluid at regular intervals and then urinate on a regular schedule, rather than waiting for the urge. It takes about one and a half hours for fluid that you drank to get to the bladder, so try to empty the bladder by the clock, every one and a half to two hours.
- Limit the amount of caffeinated beverages like tea & coffee, alcohol, and orange juice. It's okay to have one cup of coffee or tea, but remember that caffeine can cause you to go more frequently and more urgently. Alcohol is also a bladder irritant.
- Stop smoking (yes, smoking is a bladder irritant too). It's bad any way!
- Don't try to self-treat your bladder problems by drinking less fluid! This can lead to constipation and/or urinary tract infections.

#### **Pelvic Floor Management Training**

PFMT-Pelvic Floor Management Training, may help to reduce symptoms. It would seem practical to include some form of PFMT as standard in a rehabilitative / physiotherapy programme and, if necessary, direct referral to a specialist continence physiotherapist should be consulted. This is likely to have a positive impact on people's quality of life



Study indicates that pelvic floor muscle exercises combined with electrical stimulation of the pelvic floor constitute an effective treatment for lower urinary tract dysfunction at least in male patients with MS.

#### How to strengthen detrusor muscle?

Always start exercise with an empty bladder, your first goal should be to tighten your pelvic floor muscles for 5 seconds. Then relax them for 5 seconds. Try to do 5 reps on your first day. As you gain confidence from your new routine, aim for 10 seconds at a time, relaxing for 10 seconds between contractions.

More recently, Botox injections into the bladder have been approved by the FDA to help with managing symptoms.

The message here is that bladder symptoms can be treated once these symptoms are discussed openly and proper assessment is completed. It's important to share your concerns with your neurologist if they are not able to help, ask for a referral to someone who can help. You may need a referral to a urologist to treat MS bladder symptoms.

There are also medications available that may be taken regularly or from time to time. Oxybutanin and Tolterodine, are among medications used to treat frequent urination, urinary incontinence, or urinary urgency. Effects are seen within an hour. It is taken by mouth. Common side effects include headache, dry mouth, constipation, and dizziness. **Please consult your doctor for suitability and correct dosage.** 



# SEXUAL DYSFUNCTION IN MS

**Multiple sclerosis (MS)** is a chronic progressive neurological disease, which is most likely to develop in young adults at an age that is an important time of life for sexual activity. Sexual dysfunction (SD) is a common reported problem among patients with MS. Unfortunately, it often remains under diagnosed , and can affect MS women's quality of life negatively.

In a recent study in UK, people with MS completed a pack of questionnaires on sexual functioning, fatigue, anxiety and

depression and day-to-day life. 431 people answered questions on sexual functioning.

Of those who were sexually active, only 12.5% reported no impact on any aspect of sexual function. These results show that the effect of MS on sexual functioning is significant. The psychological aspects of MS affecting sexuality - such as feeling less attractive or guilt and tension about sexually satisfying a partner - were found to have a considerable impact, contributing significantly to the other areas of sexual problems. Depression, rather than affecting sexual functioning, was found to be affected by the psychological aspects, with worries about sexual functioning increasing depressive symptoms.

The psychological aspect of sexual problems, an area which is frequently neglected during discussions with health professionals, is clearly important to take into account. The researchers highlight the need to address people's worries about sexuality, offering the potential to reduce depression.

Of those who were sexually active, only 12.5% reported no impact on any aspect of sexual function.

Sexual problems were classified into three categories:

• Primary-MS directly affects sexual response, such as problems with orgasm, numbness in genital area or vaginal lubrication



• Secondary-MS symptoms indirectly affect the sexual response, such as bladder or bowel, pain or spasticity problems which make sexual activity more difficult

• Tertiary- psychological and social aspects of MS that affect sexuality, such as being afraid of being rejected because of MS, feeling less attractive or concerns about sexually satisfying a partner. These aspects were grouped together as "worries" by the researchers.



A great majority of the people (83.5%) experienced some MSrelated symptoms that directly affect their sexual functioning. Almost two-thirds (63.8%) indicated that they were affected by all three areas.

As expected, the study revealed a strong connection between level of disability and all three categories of sexual problems. Men had significantly more "worries" than women, although the type of worries varied by gender with women being more likely to worry about feeling less attractive due to their MS and men being more likely to worry about sexually satisfying their partner. Depression, rather than any direct problem of sexual functioning, was found to be affecting people's desire & performance, and this issue led to further increasing depressive symptoms.

#### What does it mean?

These results show that the effect of MS on sexual functioning is significant. The "worries" were found to have a considerable impact, largely contributing to the other areas of sexual problems. The psychological aspect of sexual problems, an area which is frequently neglected during discussions with health professionals, is clearly important to take into account.



The researchers highlight the need to address people's worries about sexuality, offering the potential to reduce depression. If MS damages the nerve pathways, sexual responseincluding arousal and orgasm-in MS persons can be directly affected. Sexual problems also stem from MS symptoms such as fatigue or spasticity, as well as from psychological factors relating to self-esteem and mood changes.

Sexual problems if not dealt on time and understood thoroughly may lead to separation and diversion of mind of partners causing heart aches and mental trauma which may lead to deterioration of MS and quality of life.



# WHAT CAUSES SEXUAL PROBLEMS FOR MEN & WOMEN WITH MS?

For men with MS , sexual problems are caused by a combination of physical, psychological, emotional and social factors. These fall into three broad groups arising directly from MS damage to nerve pathways in the brain and spinal cord that process erotic stimuli and control sexual feelings and responses.

• Or indirectly from symptoms of MS, such as bladder symptoms, fatigue, low mood and depression or spasticity.

• from prescribed medications or from the wider

<sup>1</sup> consequences of living with MS.

This can undermine your sense of self, sexual identity and enjoyment, and your confidence as a sexual partner or potential partner. Emotional reactions can be an issue for both the man with MS and his partner, and relationship difficulties are commonly reported.

Swati a cheerful young working MS person felt that her husband was no longer interested in her and ignored her constantly; she was so disturbed that it started affecting her attitude towards her child and in laws. She felt no one understood her problems. When she approached us and confided in us, a visit to her house was arranged and both she and

her husband were counseled. It helped them, as we were in constant touch and her husband and he started paying attention to her. Just talking about it led to improvement in Swati's health & attitude. Concentrating on sex can sometimes get in the way of the romance that brings people together and distract people from the companionship that is an essential part of a relationship. Simple closeness, such as holding hands or cuddling, and enjoying each other's company are vital to a relationship and can reassure both partners that they are the object of affection. This approach brings in immense confidence in the MS person.





#### Talking about it ..

The most important starting point for managing sexual issues is being willing to talk about them. Many people find it difficult to talk about sexual problems with their partner or close friends, let alone a GP or their MS counselor. But remember that sexual problems can be symptoms of MS and deserve to be taken seriously and there are approaches to manage the effects. Many healthcare professionals, such as your GP or MS Society Counselors are used to talking about such matters on a regular basis with confidentiality. If you are not satisfied with the suggestions, ask to be referred to a professional with more

experience in this area. Don't give up; help is out there, but you may need to be persistent. Whether you're in a relationship or not, difficulty in satisfying your sexual needs can be a cause of frustration, disappointment and distress. The most important starting point for managing sexual problems is to be willing to talk about them. Talk to someone that you feel safe and comfortable with. This may be your partner, a close friend or a health professional such as your GP. You may prefer to discuss some issues more anonymously via a help line or online group.

Many MS persons, both men & women have frequently reached out to our senior counselors at MSSI Delhi in total confidence.

#### What causes reduced sexual desire?

A range of factors can have a role in reducing your desire sex.

• A loss of self-confidence may add to your doubts about expressing your sexuality or make you feel self-conscious about how you look to others. This can make you feel isolated, less attractive and result in less interest in sex. You may worry that you're no longer fulfilling your sexual role in a relationship -even if your partner doesn't think there's an issue. Although you might not experience desire before sex, this doesn't mean you can't become aroused or still respond to and enjoy intimacy or sexual activity.



• It's also important to remember that many women even

without MS will experience some of these issues such as loss of desire and vaginal dryness. These are common problems in the general population and can be due to a number of causes unrelated to MS such as aging, menopause, alcohol or drug use, or other health related conditions.

• MS symptoms may affect your sex drive. For instance, fatigue and depression can impact on desire, or pain and spasms may make sex physically uncomfortable. Fear of symptoms can also play a role. For example being anxious about losing control of your bladder or bowels during sex might mean you don't anticipate sex, and the pleasure it can bring, in the same way as before.



• Reduced sexual desire is common in the general population and issues unrelated to your MS can also play a part. Stress, anxiety and depression can all have an effect, as can worrying about things like work or finances. Physical factors such as hormone imbalances can lower your sex drive, as can alcohol or drug use.

• Finding effective treatment for your sexual issues needs careful analysis . For example, if fatigue is affecting your sexual performance, a pill that makes it 'easier' to be aroused may not resolve the problem of physical stamina. Similarly, other medication alone won't resolve feelings of being unattractive or sexually less desirable.



• Rather than focusing on "the act" itself, it might be more fulfilling and rewarding to explore more mutually caring and supportive approaches, such as focusing on touch and sensuality.

• Explore each other, learn new areas of sensitivity, newer erogenous zones in your bodies, go for longer foreplay etc.

#### **Talking to partners**

If you are in a relationship, it's important to reassure your partner that they are not the source of any sexual difficulties. Without this understanding, they might misunderstand changes in desire or arousal as a reflection on themselves - a sign of loss of affection or imagine that you have lost interest in them sexually, they may

feel rejected or that they've failed you in some way. If you don't discuss these issues, it can lead to cracks in the relationship that might be irreparable by the time you eventually seek help.

#### SOME IDEAS FOR RAISING THE SUBJECT OF SEX

If you do decide to approach your health professional, you may find it helpful to note down your problems and questions on a piece of paper as it is easy to forget important points when you are talking about a sensitive subject like sex. It may increase your confidence to rehearse what you are going to say. Before you attend your appointment, it might be helpful to think about the actual words you want to use when you are discussing sexual difficulties. If you choose words that you feel comfortable with, this may help you to relax. This might be more general terms such as 'private parts', 'down below' or you might prefer more biological terms to make sure there's no misunderstandings.

#### **IDEAS FROM PEOPLE WITH MS**

- Some people start by apologizing for bringing the subject up, but it allows them to break the ice and talk about the subject and it then becomes much easier.
- Some others favour the direct approach something like "Sex just isn't what it used to be" something that compares before with now.
- "Doctor, I'd like your help. I'm having problems with my sex life, could it be my MS?" The same question can be put across to MS counselors or friends.

Swati had said to us – "I'm finding that my MS fatigue and incontinence is getting in the way of intimacy, is that something I can talk to you about?"

We from MSSI had several telephonic discussions and counseling sessions with Swati. MS can bother you constantly but it does not stop you from making your self attractive, not giving in to outside pressures, create inviting surroundings & set the mood. Rest as much as you can to feel fresh when your partner is around.

In India parents/parents in law play a big role too, especially in a joint family system. Most often they do not understand the issue or it is a big taboo for them to talk to children leading to deep discontentment and change of attitude towards the MS person. For example Swati's in laws never supported her or even tried to understand her problems. They felt she was causing unhappiness in their son's life, and he was the victim . Consequently they shunned he , which made both her & her husband more miserable, as he was also divided between family pressures & love for his wife!

After MS Society intervened giving subtle advise to both partners, things improved for a while & they lived amicably together for 5 years. Unfortunately, constant pressure from family members caused them to ultimately part ways.

#### We would advice all young caring married couples to try and become loving and understanding caregivers also. This will save lot of unhappiness and relapses. PARTNERS NEED TO BECOME LOVING AND UNDERSTANDING CAREGIVERS.



### **5 STEPS TO TAKE IF YOU'RE UNHAPPY** WITH YOUR CURRENT MS TREATMENT

While multiple sclerosis has no cure, many treatments are available that can slow the disease's progression, control flare-ups, and manage symptoms. Some treatments may work well for you, but others may not. If you're not satisfied with your current treatment, you might want to try something else.

There are many reasons to consider changing treatments. Your current medication might have side effects that bother you, or it may no longer seem to be as effective as it was. You might be having challenges taking your medication, such as missing doses or struggling with the injection process even high costs.

A variety of treatment options are available for MS. If you're unhappy with your current treatment plan, here are five steps you can take to change it.

#### **1. ASSESS THE EFFECTIVENESS OF YOUR CURRENT TREATMENT**

- ✓ You might want to switch treatments because you're not sure if the medication you're taking is effective. Ask your doctor how you can tell if your medication is effective.
- Don't stop taking your medication or change your dose without talking to your doctor first.
- ✓ Medication can be working properly even if your symptoms seem to be the same. This is because the medication is preventing new symptoms from developing as it controls inflammation.
- ✓ It may be that your current symptoms simply aren't reversible, and your treatment is aimed instead at preventing your condition from progressing.

Sometimes it's not the medication that needs changing but the dose. Ask your doctor if your current dose should be increased. Also make sure that you've been taking your medication as prescribed.

If you still think that your current treatment isn't working, make sure that you've given it enough time. Medication for MS can take between 6 to 12 months to take effect. If you've been on your current treatment for less time, your doctor may recommend that you wait before considering a change.



#### 2. BE SPECIFIC ABOUT WHAT YOU WANT TO CHANGE

Whatever your reason for making a change, you should be clear with your doctor about what's not working. Maybe the medication you're on makes you moody or requires regular liver function tests. Perhaps even though you've received training to self-inject your medication, you might still dread the task and want to switch to an oral alternative. Specific feedback about your current treatment can help your doctor recommend another option that's better for you.

#### **3. MAKE NOTE OF LIFESTYLE CHANGES**

Changes to your daily life can sometimes affect your treatment. Tell your doctor about anything that's different such as your diet, activity level, or sleeping patterns.

Dietary factors like salt, animal fat, sugar, low fiber, red meat, and fried food are linked to increased inflammation that can make MS symptoms worse. If you think you're having a relapse, it might be because of a dietary factor and not because your medication has stopped working.

Update your doctor about any lifestyle changes that could be affecting your treatment so that together you can make an informed decision.

#### 4. ASK FOR CURRENT TESTING

Increased lesions on an MRI scan and poorer outcomes from a neurologic exam are two signs that a treatment change might be in order. Ask your doctor if you can have current testing done to see if you should switch medications.

#### 5. S.E.A.R.C.H.

The acronym **S.E.A.R.C.H.** acts as a guide for choosing the best MS treatment based on the following factors:

- Safety
- Effectiveness
- Access
- Risks
- Convenience

#### CONCLUSION

There are multiple treatment options available for MS. If you want to change your current treatment, be clear about why, so that your doctor can help you choose another that's a better fit for you.

Sometimes treatments are working as intended even if you don't notice any changes. Check with your doctor to see if this is true in your case before switching medication.

As you consider your options, continue taking your current medication, and **don't change** your dose until you speak with your doctor.

## ORAL VS. INJECTABLE MS TREATMENTS

## WHAT'S THE DIFFERENCE?

MS Society counselors are often asked for advice on Disease Modifying Drugs (DMDs) by MS persons before they start on a particular treatment.

As a support group working for the welfare of people with MS, we can share with you about available Disease-modifying therapies (DMTs) that are designed to slow the long-term progression of Multiple Sclerosis, reduce relapses, and prevent new damage from occurring. We give information only.

All MS persons should take informed decisions based on the advice of their neurophysicians who will guide them regarding the most appropriate DMTs/DMDs for them.

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 after discussion with a neurologist and should take into consideration the unique health and life circumstances of each individual.

## HOW TO CHOOSE THE BEST MS TREATMENT FOR YOUR LIFESTYLE

DMTs can be taken **orally or by injection**. Injections can be either self-injected at home or given as intravenous infusions in a clinical setting. Both oral and injectable medications have benefits and potential side effects. Many come with specific warnings from the Food and Drug Administration (FDA).

There are a variety of treatments for multiple sclerosis (MS) designed to change how the disease progresses, to manage relapses, and to help with symptoms.

Disease-modifying therapies (DMTs) for MS fall into three categories:

## **1. SELF-INJECTABLE 2. INFUSION 3. ORAL**

With so many options, it can be hard to decide which treatment to try first. Your doctor can help you weigh the pros and cons of each choice and how they impact your lifestyle. Here's more information on each type of medication to help you make an informed decision.



**SELF-INJECTABLE MEDICATION-**These medications are given by injection, which you can do yourself. You'll receive training from a healthcare professional and learn the proper way to inject yourself safely. These are simple pen like injections which have to be loaded with a cartridge of the drug. It looks similar to a diabetes injection.

Self-injectable medications include:

## 1. GLATIRAMER ACETATE (COPAXONE, GLATOPA)

## 2. INTERFERON BETA-1A (AVONEX, REBIF)

## 3. INTERFERON BETA-1B (BETASERON, EXTAVIA)

## 4. PEGINTERFERON BETA-1A (PLEGRIDY)

You can inject these medications either subcutaneously (beneath the skin) or intramuscularly (directly into the muscle). This may involve a needle or an injection pen. Most of these medications can cause redness, swelling, and pain at the injection site, in addition to other side effects.

**DOSAGE:** The frequency of injections ranges from daily to once per month. The side effects of most injectable medications are unpleasant but usually short-lived and manageable. You may experience pain, swelling, or skin reactions at the injection site if using the same spot repeatedly. Many of these medications may cause flu-like symptoms, as well as liver test abnormalities. If you're comfortable self-injecting and prefer not to take oral medications daily, injectable treatments might be a good choice for you. Glatopa requires daily injections but others, such as Plegridy, are done less frequently.

## **COMMON SELF-INJECTABLE MEDICATIONS**

Self-injectable medications make up the largest category of DMTs. They're used for the long-term treatment of relapsing-remitting MS (RRMS).

## Avonex (interferon beta-1a)

- · Benefit: works as immune system modulator, has antiviral properties
- · Dose frequency and method: weekly, intramuscular injection
- · Common side effects can include: headache, flu-like symptoms

 $\cdot$  Warnings include: liver enzymes and complete blood count (CBC) may need to be monitored

## **Betaseron (interferon beta-1b)**

- · Benefit: works as immune system modulator, has antiviral properties
- $\cdot$  Dose frequency and method: every other day, subcutaneous injection

## **INTRAVENOUS INFUSION MEDICATIONS**



These medications are given intravenously in a clinical setting. In the case of treating MS through intravenous infusion, instead of entering your system intramuscularly or subcutaneously, infusions go directly into a vein.

You cannot take them yourself at home, so you must be able to get to a clinic or nursing home for your appointment.

Intravenous infusions can result in increased risk of infections in addition to other side effects.

Infusion medications include:

- **1. ALEMTUZUMAB (LEMTRADA)**
- 2. MITOXANTRONE (NOVANTRONE)
- 3. NATALIZUMAB (TYSABRI)
- 4. OCRELIZUMAB (OCREVUS)

## THE SCHEDULES FOR INFUSION MEDICATIONS VARY: DOSAGE:

- Lemtrada is given in two courses, starting with five days of infusions followed by a second set one year later for three days.
- Novantrone is given every three months, for a maximum of two to three years.
- Tysabri is administered once every four weeks.

Common side effects include nausea, headache, and abdominal discomfort. In rare cases, these medications may cause serious side effects such as infection and heart damage. Your doctor will help you weigh the risks of taking these drugs against the potential benefits.

If you want the help of a clinician when administering your medication and don't want to take pills every day, infusion medications might be a good choice for you.

## LEMTRADA (ALEMTUZUMAB)

- **Benefit:** suppresses myelin-damaging immune cells
- **Dose frequency:** daily for five days; one year later, daily for three days
- Common side effects can include: nausea, vomiting, diarrhea, headache, rash, itching
- Warnings include: can cause cancer and idiopathic thrombocytopenic purpura (IPT), a bleeding disorder

## MITOXANTRONE HYDROCHLORIDE

This medication is only available as a generic drug.

- \* **Benefit:** works as immune system modulator and suppressor
- Dose frequency: once every three months (lifetime limit of 8 to 12 infusions over two to three years)
- Common side effects can include: hair loss, nausea, amenorrhea (irregular periods)
- Warnings include: can cause heart damage and leukemia; only appropriate for people with severe cases of RRMS, due to the high risk of serious side effects

## **OCREVUS (OCRELIZUMAB)**

Ocrelizumab (Ocrevus) is the only medication that's FDA-approved for people with primary progressive MS (PPMS). It's also approved to treat RRMS.



## **ORAL MEDICATIONS**

You may be able to take your MS medication in pill form, if that's what you prefer. Oral medications are easy to take and are a good option if you don't like needles. If you're not comfortable with needles, there are oral options for treating MS. Taken daily or twice daily, oral medications are the easiest to self-administer but require that you maintain a regular dosing schedule.

## AUBAGIO (TERIFLUNOMIDE)

- **Benefit:** Works as immune system modulator, inhibits nerve degeneration
- \* Dose frequency: Daily
- Common side effects can include: Headaches, liver changes (such as an enlarged liver or elevated liver enzymes), nausea, hair loss, reduced WBC count
- **Warnings include:** can cause severe liver injury and birth defects

## GILENYA (FINGOLIMOD)

- Benefit: Blocks T cells from leaving lymph nodes
- \* Dose frequency: Daily
- Common side effects can include: flu-like symptoms, elevated liver enzymes
- Warnings include: can cause changes in blood pressure, liver function, and heart function

## **TECFIDERA (DIMETHYL FUMARATE)**

- Benefit: has anti-inflammatory properties, protects nerves and myelin from damage
- Dose frequency: twice daily
- **Common side effects can include:** gastrointestinal changes, reduced WBC count, elevated liver enzymes
- Warnings include: can cause severe allergic reactions, including anaphylaxis

Oral medications include:

- 1. DIMETHYL FUMARATE (TECFIDERA)
- 2. FINGOLIMOD (GILENYA)
- 3. TERIFLUNOMIDE (AUBAGIO)

Side effects of oral medications may include headache and abnormal liver tests. **DOSAGE:** 

- Aubagio and Gilenya are taken once per day, and
- Tecfidera is taken twice per day.
- Common side effects can include: flu-like symptoms, low white blood cell (WBC) count
- Warnings include: liver enzymes and CBC may need to be monitored

## Copaxone (glatiramer acetate)

- Benefit: works as immune system modulator, blocks attack on myelin
- Dose frequency and method: daily or 3 times per week, subcutaneous injection
- Common side effects can include: flushing, shortness of breath, rash, chest pain
- **Warnings include:** injection sites can become permanently indented because fatty tissue is destroyed (as a result, careful rotation of injection sites is recommended)

## Extavia (interferon beta-1b)

- **Benefit:** works as immune system modulator, has antiviral properties
- Dose frequency and method: every other day, subcutaneous injection
- Common side effects can include: flu-like symptoms, headache
- Warnings include: liver enzymes and CBC may need to be monitored

## Glatopa (glatiramer acetate)

- Benefit: works as immune system modulator, blocks attack on myelin
- Dose frequency and method: daily, subcutaneous injection
- Common side effects can include: redness, swelling, pain at the injection site
- **Warnings include:** injection sites can become permanently indented because fatty tissue is destroyed (as a result, careful rotation of injection sites is recommended)

## Plegridy (pegylated interferon beta-1a)

- Benefit: works as immune system modulator, has antiviral properties
- Dose frequency and method: every two weeks, subcutaneous injection
- Common side effects can include: flu-like symptoms
- Warnings include: liver enzymes may need to be monitored

## Rebif (interferon beta-1a)

- Benefit: works as immune system modulator, has antiviral properties
- Dose frequency and method: three times per week, subcutaneous injection
- Common side effects can include: flu-like symptoms
- Warnings include: liver enzymes may need to be monitored

- **Benefit:** targets B cells, which are WBCs that damage nerves
- **Dose frequency:** 2 weeks apart for first two doses; every six months for all later doses
- Common side effects can include: flu-like symptoms, infection
- **Warnings include:** can cause cancer and, in rare instances, life-threatening infusion reactions

## TYSABRI (NATALIZUMAB)

- Benefit: inhibits adhesion molecules, which disrupt the immune system
- **Dose frequency:** every four weeks
- **Common side effects can include:** headache, joint pain, fatigue, depression, abdominal discomfort
- **Warnings include:** can increase risk of progressive multifocal leukoencephalopathy (PML), a potentially fatal brain infection.

## IN CONCLUSION:

- Taking your medication as prescribed is important for it to be effective. For example you need to follow an organized schedule if you take daily oral doses. Setting up reminders for yourself can help you stick to a schedule and take each dose on time.
- Disease-modifying therapies are available in different forms, including self-injectable, infusion, and oral treatments. Each of these forms has side effects as well as benefits. Your doctor can help you choose a medication that's right for you based on your symptoms, preferences, costs and lifestyle.



## STORIES OF STRENGTH Dr Kshma Swarnkar

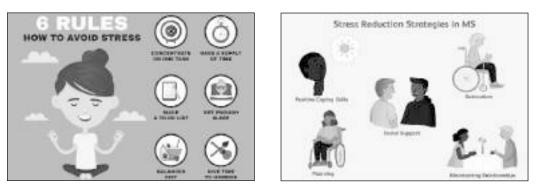
A debilitating disease can change one's perspective on life. It can either help you evolve or push you into the deep end. While today, I can say that my disease has helped me evolve into a more positive version of myself; it was not always so. Back in 2018, when I was detected with Multiple Sclerosis (MS), I was shattered. I felt I was failing in my roles as a daughter, sister, wife and most importantly, a mother.

At the time of diagnosis, I could neither see clearly, nor balance myself well, and had to discontinue my work of a science tutor online. Teaching is such a responsible profession; we're empowering the next generation with skills for the future. It was very disappointing for me to leave it. I felt disabled. But slowly, as my treatment began, I started regaining my confidence. I started believing in a few mottos in life like, 'Be happy, always smile' and 'Be positive and stress-free'. Usually, people consider those with MS to be disabled; Whereas, I believe, we are differently-abled! We don't consider ourselves as 'patients'; we just have a different way to perceive life and live it with more energy!

According to medical research, MS occurs because of a hyper active immune system. Just imagine – a person whose immune system is so strong, how strong they might be as an individual! Because I chose to look at my condition positively and not let it depress me, today, I am able to lead a normal personal and professional life. MS is not a disease; in fact, it is a phenomenon present in those who have the ability to work harder and face hardships with more strength. There is not much to worry if you have been diagnosed with MS.

It gave me a lens to view myself in a different perspective and motivated me to lead a normal life and strive to achieve my goals.

## RESEARCH HAS SHOWN THESE TECHNIQUES HELP TO HELP REDUCE STRESS IN THE SHORT- AND LONG-TERM.



## How can you relax your mind and body?

- Take slow, deep breaths. Or try other breathing exercises for relaxation.
- Listen to soothing music.
- Practice mindful meditation.
- Write... Express your thoughts, it helps make you feel better
- Use guided imagery.
- Take a break from the stressor. It may seem difficult to get away from a big work project, a crying baby or a growing household expenses.
- Exercise.
- Smile and laugh.
- Get social support.
- Get a change of environment-step out.
- Make new friends.
- Develop hobbies & interests that occupy & distract you.
- Meditate.
- Light yoga.

## **8 DRINKS THAT CALM**

- Green tea. This powerful drink contains a brain-relaxing compound called theanine to reduce anxiety.
- Valerian or in Hindi JATAMANSI and NAKLI JATAMANSI (found in Uttarakhand Himalayas and Nepal). This medicinal herb-often found in bedtime tea blends-has been credited with reducing nervousness, anxiety, and insomnia.
- Cherry juice.
- Black tea.
- Water. Infuse with a slice of lime or Orange.
- Fresh veggie juice.
- Fresh Haldi milk.
- Amla Juice.

## **GINGER TO SHARPEN YOUR BRAIN AND BEAT STRESS**

**Ginger** has benefits beyond flavoring your favorite stir-fry recipe or easing an upset stomach. Animal studies have also indicated that **ginger** can influence serotonin levels and may **treat** and reduce **anxiety** as successfully

## Are bananas good for anxiety?

Eating potassium-rich foods such, as pumpkin seeds or **bananas**, may help reduce symptoms of stress and **anxiety** 

## FAQ'S ON STEM CELL TREATMENT: AHSCT

#### Will my MS be cured forever after AHSCT? Will my legs get strong again?

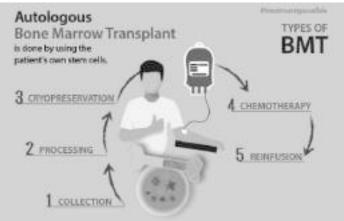
The chance of MS not progressing could be around 60% Chance of deformity in limbs or posture getting better is 30 %

#### I have had MS for 5 years. I do not have much difficulty and I am independent. Shall I go for it now or wait?

Early intervention is always best. However best results are in RRMS and PPMS only. NO benefit in SPMS (Secondary Progressive MS)

## If there is no visible disability, how will I know if it is successful?

Doctors will monitor by number of attacks once patient is off medications. This could take time. at least 1 year.



## How many MS transplants have been done in India so far? What is the ratio of success?

One Delhi Hospital alone has performed over 60 transplants. 3 year data shows 5 people (under 10%) had recurrence/repeat attack or suspected recurrence. 40% have shown no visible improvement or change in their condition

## How long does the MS person remain in hospital?

25-30 days on an average . May take longer if some fever or infection develops

## What precautions should be taken after coming home?

Once the patient gets discharged from the Bone Marrow Transplant (BMT) unit, the caregiver has a major role to play in the rehabilitation. Patient has to be kept in isolation for a further 4 weeks post BMT and start physiotherapy as soon as possible to tone up the muscles. Controlled diet is given and raw food like salads and even fruit etc must be avoided for 3 months.

Medication will continue for 6 months and vaccination needs to be done after 1 year.

## Is there a risk to life after AHSCT ?

Chance of death is 1 %

## Has this procedure been approved by ICMR, FDA and AIIMS?

NO Everybody is doing it as part of a research process.

## Stem Cell Therapy - Will it work for me?

## Stem cell therapies are a type of largely experimental treatments for multiple sclerosis (MS).

In this A-Z entry we explore what stem cells are, how they can be used to treat MS, some of the risks associated with stem cell therapies and treatment availability.

Stem cells are part of the body's normal repair system which replaces damaged or dying cells where possible. Stem cells are unspecialised as they haven't developed to carry out a particular function yet. Each stem cell has the potential to develop into one of a number of different cell types depending on the body's needs at a particular time, such as becoming a nerve cell, a red blood cell or a heart muscle cell. Once they've undergone this change they're known as specialised cells and they can't go on to change again.

Researchers are exploring whether it's possible for stem cells to become cell types which could slow MS disease activity, repair existing damage or replace faulty parts of the immune system or nervous system. Although stem cell therapy is routinely used for conditions such as cancer of the blood (leukaemia), it's still largely seen as an experimental treatment for multiple sclerosis (MS).

The most studied type of stem cell therapy for **MS is autologous haematopoietic stem cell transplantation** (often shortened to AHSCT, ASCT or HSCT). This uses your own stem cells, which are collected and then injected back into your body. Early results have been encouraging and understanding how best to treat people with stem cells is improving.

AHSCT in MS has **not** been formally assessed for use commercially outside clinical trials, but a small number of centres have begun to provide it under specific circumstances to a number of people.

The people accepted for treatment generally either have a very aggressive type of MS or continue to have relapses even after trying one or more disease modifying drugs , where no other treatment is helping them.

## How is AHSCT thought to work in MS?

Haematopoietic (pronounced hee-mato-poy-etic) stem cells are found mainly in our bone marrow, although small numbers circulate in our blood. They develop into the different types of cells found in the blood including some cells which are part of the immune systemthat is those cells which help fight infections and diseases in our body. They're produced in large numbers throughout our lives to continually replenish our blood and immune system as cells die and are replaced in a natural life cycle. The aim of AHSCT is to replace or reboot your body's immune system so that it no longer attacks your myelin or causes inflammation in your brain and spinal cord. AHSCT uses high doses of chemotherapy to wipe out your existing immune system, which is then rebuilt using stem cells collected from your blood before you have the chemotherapy. The hope is that your rebooted immune system will stop attacking you and there will be no further damage.

Using your own stem cells minimises the risk of them being rejected by your body. If the stem cells come from someone else (a donor) it's known as an allogeneic transplant – this is associated with a higher risk of complications than an autologous (self) transplant, so it's not generally used for MS.

## What does the AHSCT procedure actually involve?

There are six main stages to the procedure, the first five take place over several weeks.

## Stage 1

The first stage is known as mobilisation, where a combination of drugs are given to encourage your stem cells to move from your bone marrow and into your blood stream so they can be collected. Mobilisation is carried out by giving an infusion (through a drip) of a chemotherapy drug (cyclophosphamide) and injections of a synthetic form of a natural growth factor called G-CSF (granulocyte-colony stimulating factor). Your MS symptoms can get temporarily worse during this phase.

## Stage 2

This involves collecting (or harvesting) your stem cells, it typically happens about 10 days after mobilisation once blood tests have shown that there are enough stem cells present in your bloodstream and takes between half a day and one day. You are connected to a machine which collects your blood through a needle in your arm, separates out the stem cells and then returns all the other components of the blood to your body.

## Stage 3

The third stage involves freezing (or cryopreserving) your harvested stem cells, ready for when they are returned to your body at a later stage.

## Stage 4

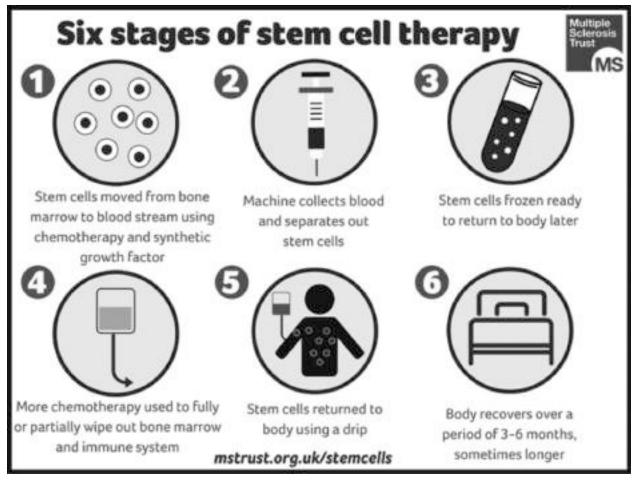
Stage four of the process is another round of chemotherapy, known as conditioning chemotherapy, this gets your body ready for the return of your stem cells. It may involve either completely wiping out (myeloablative or high intensity chemotherapy) or partially eliminating (non-myeloablative or low intensity chemotherapy) your bone marrow and immune system, hopefully destroying the ('bad') cells that are involved in MS disease activity. More recent procedures have tended to use the less aggressive lower intensity chemotherapy method. This stage usually takes several days and you may need to take drugs to control any nausea and vomiting which are common side effects of the chemotherapy. You may also be given steroids to dampen down any immune reactions.

## Stage 5

The fifth stage is transplantation, also known as stem cell return, where your stored stem cells are thawed and returned to your blood by infusion (through a drip). This is often a couple of days after the conditioning chemotherapy and will only be done once all the chemotherapy drugs have cleared from your system. It takes a couple of hours and is similar to having a blood transfusion. The stem cells make their way to your bone marrow (engraftment) and should start making new blood and immune cells within 10 to 30 days. During that 10 to 30 day period, you have, in effect, no immune system which explains some of the risks and side effects set out below.

## Final stage

The sixth and final stage is recovery. AHSCT is a complex, aggressive procedure and recovery can take a considerable length of time. You should expect to be off work for quite a while as typically you need three to six months to recuperate from the procedure. However, some people can take more than a year to recover.



## **Risks and side effects of AHSCT**

There are several potential side effects both during and after the procedure.

Susceptibility to infection, also known as being immune-compromised, is common immediately after the conditioning chemotherapy and until your immune system has been rebuilt by your stem cells following the transplantation stage. This means during this phase your body has little or no immunity or power to fight even simple infections. You should be closely monitored by your health professionals to make sure that you remain as well as possible and you are likely to be all alone in an isolation room in hospital for many weeks. Even your caregiver & family members will need to take precautions to avoid introducing infections when they are allowed to visit you.

What might normally be a low threat to your health can be very serious, even life threatening, during this period. Also, previous infections that you may have had, particularly with the viruses that cause shingles, cold sores and herpes, may become active again. You may be given antibiotics and transfusions to support you through this vulnerable time.

It's possible to develop other autoimmune conditions, particularly autoimmune thyroiditis where the body sees the thyroid, and the hormones it produces, as threats and so attacks them.

You may experience side effects from the chemotherapy, which can include fatigue,

weakness and a temporary loss of appetite. You will be at an increased risk of bleeding and bruising and your MS symptoms may also be worse for some time. Hair loss is common but should only last between one and six months, although your hair may grow back a slightly different colour or texture. Other longer term side effects can include lowered fertility, or early menopause, if high dose chemotherapy has been used. There is a risk of dying due to the procedure. Although treatment procedures are improving, clinical trials since 2001 have still had treatment-related death rates of one or two people in every 100 (1.3%), according to analysis by the European Group for Blood and Marrow Transplantation (EBMT). The majority of deaths were due to infections. However, looking at transplants carried out since 2005, the death rate has decreased further still to around 1 in 330 (0.3%).

**Is AHSCT available for MS in India?** Until recently, treatment with stem cells was seen as purely experimental for people with MS and was only available in a few foreign countries & limited centres in India through clinical trials.

However, treatment is becoming quite common at a number of centres across the country, but the number of people who are accepted for treatment is still extremely small. One must also be aware of certain Doctors from big & small private Hospitals in India and abroad, who are offering AHSCT as a 'miracle cure' supported by online videos and advertisements , many of which may not have been verified.

There are clinics around the world that are offering stem cell treatment for MS on a commercial basis. This is sometimes known as stem cell tourism. Some, but not all of the centres, are offering AHSCT. There are other forms of stem cell treatment being researched in MS, which you can read more about later, but these are not as far advanced as AHSCT, so if you are considering going abroad you need to check exactly what kind of treatment is being offered. The MS person and his / her family must do their complete research and due diligence before taking this huge step. There are two major considerations to be kept in mind **: life risk & affordability** 

People are usually only accepted if they have a very aggressive form of MS, or if they continue to have relapses even after trying one or more of the disease modifying drugs without result. Each hospital will have its own specific eligibility criteria but many are known to take on only those MS patients who are already walking and in comparative 'better' condition so that recovery can be shown sooner. Based on the data from clinical trials, you're more likely to respond to treatment, and therefore be suitable for AHSCT, if you meet the following general criteria:

• You have relapsing MS or progressive MS with evidence of continuing inflammatory disease, for example, active lesions are seen on recent MRI scans.

• You are continuing to have relapses when on a disease modifying drug treatment (at least one drug tried – though some centres suggest that AHSCT should only be considered in people who have relapses even after treatment with Lemtrada (alemtuzumab) and/or Tysabri (natalizumab), or in whom these drugs cannot be considered)

• You are early in your MS disease course before the onset of any significant irreversible disability. Disability is often measured using the EDSS scale. Exact requirements will vary but would typically require the ability to walk at least 100m with or without using a single walking aid and with or without resting (EDSS of 6 or below)

• You are fit enough to undergo the treatment regimen.

In very few cases people with very aggressive MS, who have developed severe disability in the previous year, have also been accepted for AHSCT.

On going research & studies in AIIMS are in the process of conducting audits and follow up of MS patients who have received AHSCT from AIIMS. From this study we hope to understand how people with MS can be assessed and selected for stem cell treatment and what is needed to develop safe, high quality services for the future. If you are considering AHSCT, whether through a government/ ICMR sponsored trial or privately, you would need to be referred by your usual neurologist to the relevant haematologist and neurologist. Both specialists would need to assess your suitability for treatment.

We are aware that centres in India as well as Mexico, Russia, China and Israel are offering the AHSCT procedure to people with MS, including people with progressive MS. The cost of treatment varies widely but can range between Rs.30 Lakhs and Rs. 75 Lakhs, by the time you add travel, stay, Visa & other costs for the MSp and caregiver.

If you are considering going abroad, it will be important to find out:

- exactly what kind of treatment is provided-is it AHSCT or something else?
- whether the clinic is regulated to international standards
- whether others have benefited from treatment at the clinic
- do not depend on videos posted online. Some have been found to be fake or using actors !
- what follow up is provided
- how safety, side effects and the effectiveness of treatment are monitored over time

• what is, and is not, included in the price quoted and what you will need to pay for in addition to flights and possibly hotel accommodation, for example whether there will be any additional medications that you have to pay for once you're home. The risk of having additional costs may be high if you develop complications after the initial treatment.

It will also be essential to make sure that there will be proper follow up and support in place once you have returned home. Ensuring an infection free sanitized environment within your own home is also essential.

## **Key considerations**

When considering any treatment, it is vital to weigh up all the different factors, discuss your options with health professionals, family and friends before deciding what seems best for you as an individual. Feel free to reach out to the MS Society who can introduce you to real people who have been through this treatment and they can share their experiences with you. In Delhi Chapter we have more than a dozen MS persons having varying degrees of disease progression who have gone through AHSCT both in India and abroad. Clinic websites will probably include personal stories but may only show you their most successful cases. You may be able to get a more accurate idea of success rates by asking on forums or groups, although, inevitably, people are more likely to talk about successes than side effects, complications or failure. Some people with MS have blogged about their experiences of having stem cell therapy. To know about stem cell therapies, it is important to look critically at the risks and not only the hope that is offered.

Below is our list of suggested actions if you, or someone you care about, think that AHSCT may be an appropriate treatment option.

## Get independent information .

## Seek the opinion of your MS specialist team

Consult your MS team of Doctors and other health professionals as they know you and your MS well. If your relapses are not well controlled by a disease modifying drug, they may suggest that you try an alternative. In some circumstances, your MS team may agree that AHSCT is appropriate. You will need a referral from your neurologist to take part in some clinical trials or to attend most hospitals providing AHSCT. You may need to provide some evidence of your MS disease activity, such as a recent MRI scan, or your history of previous treatments.

Your MS doctor must remain involved with your longer term care once you have recovered from the AHSCT procedure and no longer need the involvement of the AHSCT multidisciplinary team. So do take him into confidence before making your decision.

## Check the credentials of the team

Check that the hospital where you will be treated has experience of stem cell transplantation in people with MS as worldwide experience is limited to a few centres. Visit the websites of clinics offering treatment to understand exactly what they offer and to whom, the process you would need to go through, the cost and any follow up support that is available. You could ask the clinics for any information sheets and eligibility criteria. Treatment should include assessment by an MS specialist neurologist and a haematologist working together as part of an AHSCT multidisciplinary team. Treatment should be explained in a written "informed consent document" in a way that you can easily understand. Do not feel shy or scared to ask. You can insist on it being explained in your mother tongue in a easy and simple language. Take time to go through the forms.. You should have the opportunity to ask questions at all stages of the process.

## Balance the risks and benefits to your health

Stem cell therapy has the potential to bring significant benefits to some people with MS. Good progress is being made through clinical trials and the outcomes of treatment are improving as more is learned. However, as research is still at an early stage, stem cell therapy is not widely practiced and the results of treatment for a particular person cannot be predicted. The risks should be very carefully considered, including the possibility of treatment-related death, and weighed up against the potential benefits.

## Find out about after care

It is important to know what care will be available after your AHSCT treatment especially if you are considering going abroad. What support will be available if you experience complications or side effects? This should be outlined exactly so that you know what to expect and who to contact if you have any concerns.

## Consider the costs

Treatment in a clinical trial should be free. In addition, a very small number of people are

being accepted in the Government Hospitals like AIIMS. Even here certain costs have to be met by the MS patient. This could be anywhere between 10-12 Lakhs.

In the private sector Hospitals, the quotes for treatment vary widely. Before making any commitment, it is important to establish the full costs of treatment including assessment, tests, treatment and follow up appointments. You will need to budget for your travel and for accommodation costs for anyone going with you. You may also need accommodation for yourself if you are discharged from hospital but don't feel strong enough to travel home straight away, or if you develop complications and need to extend your stay.

Private Hospitals in India are offering this treatment at an average cost between 12-14 Lakhs

It is important to be cautious as there have been examples in the past of unscrupulous people making a profit by offering worthless treatments to people with MS at very high costs. Some clinics did not even check whether a person had MS or not.

#### Future directions for stem cell research

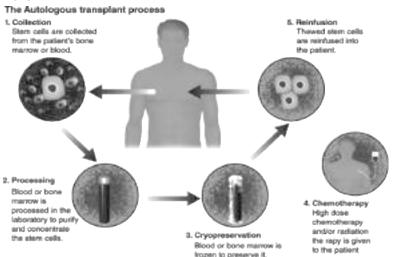
Stem cell treatments have huge potential for the future treatment of people with MS but the disease process in MS is still poorly understood so more information is needed.

At this time it is still early to predict whether this is the ultimate MS treatment or not, as most MS persons have had this treatment only 6-7 years ago. What will be the long term effect is not possible to judge today.

Key questions for research include:

- How can stem cells be encouraged to develop into cell types that can treat MS?
- Which cells or systems in the body should be targeted?
- Why do some people benefit more than others from treatment?

The results of these avenues of research should allow the design of more effective clinical trials and produce better outcomes for people with MS. We need to be patient & wait for some of these answers.



## Advice regarding aHSCT Autologous Haematopoietic Stem Cell Treatment

(aHSCT) includes intensive chemotherapy treatment. This severely weakens the immune system for a period of time. People who have recently undergone treatment should consider extending the period they remain in isolation during the COVID-19 outbreak. People who are due to undergo treatment should consider postponing the procedure in consultation with their healthcare professional. Seeking medical advice for relapses and other health concerns

People with MS should still seek medical advice if they experience changes in their health that may suggest a relapse or another underlying issue such as an infection. This can be done using alternatives to in-person clinic visits (such as telephone or video consultations) if the option is available. In many cases, it is possible to manage relapses at home.



The use of steroids for treating relapses should be carefully considered and only used for serious relapses. Where possible, the decision should be made by a neurologist experienced in the treatment of MS. People who receive steroid treatment for a relapse should be extra vigilant and may want to consider self-isolation for an appropriate amount of time to reduce their risk from COVID-19.

People with MS should continue to participate in rehabilitation activities and stay active as much as possible during the pandemic. This can be done through remote sessions where available or in clinics as long as facilities are taking safety precautions to limit the spread of COVID-19.

People with concerns about their mental health should seek advice from their healthcare professional.

Advice for children or pregnant women with MS: At this time there is no specific advice for women with MS who are pregnant. There is general information on COVID-19 and pregnancy on the US Centre for Disease Control and Prevention website. There is no specific advice for children with MS; they should follow the advice above for people with MS.

#### - World Health Organisation Guidelines (WHO) & MSIF Sources

## HAVE YOU HEARD OF ORAC?

Covid times have taught us that we can go back to nature for a healthy Life and for building up our immunity. Have you heard of ORAC.

\*ORAC is Oxygen Radical Absorbance Capacity. \*Higher ORAC, Better will be oxygen carrying capacity of blood & Lungs oxygen capacity.

In the Future, our survival will be based on our Immunity

Why spices are important for our Life? Look at their ORAC Values

: 314,446 ORAC Clove Cinnamon: 267,537 ORAC Coffee : 243000 ORAC Turmeric : 102,700 ORAC Cocoa : 80,933 ORAC : 76,800 ORAC Cumin : 74,349 ORAC Parsley : 67,553 ORAC Tulsi Thyme : 27,426 ORAC Ginger : 28,811 ORAC



Extracts of Ginger, Tulsi, Turmeric are at least 10 times higher ORAC Values. That's how they become effective.

## OXYGEN CARRYING CAPACITY OF THE BLOOD CAN BE ENHANCED USING NATURAL FRUITS, VEGETABLES, SPICES, HERBS ...THAT HAVE HIGH ORAC VALUE!

#### **OXYGEN RADICAL ABSORBANCE CAPACITY**

PREVENTS: CANCERS, NEURO-DEGENERATIVE DISORDERS, DIABETES, & SO MANY CHRONIC CONDITIONS

Nature boosts immunity ...

High ORAC foods and Nutrients such as iron, vitamin C, Zinc, omega 3, Magnesium and Vitamin D helps boost our body's defence mechanism.

Apart from Tulsi, Ginger, Pepper, Turmeric, Cinnamon, Clove, herbs like Brahmi, Mulethi, Ashwagandha, Shatavari, Arjunarishtam, Peppermint, coriander seeds, cumin black seeds are catching attention of Scientists.

So, this is more than any vaccine one need for self immunity. Without any side effects.

Since 80% of Corona positive patients had no symptoms at all, leaves uncertainty for all of us!

Testing 130 crore population is next to impossible. Even if we test daily 100000 people, we will need over 35 years to just test!

This suggests our future is our immunity just like intel inside in computers, we have to inbuilt immunity inside!

## GLOBAL COVID-19 ADVICE FOR PEOPLE WITH MS :

COVID-19 is a new illness that can affect your lungs, airways and organs. It is caused by a novel coronavirus that was first detected in people in China in December 2019 and has since spread to other parts of the world. There is currently limited evidence on how COVID-19 affects people with multiple sclerosis (MS).

The advice below was developed by MS neurologists and research experts from MSIF's member organisations. It is based on expert opinion and preliminary data that is still being analysed, so should be taken with caution. This advice will be reviewed and updated as further evidence about COVID-19 becomes available.

## Advice for people with MS

People with underlying lung and heart conditions and those aged over 60 years are more likely to experience complications and become severely ill with the COVID-19 virus. This group will include many people living with MS, especially those with additional health complications and mobility issues.

Current evidence suggests that simply having MS does not increase the risk of dying from COVID-19. However, the possible long term consequences of having MS may make people more susceptible to having a severe case of COVID-19. The risk of having to go to hospital for COVID-19 rises with age, progressive MS and higher levels of disability.

All people with MS are advised to follow guidelines for reducing the risk of infection with COVID-19.

## The World Health Organization recommendations include:

- Wash your hands frequently with soap and water or an alcohol-based hand rub
- Avoid touching your eyes, nose and mouth unless your hands are clean
- Try to practice social distancing by keeping at least 1 meter distance between yourself and others, particularly those who are coughing and sneezing
- Avoid going to crowded places
- When coughing and sneezing, cover your mouth and nose with a flexed elbow or tissue
- Practice food safety by using different chopping boards for raw and cooked foods and wash your hands between handling them In addition, we recommend that people with MS should:
- Wear a face mask in public and ensure that you are using it correctly by covering both nose & mouth.
- Avoid using public transport where possible
- Where possible, use alternatives to face-to-face routine medical appointments (for example, telephone or video appointments). Certain groups of people with MS may be at an increased risk of becoming severely ill or dying with COVID-19.

The following groups should take extra care to minimise their exposure to the virus: People with progressive MS  $\bullet$  People with MS over the age of 60  $\bullet$  People with higher levels of disability (for example, an EDSS score of 6 or above)  $\bullet$  People with diseases of the heart or lungs.

Caregivers and family members who live with, or regularly visit, a person with MS in one of these groups should also follow these recommendations to reduce the chance of bringing COVID-19 infection into the home.

National lockdown measures in place in many parts of the world might be relaxed in the coming weeks and months. Until our understanding of the coronavirus improves, people with MS in these higher risk groups and their caregivers should continue to follow the advice above to reduce their risk of contracting COVID-19.

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

- People with MS currently taking DMTs continue with their treatment.
- People who develop symptoms of COVID-19 or test positive for the infection discuss their MS therapies with their MS care provider or another health care professional who is familiar with their care.
- Before starting on any new DMT, people with MS discuss with their healthcare professional which therapy is the best choice for their individual disease course and disease activity in light of COVID-19 risk in the region.

## The following information should be considered during decision making:

- Interferons and glatiramer acetate are unlikely to impact negatively on COVID-19 severity. There is some preliminary evidence that interferons may reduce the need for hospitalisation due to COVID-19.
- The limited evidence available suggests that people with MS taking dimethyl fumarate, teriflunomide, fingolimod and siponimod do not have an increased risk of more severe COVID-19 symptoms or death.
- Therapies that target CD20 ocrelizumab and rituximab may be linked to an increased chance of being admitted to hospital or requiring intensive care treatment due to COVID19. This preliminary finding requires further investigation.
- More data on the use of natalizumab, alemtuzumab and cladribine during the COVID-19 pandemic are required to make any assessment of their safety.
- People with MS who are currently taking ocrelizumab, rituximab, ofatumumab or ublituximab and are living in a community with a COVID-19 outbreak should be extra vigilant and may want to consider self-isolation to reduce their risk of infection.
- People with MS who are currently taking alemtuzumab or cladribine and are living in a community with a COVID-19 outbreak should discuss their current lymphocyte counts with their healthcare professional. If their counts are considered to be low they should isolate as much as possible to reduce their risk.
- Recommendations on delaying second or further doses of alemtuzumab, cladribine, ocrelizumab and rituximab due to the COVID-19 outbreak differ between countries.

People who take these medications and are due for the next dose should consult their healthcare professional about the risks and benefits of postponing treatment.

## **BUILD YOUR OWN EXERCISE ROUTINE**



If you want to keep active with MS, there are many different types of exercise you can try that will benefit you.

In the past, people with multiple sclerosis were advised to avoid exertion. It was felt that since many people with MS experienced fatigue and found their symptoms worsened when hot, it was best to avoid activities that could be seen as tiring.

It turns out that this was not good advice. Regular, moderate exercise is now known to be an important part of maintaining good health and wellbeing for people with MS. There is evidence that it can help with many MS symptoms, and also with general quality of life.

Before you begin an exercise programme, you might like to find out the right exercise for you and some things to think about before you start.

## How can exercise help with my MS symptoms?

There have been many studies to look at the benefits of different kinds of exercise for people with MS. It can be hard to compare these studies, but they have in general shown exercise to be valuable for people with MS.

**Moderate exercise** has been shown to improve strength, mobility and bowel and bladder function for people with mild to moderate MS. Exercise is also helpful in helping maintain a healthy weight. This reduces your chances of getting other difficulties , and a regular exercise routine can also reduce the impact of some MS symptoms, such as pain and fatigue.

Exercising is good for the mind and brain, not just the body. In general, exercise has been found to be neuroprotective, to improve symptoms of depression, improve mental capacity & concentration, speed, memory, executive function and mental flexibility. These boosts can last for several days after exercising.

Try to maintain regular aerobic activity, as the positive benefits reduce soon after you cease exercising.

Many people with MS have understandable concerns about beginning an exercise programme. There are a number of issues that you might wish to think about, but they need not be barriers to starting exercise. Here we provide practical tips to help you get started and keep going with your chosen activity. Everyone's MS is different, and you know best how your MS affects what you can do. However, you could ask yourself what is holding you back from being more active, and see if there are ways to overcome those issues.



## Before you start to exercise

There are several common challenges facing a person with MS who wants to exercise. Fortunately, a bit of preparation can stop them become barriers to exercising.



## **Overheating**

Heat sensitivity is a common MS symptom. If you find that you get hot and uncomfortable when you exercise, try to cool the environment you are in. Take off a layer of clothing, open a window or go outdoors if it is cooler.

A fan or a cold water spray might also be useful, as can having a cool bath or shower before you start to exercise. You can also keep a bowl of cold water with a few cubes of ice handy-when you feel your body heat up, stop and dip a soft face towel, squeeze &

wipe your face, neck and arms.

Research shows that drinking iced water before exercising can help people with MS exercise for 30% longer and reduce fatigue following aerobic exercise.

## Fatigue

If fatigue is a problem for you, you may want to focus on exercise to strengthen your muscles, or resistance exercise. It is important to acknowledge, both when exercising and in daily life, that it is not a good idea to 'work through' fatigue-you may end up feeling worse, often for days afterwards.

Temperature can also affect fatigue. Everyone can feel drained of energy in hot or humid weather, but with MS the effect is often exaggerated. See the tips above for ideas.

Choose an exercise that does not require extra effort for you. If you have problems with balance, choosing swimming or aqua-aerobics would allow the water to support you as you exercise. Using a recumbent bike or stepper rather than an upright one can lessen fatigue. You will be using less energy to just stay on the equipment and be able to focus on getting benefit from the exercise itself.



**Mobility** If your mobility is limited, that means if you are unable to walk or stand for long , you can still get meaningful exercise, even without leaving the house. Just sit and do some deep breathing exercises and meditation. These require no special clothing or equipment, and you can fit them in around your day.

You might find it difficult to make yourself breathe deeper and get your heart rate going if your balance is not so good or your legs tire very quickly. There are things you can do sitting in a chair.

**Seated jogging:** Get your arms and legs pumping as if you are running but stay seated. Even if you keep going for just one minute you will find your heart rate has gone up and you are breathing deeper. You can also split your arms and legs so that you can simply 'arm jog' or keep your arms still and 'march' with your legs.

Punching: Punch your arms alternately forward or upward. This one is good if you are feeling a bit stressed - you can imagine all sorts of people or situations that have made you feel a bit fed up and punch them away!

## **Recovery:**

If you have MS, it might take you longer to recover from exercise than someone without MS. You have to learn to listen to your own body and be honest with what it is telling you. The attitude of 'no pain, no gain' does not apply in MS. Whilst someone without MS can



push themselves to exhaustion and then recover within half an hour, a person with MS should **be prepared to stop before their body is telling them they have reached their limit.** Some people have a misguided belief that if you push hard enough and it hurts then it must be doing some good. If you spend more time recovering from an activity than doing it, you may not have the balance quite right!

As you get used to exercising, you will likely find that your recovery rate improves.

## **Getting started:**

There is a well understood connection

between exercise and mood. Being active helps with symptoms of depression and low mood. However, it doesn't take much to put any of us off doing exercise. Feeling low or fatigued might mean you avoid exercising, even though you know that it will help in the long run, and that you'll feel better for it afterwards.

It could take some effort to get yourself past the mental barriers that are stopping you exercising. This is normal, but it will get easier once you start to feel the difference that exercise is making to your life and your MS.



Do speak to your doctor or MS team if you are struggling with depression or fatigue. They may be able to help you.

Some people find that not thinking about it, and just doing it helps. Have your bag ready packed for the gym, so you can just pick it up and go. Wear comfortable shoes so that you don't have an excuse not to go for a walk. Encouragement from family or team-mates can help too.

## Keeping Going

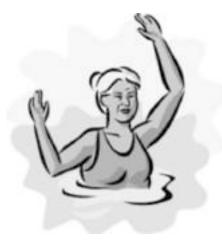
The positive benefits of exercising do wear off if you stop. It is important to find exercise that you enjoy doing because then you will keep it going.

It is also useful to think about the reasons why you might give up on exercising once you have started.

Everyone is individual and some people like to exercise in a group setting in a class or as part of a team. Others like to work individually, maybe at the gym, swimming pool or at home. Find what is right for you.

• Set sensible targets. You might lose motivation if you don't achieve your goals in a reasonable time frame. Start small and then you can increase the challenge later.

• Other people can help keep you motivated. You might like to join an exercise programme, class, or an online community where you can share your progress and



motivate each other. If you prefer to exercise alone, tell people about your targets and ask them to support you.

- Don't worry if you miss a day, everything counts. Take pride in what you have achieved, and don't be too hard on yourself if you get set back.
- Boredom is a real issue for many people. You might get tired of doing the same activity week after week, so be prepared to add some variety to your routine.
- Put on your favourite peppy music while you exercise. find out about interesting activities in your neighbourhood like Zumba , dance work outs, Pilates or laughter clubs.
- Use an app or gadget to make it a game, maybe counting footsteps or distance travelled Challenge yourself to improve a little each week. Start gently and build up gradually.
- Find a good time of the day or week to exercise. Build exercise into your daily life, like allowing extra time to walk instead of taking the car.
- Make it a point to go to the local shopping area with your family for daily shopping like fetching milk, bread etc. You will be surprised how many friends you will make along the way.
- Do it for a good cause! Raise money, awareness or just do something to make a difference, like picking up litter when you go for a walk or jog. You'll find you keep going when others are counting on you.

## This happened to me: Finding motivation

Neha writes: 'On a wet, cold day, I really don't want to get out and run. I just want to curl up back in bed. But when I drag myself out, I do feel better later. I just have to remember that every time!'



Getting exercise into your daily routine Staying active doesn't have to involve special clothes and equipment. Anything that makes you breathe a bit deeper and gets your heart rate up counts as 'exercise'. It could be dancing, swimming, gardening or just walking.. You can make small changes to boost your cardiovascular fitness - perhaps walk faster for part of your regular route (between landmarks such as seats in the park or market place), climb the stairs instead of using the lift, dig the garden a bit more vigorously. The increase in speed or effort need only be for part of the activity but you should be aware of breathing deeper and feeling a bit warmer from the effect on your circulation. A great suggestion from one of our Delhi based members Anita is to find place to exercise & have fun at the same time. Anita regularly goes to a popular Mall, specially during the warm weather, and just walks in cool comfort while enjoying the cheerful environment. She puts on her ear phones, listens to her favourite music & walks in the cool comfort regularly. Smart girl! It is good to have a trigger to remind you to exercise. Maybe do one of these exercises when the adverts or weather come on the television, or when waiting for the kettle to boil. Exercise in short bursts will still make a difference to your fitness. Stand up, walk around the room or around the house, move your arms up



and down or rotate them , twist your hips and waist.

When you start your programme, pick out a couple of exercises that you know you will be able to do and build up gradually. At first you could pick maybe two exercises and do them every day at least once - perhaps in the morning and in the afternoon. Then pick a day in the week and a good time in the day. Select a few more different exercises and go through a longer programme.

Set small goals initially.. There's no point in setting your target so high that you will not be able to reach it. You may find you can do more repetitions of each exercise but it is sensible to start with a low number and build up gradually. When you want to increase the number of exercises only add one or two repetitions for at least three days before you do anything more.

Make sure you check how you feel - especially for signs of increased fatigue - before challenging yourself further.

Finally, when you are exercising, it's important to breathe! A lot of people hold their breath when they exercise and that's not a good idea!

## **NEW INITIATIVES BY MSSI DELHI**

Each year since 2009 we have been marking 30 May as WORLD MS DAY. A day where people with MS, their friends, families, medical professionals and generally everyone across the globe gathers together to show solidarity with, raise awareness & funds for people with MS. World MS Day 2020 the International theme chosen was MS Connections.

In Covid times, gathering together physically was impossible but every single country came together like never before and truly lived up to World MS Day theme MS Connections!

They say every adversity creates new opportunities. The Delhi Chapter of WMSD was quick to recognize the opportunity of living in a digital world. here's what we did:

## **Connect from Home with MSSI Delhi-**

Virtual Home Visits to connect MSSI Delhi PwMS, caregivers and families through Zoom or WhatsApp video calls. Launched in May, and carrying on through the year, MSSI Delhi will reach out to over 700 registered PwMS and their Caregivers, spread in several states & cities in North India for support and counseling.

The purpose of this project is to reach out to all the persons with MS who may be house bound, or unable to travel either within Delhi / NCR or even from some distant towns & cities due to their own physical challenges, family difficulties, lack of transport or cost of travel.

MSSI Delhi Counselors & Volunteers video call you, meet your family members, get to know you better, assess your circumstances & offer advice (and lots of motivational cheering up!) We are keen to meet caregivers, children, parents, siblings etc. This face to face meeting makes our earlier telephonic chats more personal and interesting.

This connection has been specially beneficial during the long lock down period, when PwMS often felt isolated & low. So we were able to meet, reach out and solve some of your day to day issues without exposing you (or ourselves) even as Corona raged around the country.

These meetings will continue on a regular basis, more so as Delhi NCR is so spread out, that in spite of our best efforts, we are unable to meet each & everyone of you regularly.

So if you want us to visit, just send us a message, and we will work out a mutually convenient time to chat, discuss, laugh, joke, join your birthday party or have a serious discussion.

The Project coordinator is Meenakshi Bhujwala-But feel free to reach out to whomsoever you feel comfortable to chat with.. all of us are here for you.





## **Building Community Connections-**

We are challenging social barriers that leave people affected by MS feeling lonely and socially isolated by connecting PwMS through virtual localised Micro-connect groups on WhatsApp. These are groups of PwMS living in areas close by to each other, but who till now were not connected or were not aware of each other they are now like a MS Family, in one area, who can be reached for sharing, caring and checking how you're faring !

All these groups in turn are connected to MSSI Delhi volunteers through Micro group volunteers. So now you are not alone!

These wonderful new families in turn, connect & interweave all the PwMS registered with MSSI Delhi who belong to the larger areas across all of Northern India (Punjab, UP, Uttarakhand, Rajasthan, Himachal, Haryana, Delhi NCR, Jammu and Kashmir).

**Each Micro group** is led by self motivated, effective & enthusiastic Persons with MS who will assist senior MSSI members . These senior members will be observing the activities of the group and are always there to help, guide and counsel you .

MSSI Delhi has already formed 7 such What'sApp groups with attractive and easily recognizable common DPs and names.

## The MSSI Micro Connect group at the moment are

Haryana (Faridabad)	– Led by	Shama Nagpal
UP (Meerut) & Uttarakhand	– Led by	Gaurav Goel
Gurgaon	– Led by	Panchmi Bhardwaj
Noida & Greater Noida	– Led by	Harleen Chadha
Himachal (Chandigarh)	– Led by	Anju Bhatia
Rajasthan	– Led by	Puja Chaudhry
Punjab	– Led by	Ruchika Khanna

Please feel free to reach out to these wonderful young leaders in your area, and get connected right away!

There are more groups to be formed for Ghaziabad-UP and 4 regional zones in Delhi. These groups have been a roaring success (-although there are always some quiet ones who we will draw out soon)

The groups are constantly buzzing with interactions, members are feeling energized and comforted with the knowledge that they are not fighting MS alone-there is a friend close by around their own locality. Through this new initiative a number of new MS persons enrolled and registered during the April-June period, who came through networking efforts of these Micro group members. This is truly *#MSConnections* in action!

- The members of the connect groups found great solace in meeting each other and are sharing their stories.
- Some thought they were the only isolated cases in the area and were depressed.
- This project lifted the spirits of all the members with the feeling that there are more understanding friends who are in a similar situation.
- Through exchange of each one's experience, and the help, information & advice given by MSSI Delhi, these members feel more equipped & empowered to carry on with their lives.
- Several of them participated in Webinars for the first time, shared motivational as well as exercise/meditation/yoga videos circulated by MSSI Delhi representatives on the group.
- This project is initiated and led by Bipasha Gupta.

## **Connections to Quality Care**



Many of our MS persons were missing the routine of their exercises & physiotherapy which was halted abruptly due to the lock down.

To bridge the gap, MSSI Delhi decided to make their own videos as per the needs of their members for circulation within the member community as well as posting on Social Media Sites.

Home MS Physiotherapy and Occupational therapy Videos were made in Hindi and English. Two short inspiring motivational videos featuring actress **Mandira Bedi** and clinical psychologist Dr Ashima Puri, also a PwMS, were shared in WhatsApp groups and posted on MSSI social media handles. These were very well received, with all 4 videos were uploaded

on social media and shared widely.

In fact, Mandira Bedi's video was featured as one of the FAMOUS SHOUT OUT on the MSIF/ World MS Day website garnering many 'likes' around the world.

## We encourage every one of you to follow, like & share MSSI posts on





## MSSI Delhi's collaboration with GTT-Global Talent Track





MSSI Delhi & GTT are collaborating through this zero cost initiative in the area of diversity (Specially Abled) . Many of our young, well educated and qualified PwMS are facing great challenges in finding suitable jobs due to their condition. There are many candidates who are very capable but sometimes cannot work in regular jobs due to problems of access, timings, commuting etc.

We are looking forward to train these job hopefuls and empower them to face interviews and get selected. The no cost, online 'Employability Training Programme' aims to provide skills including public speaking & presentation, business communication, problem solving and decision making, grooming and personality development, adaptability & flexibility, confidence building, basic computing knowledge and interview skills to improve employment opportunities and help our PwMS lead a life with self-esteem, conquering the hurdles of life.

This tie up has proved to be a very exciting new 1st of its kind project where MSSI Delhi's young candidates are being trained for job opportunities in the corporate sector, PSUs and other organizations who are supporting specially abled candidates & are offering opportunities to them. Members for 3 batches of 12, 15 and 18 candidates each were shortlisted screened and placed on the lists. All the candidates' profiles have been recorded systematically with their professional & personal info.

So far 2 batches have undergone very professional and thorough on line job training sessions conducted by GTT trainers under the supervision of project coordinators.

A total of 15 candidates from the first 2 Batches are undergoing various stages of interviews for online jobs.

## The project is very beneficial as:

- This has created a new kind of enthusiasm amongst the candidates.
- After being homebound for so long they suddenly realised that they are still employable with the right inputs.
- This has been a wakeup call for young MS persons who lost hope.
- MSSI strongly believes that diversion of mind is a better medicine for the well being of PwMS.

This project is being handled by Bipasha Gupta & Puja Chaudhary



## MSSI DELHI wishes to thank you all.

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We also wish to thank the faculty at the **Neuro Sciences Centre, AIIMS Indian Spinal Injuries Center** and all Hospitals & Doctors of Delhi/NCR for your continued support.



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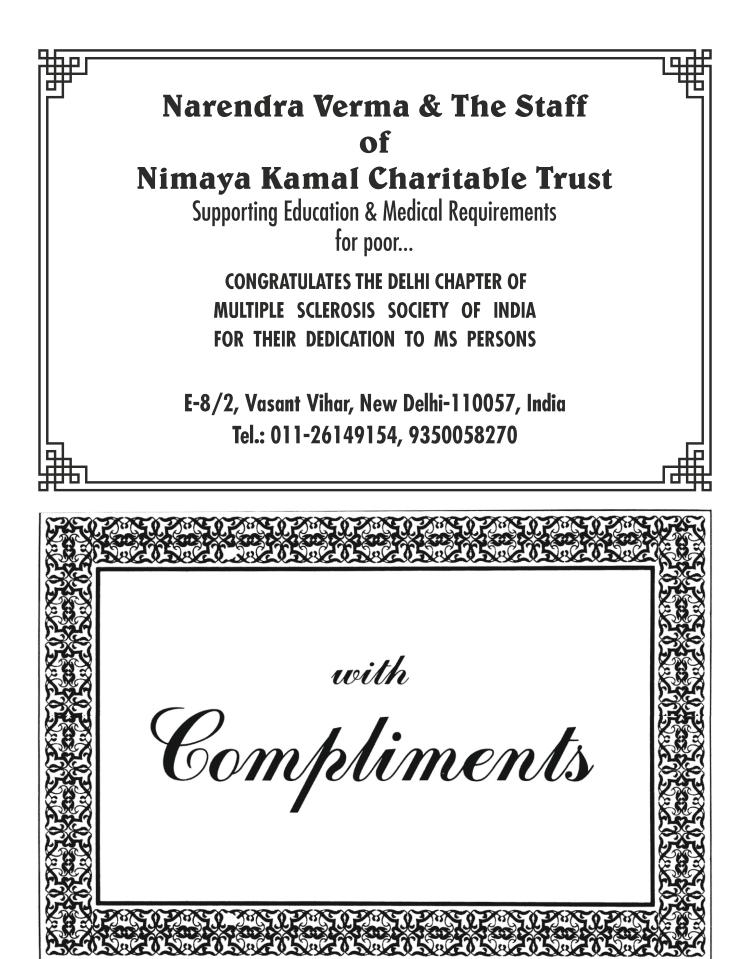
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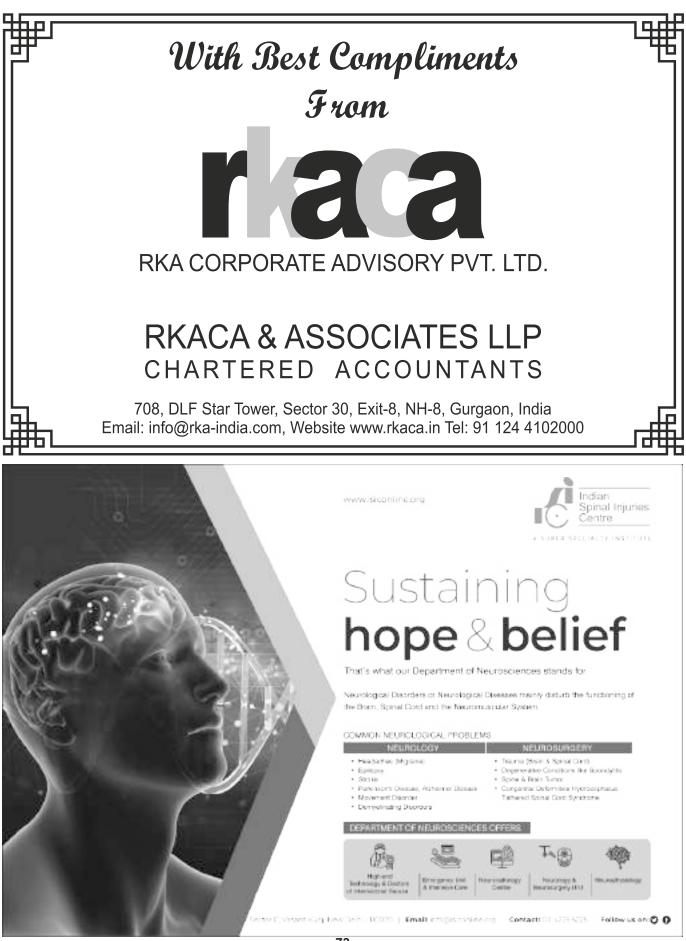
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