



Information for You from Your Health Care Team

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is a disease that can attack your central nervous system (CNS). The brain, spinal cord and the optic nerves can all be affected by MS. MS causes damage to the protective coating of the nerve fibers. This protective coating is known as myelin (my-a-lin). When the protective coating becomes damaged, there is a breakdown in the flow of information along the nerves. The following symptoms can occur:

- Weakness
- Depression
- Bowel & Bladder Problems
- Tiredness
- Numbness
- Sexual Problems
- Tingling feeling
- Pain
- Balance & Coordination Problems
- Emotional Changes
- Vision problems
- Muscle Spasms
- Difficulty with Thinking

Symptoms that occur less often are:

- Difficulty with swallowing
- Hearing Loss
- Headaches

Types of Multiple Sclerosis:

- **Relapsing- Remitting Multiple Sclerosis (RRMS)** This is the most common form of MS. 85% of people are diagnosed with this type. This type of MS results in a gradual decrease in neurological functioning over time. The progression can then stop and individuals may recover partially or even completely. The symptoms can then be inactive for months or even years.

- **Primary- Progressive MS (PPMS)** This is a less common form of MS. 10% of people are diagnosed with this type. The onset of this type is slow. There is continuous progression of decreased neurological functioning. The time this takes to progress may take months or even years.
- **Secondary- Progressive MS-(SPMS)**-This type of MS may follow after having Relapsing- Remitting MS. There may be a break from this type of MS or the symptoms can remain constant with no break from the disease. It may result in a progressive disability for some people. 50% of people with Relapsing-Remitting MS will have developed some form of the Secondary- Progressive MS within 10 years.
- **Progressive Relapsing MS (PRMS)** This is the rarest type of MS. 5% of people will experience this type of MS. There is continuous steady decrease in neurological functioning from the time of diagnosis. There may or may not be relapses, in which there could be some recovery. However, it usually progresses without remissions.

Speak Up if You Have Questions

References:

MS Association of America www.msassociation.org

MS Coalition www.multiplesclerosiscoalition.org

American Academy of Neurology www.aan.com

American Medical Association www.ama-assn.org

American Neurological Association www.aneuroa.org

MEDLINE plus www.nlm.nih.gov/medlineplus

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Multiple Sclerosis (MS) Problems and Treatment

Fatigue

Affects 2/3 of patients and is one of the most disabling problems of MS.

- Exercising done early in the day can be helpful.
- Preventing overheating can improve fatigue.
- A medicine called **Provigil (Modafinil)** is helpful in treating fatigue. A dose lower than 200mg has been found to be effective in reducing fatigue and sleepiness

Spasms and pain

Exercise can help reduce mild spasticity and pain in the lower limbs. Exercise will also help to keep muscles toned

Medicines used for spasm and pain are:

- **L'Oreal (Baclofen)** is used for severe spasticity.
- **Zanaflex (Tizanidine)** is also used to decrease spasticity without leg weakness. This medicine takes 1 week to work.
- **Keppra (Levetiracetam)** and **Neurontin (Gabapentin)** can help to reduce spasticity
- **Valium (Diazepam)** this is used for spasticity and also if anxiety is a problem.
- **Dantrolene** is a medicine that can be used for people who are unable to tolerate **Baclofen** or **Valium (Diazepam)**. This medicine is used if wheel chair bound or if muscle weakness is not debilitating.
- In severe cases of spasticity surgery may be used to cut tendons are that are involved with the spasticity.

Bladder problems

You may be unable to control the urge to urinate. It is helpful to know where restrooms are, and if they are easily available. Try not to drink fluids before going out and empty the bladder.

Medicines for bladder problems include:

- **Pro-Banthine (propantheline)**, **Detrol (Tolterodine)**, and **Ditropan (Oxybutynin)** which all help to reduce the urge to urinate.
- **Interstim**: is a treatment that involves sacral nerve stimulation. An electrical impulse is sent to the sacral nerves to help retrain them.

Urinary retention

This is when individuals have difficulty emptying the bladder completely. The urge to urinate can be stimulated by tapping or pressing against the bladder with your fist or hand or straining.

Medicines for this bladder problem include:

- **DDAVP** (Desmopressin) **and Ludiomil** (Maprotiline. **DDAVP**: is a medicine that controls the amount of urine your kidneys make
- **Ludiomil** is an antidepressant that is used because urinary retention is a side effect.
- Sometimes catheterization may be needed every so often or long term.
- Urinary symptoms can come and go for years.
- It is best to limit treatment to medicines or reversible therapies as long as possible.

Urinary tract infections

This type of infection is common in MS patients because of trouble emptying their bladder completely.

Urinalysis done with any flare-ups or change in bladder symptoms

- Treatment is with antibiotics

Bowel problems

MS patients may have problems with constipation because of being less active

Treatment:

- A diet high in fiber and drinking plenty of water will help you with bowel movements.
- A routine of going at the same time each day or after a meal may help to reduce losing control of the bowels.
- Exercise will help stimulate motility in the bowel.
- These strategies reduce the need for laxatives, enemas or colonic irrigation. All of which can lead to a decrease in bowel motility or an electrolyte imbalance.

Tremors

These are uncontrollable movements of the limbs that can be hard to treat and are distressing to the patient.

Facial pain

Also known as Trigeminal Neuralgia is a severe pain that often occurs on one side of the face. The pain can be triggered by a mild action such as a breeze across the face, brushing the teeth, talking or chewing.

Treatment

- Antiseizure medicines such as **Neurotin**, **Tegretol**, (Carbamazepine), and **Dilantin** (Phenytoin) are used to help reduce the pain. Other medicines being used are **Valium**, **Orap** (Pimozide) and **Elavil** (Amitriptyline).
- **Nerve Block**- This is where a medicine is injected to block the pain.
Gamma Knife Surgery- Radiation is pinpointed at the nerve to block the pain.

Emotional changes

MS can cause your emotions to be difficult to control.

Treatment

- **Neurodex** (Quinidine/dextromethorphan) – is an investigative drug that is being used to help with this problem.

Sexual dysfunction

You should discuss this with your doctor.

- Medicines such as **Viagra** (Sildenafil) & **Corticosteroids** are sometimes used to help improve sexual function.

Difficulty swallowing

You may have decrease ability to swallow food.

- Issues with swallowing need to be treated. If untreated it causes a risk of aspiration pneumonia, malnutrition, and dehydration.

Treatment

- A puree diet, soft easy to swallow food or the use of tongue and specific head positions may help to make swallowing easier.

Osteoporosis

Decrease in mobility caused by MS increases the risk factor for osteoporosis.

Treatment

- Medicines such as **Fosomax** (Alendronate), **Actonol** (Risedronate), and **Calcium with Vitamin D** supplements can help to reduce the risk of fractures due to osteoporosis.

Depression and stress:

MS is considered to be a type of auto immune disease. Stress can effect how the immune system can respond.

- Stress may worsen the disease.
- Reducing stress is a very important to help improve the over all well being in patients.

Treatment:

- Relaxation, meditation or exercise can be very helpful.
- Medicines such as **Elavil** can help or reduce the extreme mood swings that can occur in MS patients. **Norpramin** (Desipramine), **Pertofane** (Protriptyline), and **Tofranil** (Imipramine) are all medicines that may help and at the same time help improve bladder function.

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Multiple Sclerosis Common Terms

Antibodies \ˈant-i-,bäd-ē\

A protein made by the body that sticks to antigens.

Antigens \ˈant-i-jən\

A material the body senses as foreign such as toxins, bacteria and viruses. If this comes into our body it can cause the body to make antibodies.

Ataxia\ə-ˈtak-sē-ə

Is a condition where muscles are unable to work in a coordinated manner.

Autoimmune-\im-ˈyün\

This is when the body attacks its own cells. It may be against certain organs or tissues that are found in our body.

Blood brain barrier-

This is a protective membrane that blocks foreign substances in the blood from entering the central nervous system.

Cerebrospinal fluid (CSF)

Is a clear fluid that cushions the brain and spinal cord.

Cytokines-\ˈsīt-ə-,kīn\

A chemical made by T-cells. This chemical is important in causing swelling.

Demyleination

Damage to the protective coating of the nerve. This causes a break in the communication between the nerves and the rest of the body.

Fatigue\fə-ˈtēg\

Having no energy, feeling tired all the time. It can happen after activity or may continue even without any activity.

Gadolinium \gad-^əl-'in-ē-əm\

This is a medicine that is given by IV during a MRI, this helps to tell new lesions from old ones.

Lesion\lē-zhən\

This can be a wound or change in body tissue that is caused by injury or disease.

Magnetic resonance imaging (MRI)

A test that can scans the brain or the body and is able track lesions as they develop.

Myelin\mī-ə-lən\

Is a protective covering found over the nerves in the brain and spinal cord. It allows messages to travel between the brain and spinal cord and to and from the rest of the body.

Myelin basic protein (MBP)

This is the main part of myelin. When myelin breaks down it can often be found in high levels in cerebrospinal fluid (CSF).

Oligodendrocytes\-'den-drə-,sīt\

This cell in the brain makes and maintains myelin.

Optic neuritis

This is a swelling of the optic never. It usually occurs in one eye only and can cause visual loss or blindness. This is usually temporary.

Paresthesias- \,par-es-'thē- zh(ē-)

Is an abnormal feeling such as numbness, or the sensation of “pins and needles”.

Plaques-\' plək

Are areas of demyelination and swelling that can happen in MS. The plaques can disrupt or block the nerve messages that would normally pass through the area that is affected.

Receptor \ri-'sep-tər\

Is a protein found on a cell's surface that allows the cell to identify certain antigens.

Retrobullar neuritis- \n(y)ü-'rīt-əs\

Is when the optic nerve becomes swollen resulting in a rapid loss of vision and may cause pain with movement of the eye. It is usually a temporary condition

Spasticity \spa-'stis-ət-ē\

Is when muscles move against your will causing spasms, stiffness or rigidity. In MS patients this primarily affects the lower limbs.

T-Cells - T- \'seɪ\

These cells are involved with the body's immune system. Findings show that these cells are involved in the destruction of myelin.

Transverse myelitis \tran(t)s-'vərs ,mī-ə-'līt-əs\

Is a condition that involves the spinal cord. It can cause sudden low back pain and muscle weakness. It will often resolve on its own, however it can be severe and long lasting resulting in permanent disability.

White matter

These nerve fibers are the site of MS lesions.

Speak Up if You Have Questions



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Energy Conservation and Work Simplification

After an injury or illness, you may find that things that were once easy, now take more effort. You may also find that you have less energy by the end of the day.

Pace Your Activities

It is important to find a balance between activity and rest. This balance will prevent increased stress on your body and prevent you from becoming too tired.

- Rest for 5 to 15 minutes for every hour you work.
- Establish a slower, steadier pace for heavier
- Avoid fatigue by alternating medium to heavy tasks with light tasks.
- Avoid activities like lifting a child that require a sudden burst of energy.

Use proper breathing techniques during activities to prevent fatigue and shortness of breath. Take a deep breath in before starting the task, exhale when you are performing the task.

Use Good Body Mechanics

Good body mechanics involves learning how to use your body right so you do not stress your joints. These body mechanics tips can help you reduce your pain or fatigue.

- Use good posture.
- Distribute your load by using larger joints for carrying (i.e. use a backpack or shoulder bag for carrying).
- Use body leverage; carry things close to your body or slide heavy objects rather than lifting them.
- Move or change your position often to prevent stiffness and pain.
- Adjust your work heights to reduce straining of your neck, back, or arms.
- Limit overhead work and change hands when doing repetitive or prolonged activities.
- Use reachers instead of bending to get something from the floor.

Setting up Your Environment

Arrange your home to help you to simplify daily tasks and conserve your energy.

- Use space efficiently by making specific work areas.
- Arrange frequently used items within easy reach.
- Use electric appliances; sit for cooking and cleanup.
- Use long-handled tools or other equipment in the kitchen, bedroom or bathroom
- Identify things in your environment that may decrease your fatigue or improve your safety at home. (i.e. use exhaust fans, install rails, remove throw rugs)
- Gather necessary items using a tray, utility cart or basket to transport them.
- Install grab bars in the bathroom.
- Use a bath stool.
- Use a bedside commode or a raised toilet seat.
- Keep a chair near your work area.

Planning Ahead

Take time out to plan before you start out the day or begin an activity. If you plan out the way you will accomplish all that you need to do, you may decrease the amount of fatigue you experience after.

- Organize your day; space out tasks that consume more energy and include rest periods in your schedule.
- Set realistic priorities for each day and week; before each activity, ask yourself if it is something you really need to do now.
- Don't try to do everything at one time.
- Break up big jobs into smaller ones (i.e. one load of laundry each day instead of 5 loads one day a week)
- Organize your work areas; eliminate non-essentials-gather all materials you need to avoid unnecessary trips on the stairs or to different rooms in your home
- Keep things in easy reach (i.e. keep things you use all of the time on the countertops.
- Determine if there are some heavier tasks that you can have help with (i.e. carrying groceries, laundry, lawn work, snow shoveling)

Managing Your Stress

Be aware of how your body responds to stress (i.e. headache, upset stomach, stiff neck). Try out different ways to deal with stress and prevent pain and fatigue that may result from stress.

- Plan ways to deal with situations that you know may be stressful; spend time relaxing before you are faced with them.
- If you know something specifically stresses you, limit your exposure to it.
- Find positive ways to express yourself; join a support group of talk with a physician or other health care worker, or member of the clergy. Learn relaxation techniques:
 - Breathing exercises
 - Muscle relaxation
 - Meditation
 - Social/leisure activities
 - Exercise
 - biofeedback

Physical activity should be a part of your daily schedule; it helps you sleep better and recover from stress more quickly. Check with your doctor if you plan to try a physically-demanding activity you have not tried before.

Speak Up If You Have Any Questions or Concerns