

HOW IS MULTIPLE SCLEROSIS DIAGNOSED?

There is no single diagnostic test that is proof-positive for multiple sclerosis. There is a set of accepted criteria for MS diagnosis, but even this system is imperfect. Since diagnosing MS can be very difficult, it must be done by a neurologist who specializes in treating MS. As many as 10 percent of people diagnosed with multiple sclerosis actually have some other condition that mimics MS.

Examples of other conditions that masquerade as MS include inflammation in the blood vessels, multiple strokes, vitamin deficiency, and brain infection. Sometimes stress-related disorders can lead to a misdiagnosis of MS.

WHAT ARE THE ACCEPTED CRITERIA FOR DIAGNOSIS?

- Onset usually between 10 and 60 years of age
- Symptoms and signs indicating lesions of central nervous system white matter
- Evidence of two or more lesions upon examination by MRI scan (see below)
- Objective evidence of central nervous system disease on neurological examination
- A course following one of two patterns: two or more episodes lasting at least 24 hours and occurring at least one month apart, or a progressive course of signs and symptoms over at least six months
- No other explanation for the symptoms

HOW WILL I BE DIAGNOSED?

An accurate diagnosis is based on your medical history and neurological examination using tests of nervous system function. Much depends on the skill of the doctor in asking the right questions to uncover information and to properly evaluate the signs and symptoms of a malfunctioning nervous system.

In addition to a thorough medical history and neurological examination, a variety of specialized procedures are helpful -- although not always necessary -- in accurately diagnosing MS.

These include imaging techniques such as magnetic resonance imaging (MRI), spinal taps (examination of the cerebrospinal fluid that runs through the spinal column), evoked potentials (electrical tests to determine if MS affects nerve pathways), and laboratory analysis of blood samples.

WHAT DOES AN MRI SHOW?

The precise image produced by MRI gives the neurologist clear evidence of scar tissue in the deep parts of the brain or spinal cord that is characteristic of MS.

However, abnormal spots on the brain MRI can be caused by other conditions, so these images must be interpreted by the neurologist in light of all information about the patient. Similar lesions can be seen in elderly people or people with migraine headaches or high blood pressure. Confirming a diagnosis of MS and ruling out other possible causes requires expert interpretation of the MRI scan.

WILL I NEED A SPINAL TAP?

Performing a spinal tap to examine the cerebrospinal fluid might be helpful in diagnosing MS in some people, but it is no longer considered necessary in all instances.

An experienced MS team will be able to determine if you need this test to confirm a suspected diagnosis of MS, particularly if your history and physical examination suggest the presence of the disease. Abnormalities that might appear in the cerebrospinal fluid can be very helpful in establishing a diagnosis but, like other tests, spinal taps are not foolproof in diagnosing MS.

WHAT OTHER TESTS MIGHT BE DONE?

Electrical tests of the nerve pathways, known as evoked potentials, are very helpful in confirming whether MS has affected the visual, auditory, or sensory pathways. These tests are done by placing wires on the scalp to test the brain's response to certain types of stimulation, such as watching a pattern on a video screen, hearing a series of clicks, or receiving electrical impulses in your arm or leg.

Your doctor might order a blood test to help rule out conditions that imitate multiple sclerosis, but the presence of MS cannot be detected in the blood.



Exercise can help ease the symptoms of multiple sclerosis (MS), but it's important to take certain precautions if you want your exercise program to be successful. The most important thing to remember is to not overdo it.

You may have heard the principles “stretch till it hurts” or “feel the burn” as they relate to exercise, but those approaches are counterproductive for people with MS. If you overdo it, you can end up straining an already compromised muscular system, increasing pain, and causing your body and mind to become overstressed, overworked, and overtired.

Check with your doctor before beginning any exercise program. He or she might make recommendations about:

- The types of exercise best suited to you and the types you should avoid.
- The intensity of the workout (how hard you should be working).
- The duration of your workout and any physical limitations.
- Referrals to other professionals, such as a physical therapist, who can help create a personal exercise.
- program that meets your needs (The type of exercise that works best for you depends on your symptoms, fitness level, and overall health).

HOW CAN I EXERCISE SAFELY?

- Always warm up before beginning your exercise routine, and cool down at the end.
- If your goal is to work out for 30 minutes, start with 10-minute workout sessions and work your way up.
- Work out in a safe environment. Avoid slippery floors, poor lighting, throw rugs, and other potential tripping hazards.
- If you have difficulty with balance, exercise within reach of a grab bar or rail.
- If at any time you feel sick or you begin to hurt, STOP.
- Select an activity that you enjoy and HAVE FUN. Water aerobics, swimming, tai chi, and yoga are examples of exercises that often work well for people with MS.

WHAT SHOULD I DO IF I GET OVERHEATED?

Some people with MS are sensitive to heat, which means they notice that their symptoms either reappear or become worse when their body temperature rises. An increase in body temperature occurs when you exercise. Here are some tips to avoid overheating:

- Don't exercise during the hot time of the day (10 a.m. to 2 p.m.). Try to exercise in the morning or evening if you are exercising outside.
- Drink plenty of cool fluids.
- Become aware of your body. If you notice any symptoms that you didn't have before you began exercising, slow down or stop exercising until you cool down.

- Swimming and water aerobics are good exercise options to keep you cool while exercising. Ask your pool manager about the temperature of the water. Ideally, it should be between 26.66 - 28.9 degrees Celsius. Also, make sure that there are non-slip floors in the locker room and around the pool.

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IN SUMMARY

- BT therapy can be helpful when relief of spasticity is needed in a few muscle groups
- The treatment is usually safe and well tolerated, but needs to be repeated every few months to maintain the therapeutic effect.
- Daily stretching and exercise, and in some cases rehabilitation, are essential to maximize the potential benefits of treatment.

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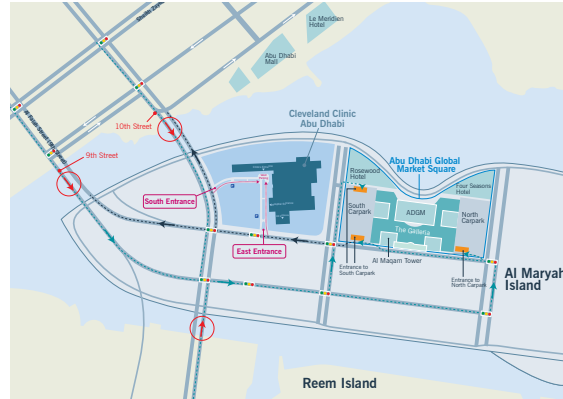
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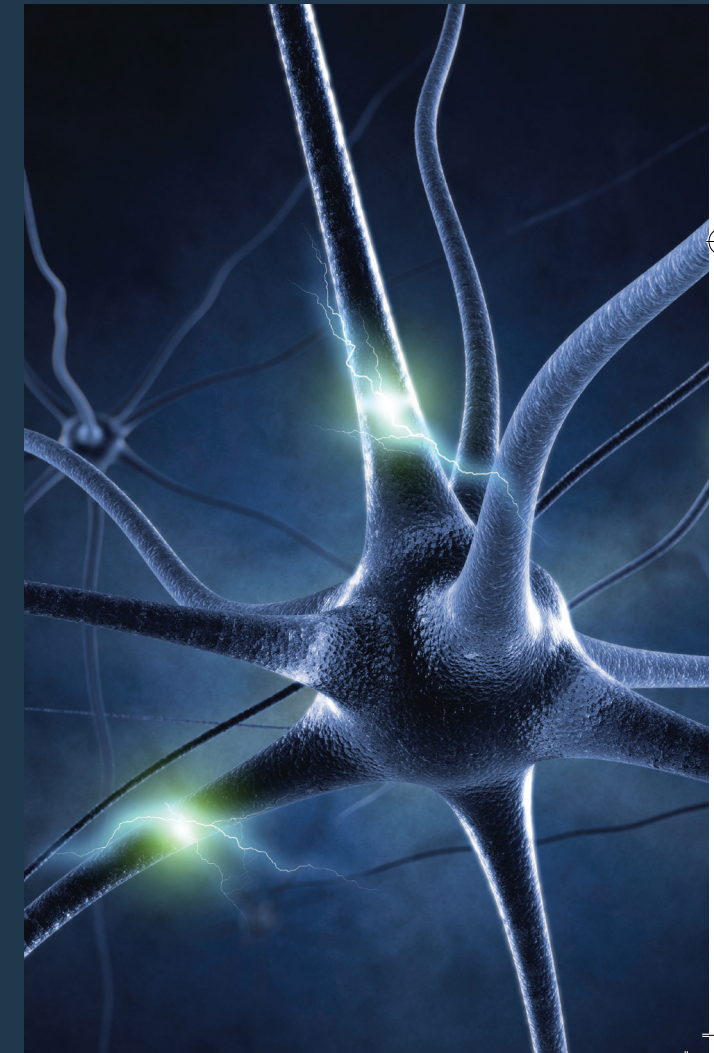
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TREATING MULTIPLE SCLEROSIS WITH BOTOX

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WHAT IS SPASTICITY?

Spasticity is a movement disorder that can occur in conditions which affect the brain or the spinal cord, such as multiple sclerosis, stroke, cerebral palsy, spinal cord injury, or brain injury. Spasticity is caused by an imbalance between signals that inhibit or stimulate the spinal cord. This results in hyperexcitable stretch reflexes, increased muscle tone, and involuntary movements.

WHAT ARE THE SYMPTOMS OF SPASTICITY?

Spasticity causes muscle stiffness and tightness which interferes with voluntary movements. Spasticity can also cause muscle spasms (jerky involuntary movements) or clonus (repetitive involuntary movement).

Stiffness and spasms are often bothersome and sometimes painful, and they interfere with the ability to carry out daily activities. Spasms may also disrupt sleep and increase daytime fatigue. When spasticity is severe, contractures (fixed limitations of range of motion) may develop.

HOW CAN SPASTICITY BE TREATED?

Stretching, exercise, and rehabilitation are the first line of interventions for spasticity. Oral medications are often effective, but may cause side effects such as drowsiness. When spasticity affects only a few muscles, local injections of botulinum toxin can be helpful. When spasticity is diffuse and severe, intrathecal baclofen (ITB) may be a good treatment option.

WHAT IS BOTULINUM TOXIN (BT)?

Botulinum toxin is a medication derived from a neurotoxin produced by bacteria (*Clostridium Botulinum*). In its natural form, this toxin causes botulism, a severe condition that can be fatal. The botulinum toxin (BT) medication is designed to be used safely without causing botulism. There are two commercially available forms of BT currently:

- botulinum toxin type A (Botox®)
- botulinum toxin type B (Myobloc®)

HOW DOES BT WORK?

Normally, the brain sends messages to the muscles so they can contract and move. These messages are transmitted via the nerves to the muscles by a substance called acetylcholine. BT blocks the release of acetylcholine from the nerve to the muscle, therefore the muscle relaxes.

HOW IS BT GIVEN?

BT is given as an intramuscular injection (into the muscle). The injections are given during an outpatient visit, which lasts 1 hour. Your health care provider will determine beforehand

which muscles need to be injected. Because BT does not travel far from the injection site, several injections are performed during one visit. To ensure that BT is injected in the right place, short electrical impulses are sent through the needle used for the injection, to make the muscle contract. In some cases, electrical signals from the muscle are recorded via the needle, for the same purpose.

WHAT CAN I EXPECT AFTER THE INJECTIONS?

There are no activity restrictions after the injections. The effect of BT is usually not felt until a few days, up to 2 weeks after the injections. We usually ask that you return for a follow-up visit or call with an update 2 to 3 weeks after the injections.

The effect of BT is expected to last between 2 and 6 months, then gradually wears off. Most often, the injections are repeated every 3 months. In many cases, physical or occupational therapy is needed after the injections to maximize the benefits of BT. In all cases, it is necessary to stretch and exercise daily at home.

WHAT ARE THE ADVANTAGES OF BT OVER OTHER TREATMENTS FOR SPASTICITY?

- BT is usually effective in relaxing the muscles injected, and provides a stable effect for several months.
- BT is preferred when only a few muscle groups are spastic, or when spasticity relief is needed in only a few muscle groups, because it allows one to treat only selected muscles.
- BT is usually very well tolerated, in part because only very small amounts of medication go into the bloodstream.

WHAT ARE THE DISADVANTAGES OF BT?

- The benefits of BT are limited to the muscles injected. Therefore, it may not be a good treatment choice when many muscles are spastic.
- The effect of the injections is always temporary, therefore the injections need to be repeated at regular intervals to maintain the therapeutic benefits.
- There are limits to the amount of BT that can be injected during one session, and to the frequency at which BT can be injected, in part because the body can create antibodies against the medication. These antibodies are not dangerous, but may neutralize the effects of BT.
- BT has been used worldwide for this indication for many years, and its benefits and risks are well-known. Therefore, insurance companies may not cover the treatment.

WHAT ARE THE SIDE EFFECTS OF BT?

- The main side effect is the pain that may occur with the injections. No local anesthesia is given in most cases, because the exact sites of injections are determined during the procedure.
- The muscles injected can be sore for a few days after the injections.
- BT causes temporary partial weakening of the muscles injected. In most cases, the benefits of spasticity relief outweigh the effects of increased weakness. BT does not cause weakness in muscles that have not been injected.
- When BT is used for a long time, it may cause atrophy (thinning) of the muscles injected. This atrophy is reversible if the therapy is discontinued.
- There have been reports of temporary side effects such as flu-like symptoms, palpitations, tingling sensations, or nausea. These side effects are rare, and usually go away within 1 to 2 days.
- There have been reports of severe side effects in adults treated with BT, such as difficulty swallowing or breathing.

WHAT HAPPENS IF I DEVELOP ANTIBODIES TO BT?

In our experience, it is rare that people develop antibodies to BT. If this happens, you may notice that the treatment does not help any more, but no harmful effects from the antibodies have been reported. In some cases, switching from one type of BT to the other helps restore the treatment effect.

HOW DO I KNOW IF I AM A GOOD CANDIDATE FOR BT THERAPY?

BT therapy is usually considered when spasticity needs to be relieved in only a few muscle groups. It can be used in addition to other treatments for spasticity. If your health care provider thinks that you may be a candidate for BT therapy, you will be scheduled for an evaluation. During this visit, you will also be given detailed information about the treatment, so you can make an informed decision.

DOES INSURANCE COVER BT THERAPY?

BT therapy is not officially approved the treatment of spasticity, and this is why insurance coverage varies greatly, depending on a few factors including the individual insurance plans. We encourage you to check with your insurance ahead of time.

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Fatigue is the most common symptom of multiple sclerosis (MS). It occurs in 75 percent to 95 percent of patients with MS. Fatigue can occur at all stages of the disease. The symptom is not related to the severity or to the duration of MS. At times, fatigue interferes with function and is an important symptom to manage. There are a variety of ways to combat fatigue in MS.

WHAT CAUSES FATIGUE IN PATIENTS WITH MULTIPLE SCLEROSIS?

The exact cause of MS-related fatigue is still unknown. There are several theories on the subject:

- One theory is that fatigue is related to the general activation of the immune system. Chemical messengers are called cytokines; these levels are higher in patients with MS and may be higher still in patients with fatigue. One way of describing this is that you may feel like you have a virus all of the time.
- Another theory is that people with MS may have to use more parts of their brain to do the same task as someone without MS; in essence, they are working harder.
- Another theory is that fatigue is related to reduced electrical transmission of signals in the brain.

Whatever the theory, we know that fatigue from MS is a very real part of the disease.

WHAT ARE SYMPTOMS OF FATIGUE?

There are two major types of fatigue in MS. These two types of fatigue are probably separate problems related to the MS.

The first type is a general feeling of tiredness. It may feel as if one has not slept the night before. This feeling may be worse in the afternoons or after activity. People may feel that they are unable to do as many tasks without getting tired as they did before. A second type of fatigue is muscular. In this type, there is increased weakness after repeated activity. Often, this occurs with walking. People may find that they are dragging one leg or are more unsteady.

ARE THERE OTHER CAUSES OF FATIGUE BESIDES THE MS?

Obviously, people with MS can be tired for other reasons. For example, they may have sleep disorders that interfere with restful sleep. People with MS may have a condition called restless leg syndrome, where they feel that they have to move their legs to get relief. They may also have periodic leg movements, which is when legs kick involuntarily during sleep. Another condition affecting sleep is sleep apnea, which is also common among the general population.

Certain medications may affect sleep or cause fatigue. Alcohol or drug use may alter sleep or cause drowsiness. Sometimes, people have other medical conditions, such as infections, anemia, or a reduced thyroid function, which can increase fatigue.

ARE THERE NON-MEDICAL TREATMENTS FOR MS-RELATED FATIGUE?

There are non-medical treatments for fatigue related to MS:

- A number of studies have shown that regular exercise, usually with some aerobic (cardiovascular) component, helps with MS-related fatigue. Regular exercise is also good for balance, endurance, weight loss, and well-being.
- It is important to use the principle of energy conservation. For example, you can use “the best time of the day” by shopping in the morning and resting in the afternoon. A brief nap may be very helpful to recharge your batteries.
- Avoid over-filling your day.
- If you are taking medications that are causing fatigue, discuss these with your doctor; together, you and your doctor may consider reducing or eliminating these drugs.
- If you are drinking too much or abusing drugs, consider working on stopping these behaviors.
- Some patients are heat sensitive and have more fatigue when they are in a hot environment or are over-heated. Having air conditioning in the summer may be very helpful. Some people may also find cooling vests to be useful.

WHAT ARE SOME MEDICAL TREATMENTS FOR MS-RELATED FATIGUE?

In general, if possible, it is good to avoid using medications. People with MS often take several medications. Limiting the number of medicines is good medical practice. It is also important in reducing costs. However, if fatigue continues to interfere with activities, medications may be useful. These medications may include:

- **Aspirin:** A recent well-designed study showed that two regular (325 mg each) aspirins taken twice a day significantly reduced MS-related fatigue and was preferred by patients over placebo. Aspirin is inexpensive and readily available over the counter. However, some people are sensitive to aspirin, and others may find it causes stomach ulcers. A trial of aspirin therapy for fatigue may be a reasonable first step in medication management. Usually, the effect can be seen after a month or two.
- **Amantadine:** Amantadine (Symmetrel®) is an antiviral medication that has been used in a number of studies in MS-related cases. The drug's effect is moderate, and side effects for some people may include nausea or a skin rash. Amantadine is given as an oral dose of 100 mg twice a day, usually in the morning and again at mid-day. One to two months is long enough to get a sense of how well this medicine is working.
- **Modafinil:** Modafinil (Provigil®) is a medication which has been approved by the US Food and Drug Administration to treat a sleep disorder called narcolepsy. Two studies have been done to test modafinil in treating patients with MS. One study showed a significant effect on fatigue, but the other did not.

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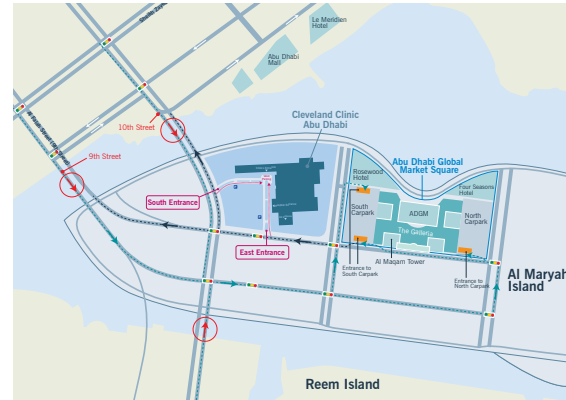
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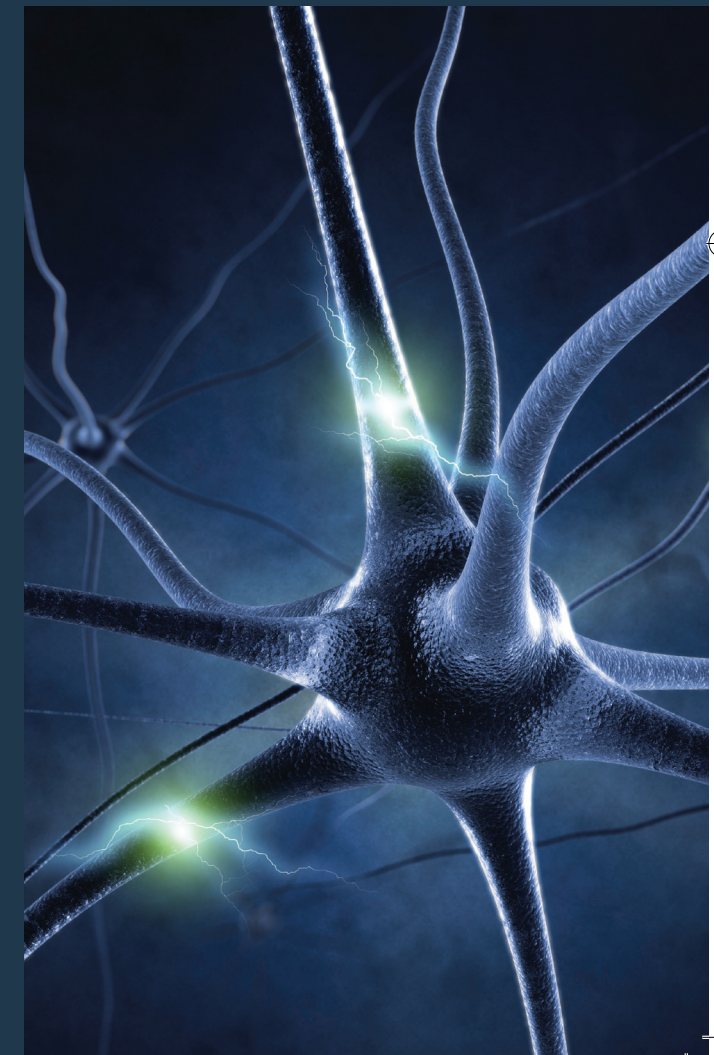
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PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS

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WHAT IS PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

Multiple sclerosis (MS) is a disorder of the central nervous system that affects about 400,000 people in the United States. Most people with MS have relapsing symptoms and experience episodes lasting days or weeks of symptoms, such as:

- numbness or tingling
- weakness of a leg or arm
- unsteadiness
- bladder difficulty
- visual symptoms

About one in ten people with MS do not have a relapsing course of the disease. These patients tend to have symptoms that gradually progress without typical relapses. Patients with the gradually worsening disease are considered to have primary progressive multiple sclerosis or PPMS.

HOW IS PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS DIAGNOSED?

First steps in diagnosing PPMS may combine a neurological history and exam with results from testing, primarily MRI imaging of the brain and spinal cord, as well as studies such as evoked potentials and spinal fluid testing.

The story of a gradually progressive neurological problem--such as weakness on one side, unsteadiness, or numbness in the legs--is characteristic. The condition must have been present for one or more years to make this diagnosis. The examination should show changes suggesting central nervous system disease. The MRI should show lesions that are characteristic of multiple sclerosis.

The spinal fluid often, but not always, shows oligoclonal banding. This is a sign that the immune system is active around the brain and spinal cord. The evoked potentials may show slowing in nerve conduction in the central nervous system. There should be no other diagnosis to cause the symptoms.

WHAT OTHER DISEASES CAN MIMIC PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

There are other diseases that can look like PPMS and need to be considered. For example, some people inherit a tendency for stiffness and weakness in the legs; a family history may be helpful. Some people with low vitamin B12 levels may develop numbness and stiffness in the legs and will show changes in their MRI scans. Occasionally, Lyme disease may look like MS. Some people with viral infections such as HTLV-1 may have a spinal cord syndrome. Sometimes discs or spinal arthritis may compress the spinal cord, or a tumor may be pushing on the spinal cord. Other diagnoses should be considered when the diagnosis of PPMS is being made.

WHAT CAUSES PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

Just as with multiple sclerosis in general, the cause of PPMS is not known. It is thought that the disease occurs in people who are susceptible to it due to some kind of genetic tendency. It is believed by some to be caused by a trigger, perhaps a virus. However, no specific cause for PPMS is known. PPMS, however, is not infectious.

WHAT IS THE PROGNOSIS FOR PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

As with multiple sclerosis in general, the prognosis varies in PPMS. Most people start to have symptoms at about age 40 or older, or about 10 years later than is typical of relapsing forms of MS. A recent Canadian study showed that many people with PPMS were able to walk years after a diagnosis, but usually patients tended to get worse over time. This worsening usually affected the ability to walk and was less likely to cause visual symptoms or tremor. Generally, thinking, memory, and intellect are relatively spared with PPMS. People who have PPMS may also have bowel, bladder, and/or sexual problems.

IS THERE ANY TREATMENT FOR PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

Research studies usually focus on medications for the relapsing forms of MS. There have only been a handful of treatment studies specifically for PPMS; the results so far have not shown a significant treatment effect. Standard medications for MS (interferons, glatiramer acetate, mitoxantrone, natalizumab) have not been proven useful in slowing the progression of PPMS.

In terms of making physical function as good as it can be, people with PPMS will be helped by exercise, stretching, physical, and occupational therapy. Maintaining mobility and fitness are as important in people with PPMS as with anyone else. In addition, there are medications which may be used to treat symptoms such as bladder and bowel urgency, erectile problems, spasticity, and pain, if such treatments are needed.

Occasionally, intermittent (on and off) intravenous (IV) steroids have been tried in patients with primary progressive multiple sclerosis. Such therapies have provided only limited results in these cases. Also, the chemotherapeutic drug methotrexate has been given in weekly oral doses to patients with PPMS. Results from research trials into new medications for primary progressive MS are still pending.

WHERE CAN I FIND ADDITIONAL INFORMATION ON PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS?

You may find the following web sites and/or organizations to be useful:

- National Multiple Sclerosis Society
- Multiple Sclerosis Association of America

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WHAT IS SPASTICITY?

Spasticity is an increased muscle tension and tightness that may interfere with useful movements. It is often present when people have had MS for a few years, and tends to be happen more often in the legs than in the rest of the body. Phasic spasms are rapid movements of limbs that occur suddenly, such as sudden flexing of a leg. Tonic spasms are a tightening of limbs in place. Spasticity may be painful and may interfere with walking, transferring, and sitting; in general, this is when spasticity is treated. While patients with spasticity may be weak, the two are not the same, and strength may be preserved in someone with spasticity.

DO PEOPLE WITH MS GET PAIN?

In the past, physicians thought that MS did not cause pain. However, recent studies have shown that up to one-third of people with MS will have pain related to their MS at some time during the course of their disease. This pain comes in a variety of forms, including trigeminal neuralgia, a syndrome involving sharp, stabbing pain in the side of the face or the jaw. It may come and go for days, weeks, or even longer. Medication may help with this. Some people develop back or neck pain, similar to the pain that many other people get. Some patients may get burning or tingling pain in the legs, arms, or body which may stay or come and go. Pain is part of MS and should be treated appropriately.

DO PEOPLE WITH MS GET BLADDER PROBLEMS?

Some people with MS will have problems with bladder function due to injury to the nerves that tell the bladder and the sphincters what to do and to the nerves that help the bladder sense when it is full. The most common symptom of bladder problems in MS is urgency, a feeling that "when you have to go, you have to go." Sometimes people find that it is hard to start going, for the urine to flow. Some people cannot tell when they have to go, or may have accidents (incontinence). Many of these symptoms can be treated either with medication or with approaches such as self-catheterization, which allows the bladder to be emptied whenever it needs to be. People with MS and bladder problems are at a higher risk of urinary tract infections. Bladder problems in MS may range from being a nuisance to being a major problem that needs to be addressed.

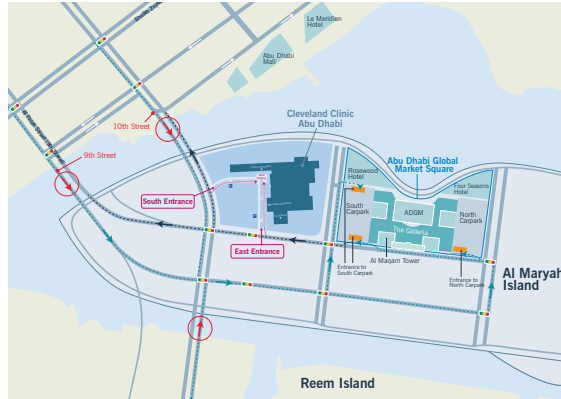
IS FATIGUE PART OF MS?

Fatigue, a sensation of being tired all the time, is very common in MS. Most patients with MS feel tired more than they used to, despite getting sleep at night. While fatigue in MS can be due to a lack of sleep or poor sleep, it is often just one of the symptoms of MS. It may be due to activation of the immune system, like fighting off an infection. It may be due to having to work harder to re-route information in the brain because of the MS. In any case, it can be treated. Taking naps helps with afternoon fatigue. Regular exercise actually improves fatigue symptoms. Avoiding very heavy meals may help. Making sure that night-time sleep is good is also useful. There are medications that have been shown to be helpful in MS-related fatigue.

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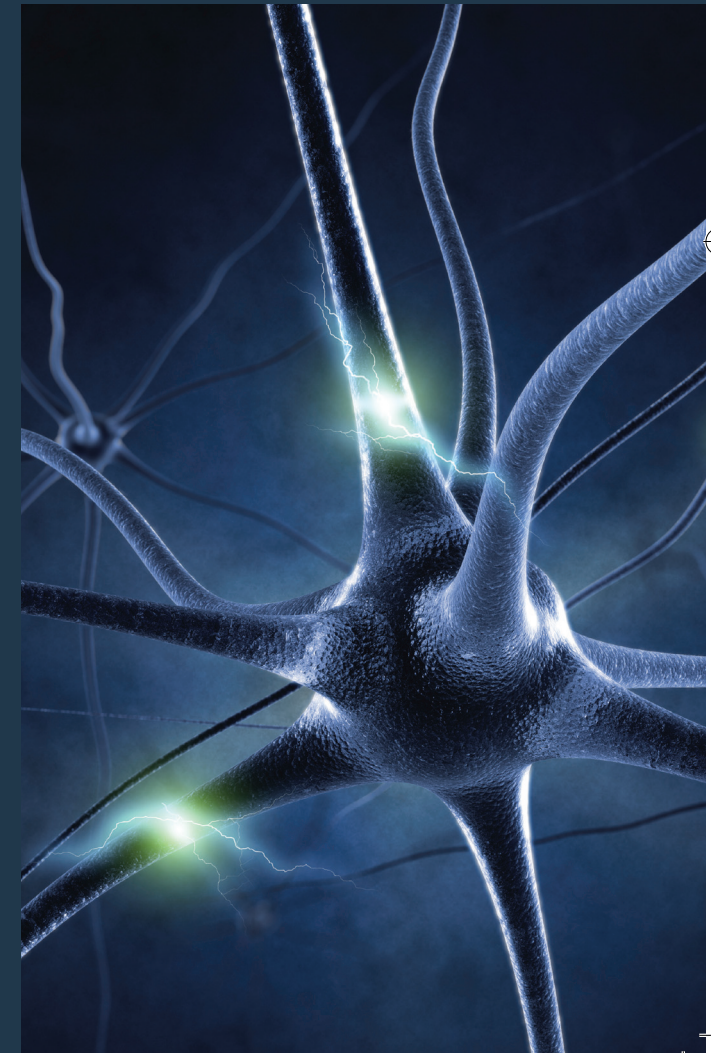
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MULTIPLE SCLEROSIS: Q&A

PATIENT EDUCATION



WHAT IS MULTIPLE SCLEROSIS?

Multiple sclerosis (MS) is a central nervous system disorder—that is, it affects the brain and spinal cord and spares the nerves and muscles that leave the spinal cord. MS is an inflammatory disorder in which infection-fighting white blood cells enter the nervous system and cause injury. It is a demyelinating disorder because the myelin sheath that protects nerves is stripped off during inflammation. When this happens, the nerves cannot conduct electricity as well as they should, causing various symptoms. Symptoms may be the type that come and go over time (relapsing-remitting MS) or progress over time (progressive MS). MS can happen to just about anyone and is long-term.

HOW IS MS DIAGNOSED?

Multiple sclerosis is often difficult to diagnose because there is no single test or finding on an exam that makes the diagnosis and because the disorder varies from person to person. In most cases, there is a history of neurological symptoms that come and go over years. The neurological exam may show changes that suggest problems with the spinal cord or brain. The magnetic resonance imaging (MRI) may show areas of abnormality that suggest MS, though the MRI in and of itself does not make the diagnosis. Spinal fluid testing may show that the immune system is active in and around the brain and spinal cord, supporting the diagnosis. Evoked potentials may assist in diagnosis. All of these need to be put together by the physician to determine if MS is the actual diagnosis. Even when all the tests are done, some people cannot be diagnosed for years after the beginning of symptoms.

WHAT ARE SOME EARLY SYMPTOMS OF MS?

MS varies from person to person so there is no 'standard' set of symptoms for MS. However, we know that common symptoms of MS include:

- Numbness or tingling in various parts of the body
- Walking difficulties
- Weakness of one or more body part
- Fatigue
- Visual blurring, and occasionally, double vision
- Dizziness
- Lhermitte's phenomenon, a symptom in which people feel electrical tingling or shocks down their back, arms, or legs when they bend their neck forwards
- Urinary symptoms, such as hesitancy when trying to urinate, or a feeling of urgency (when you have to go, you have to go)

There is no way to predict which symptoms one person might develop.

WHAT IS DEMYELINATION?

In MS, patients develop various areas in the brain and spinal cord where the myelin is stripped off of the nerves. These areas are called plaques or sometimes lesions. When the myelin is off, the electrical conduction of these nerves is altered. It is like getting a fuzzy signal on a television set. This event may affect any aspect of central nervous system functioning, causing symptoms. The symptoms may vary over time depending on how extensive the demyelination is and on factors such as fatigue and heat.

WHAT DO WE KNOW ABOUT MULTIPLE SCLEROSIS?

There has been widespread research about MS over the past 50 years. We do not know the cause of MS, but do know that it is an inflammatory disorder of the central nervous system that occurs in people with a tendency to such a problem. We know that about 350,000 people in the United States have MS, about 1 in 1,000 people. We know that it is more common further north and south of the equator, though we are still unsure why this is. Females tend to get MS about three times as often as males, a rate similar to other immune diseases. MS is more common in Caucasians, but can occur in other populations. It is not contagious, nor is it infectious.

DID I DO ANYTHING TO BRING ON THE MS OR MAKE IT WORSE?

As far as we know there are no activities that specifically cause MS or make it worse. People with MS may not tolerate heat as well as they used to and may need to avoid particularly hot or humid situations. There is evidence that having infections makes having an exacerbation of MS more likely. There does not appear to be a link to trauma. However, emotional stress has been linked to a worsening of MS symptoms. Having MS is not the fault of people who have it; it can happen to anyone.

IS THERE ANYTHING NEW THAT WE KNOW ABOUT MS?

Multiple sclerosis is being studied actively in many research institutions around the world, and new knowledge is being added constantly. For example, we now know that even with early MS, the nerve fibers themselves (the axons) are affected more than we knew before. We know from MRI studies that new lesions (abnormal areas in the brain or spinal cord) occur about 5 to 10 times as often as people with MS have new symptoms; that is, much of the disease occurs 'under the radar scope'. We know that myelin repair occurs in the central nervous system all the time. Some groups feel there are different types of immune or pathological processes going on that we call MS, and perhaps MS may be many different disorders that we have lumped together.

DO ANY OTHER DISEASES LOOK LIKE MS?

When neurologists evaluate MS they are also considering other diagnoses. While MS is the most likely cause of typical white matter changes and symptoms in an otherwise healthy young person, there are some other diseases that we consider and occasionally diagnose. These include a vitamin B12 deficiency that can cause an MS-like illness, and rarely, lupus, which may have symptoms that suggest MS. The MRI is very useful in ruling out many other disorders that could be confused with MS, and the blood tests and spinal fluid may also be helpful in diagnosing other diseases.

WHAT DOES MAGNETIC RESONANCE IMAGING SHOW IN MS?

Magnetic resonance imaging has become the single most useful test for the diagnosis of MS; MRI is sensitive to brain changes which are seen in MS. Classically, the MRI shows lesions in the white matter deep in the brain near the fluid spaces of the brain (the ventricles). The test may also show changes in the cortex or near the cortex. MRI can also show changes in the brainstem and in the spinal cord. There may be a loss of brain or spinal cord volume, a change which is called atrophy. Neurologists will occasionally use gadolinium, a heavy metal dye, to look at the brain more carefully. In a lesion that is active (a new plaque), this dye will leak out into the brain and show abnormalities. It is not clear how useful repeated MRIs are for following MS. However, many neurologists will repeat an MRI about a year after starting treatment for MS, or when there are unexplained changes in the patient's course that make it important to take another look. In MS, the MRI may not make the diagnosis, as sometimes the changes are not specific for MS. Other times the appearance may be characteristic of MS.

WHAT ARE EVOKED POTENTIALS, AND WHAT ARE THEY USED FOR?

Evoked potentials are tests where different sets of nerves are stimulated, and the activity of the brain, spinal cord, or nerves is measured electrically. Visual evoked potentials are done by flashing a checkerboard image in front of the patient and recording the brain's response at the back of the head. Auditory evoked responses are stimulated with a clicking noise in the ears, recording the brain's response. Somatosensory evoked responses are recorded after stimulation of the nerves usually in the arms or legs and are a measure of the nerve activity coming up the nerves and into the spinal cord. In MS, these tests may be normal but may show changes such as slower electricity conduction along the nerve pathways. In MS, visual evoked potentials are the most useful as they may show evidence of injury to the optic nerve not suspected clinically.

WHAT IS THE LUMBAR PUNCTURE (SPINAL TAP) FOR?

The lumbar puncture helps to show signs of inflammation and immune system activity in and around the brain and spinal cord. The test is really the only direct measure of immune activity that we can use clinically. In people with MS, there may be an increase in white blood cells and antibody formation in the spinal fluid. There may be 'oligoclonal' bands, which are a measure of immune activity found in MS but also in other immune disorders. Spinal fluid helps to diagnose other diseases such as Lyme disease and lymphomas of the nervous system. Not everyone needs a lumbar puncture, but it can be very useful.

ARE THERE DIFFERENT TYPES OF MS?

MS varies from patient to patient so that each individual has their own set of symptoms, problems, and their own course. There are people who have MS so mildly that they never even know that they have it. Of course, there are also others that have it severely. It is really a spectrum that ranges from mild to severe. An international panel of experts developed a classification of MS in 1999 that most neurologists use today:

- Relapsing-remitting: Patients have attacks of symptoms/signs, with or without recovery, but between attacks have no interval worsening.
- Secondary progressive: This is often after a few years of relapsing-remitting MS. The pattern changes from a relapsing pattern to progressive in between attacks, usually with fewer attacks.
- Primary progressive: This involves a gradual onset from the beginning and no attacks.
- Progressive relapsing: This is a rare form, and begins with a progressive course, while later developing attacks.
- Fulminant: This is a rare form, and is very severe, rapidly progressive MS.

IS THERE SUCH A THING AS BENIGN MS?

The term, "benign MS," is not part of the international classification. It is used when people have had MS for many years without developing significant measurable disability. Recent studies have shown that it cannot be predicted early in the disease and so the term can only really be used retrospectively, after people have done very well with MS for many years.

WHAT IS AN ATTACK?

An MS attack is also known as a 'relapse', an 'exacerbation,' or a 'bout' of MS. All of these terms mean the same thing—usually a worsening of MS symptoms or new MS symptoms lasting more than 48 hours and not due to infection or fever. An attack may be mild or severe; it may or may not correlate with MRI changes, though neurologists do not usually perform MRI imaging as part of an attack evaluation. Many patients have a daily variation of their symptoms; this is not an attack. Similarly, some patients may develop transient symptoms lasting only seconds such as twitching in an arm or a leg. This is also not an attack. Attacks are one marker of disease activity.

WHAT IS THE PROGNOSIS FOR MS?

Most people think that MS is a rapidly disabling disorder. This is not true for most people with MS. A recent study of people with MS in the Olmstead county area near the Mayo clinic showed that most people did well even without treatment. An older study showed that after 25 years without treatment most people were still able to walk. However, only a small percentage of people followed for years do not show some measurable signs of MS on examination.

WILL THE MEDICATIONS FOR MS MAKE ME FEEL BETTER?

There are now six FDA-approved medications to control the course of MS; four are for relapsing patients with active disease and two are for people with more severe MS or for those failing standard therapy. In general, the medications do not 'make you feel better,' but do reduce MS activity. People treated for MS are less likely to develop new attacks, have fewer new MRI changes, and tend not to progress as much as those on no treatment. So, while the medications may not make people feel better in the present, they do help prevent people from feeling worse in the future.

DOES PAIN OCCUR IN MULTIPLE SCLEROSIS (MS)?

In the past, pain was not thought of as an MS symptom. While neurologists accepted numbness, tingling, itching, and other sensory symptoms as occurring in the MS patient, they often did not recognize pain as part of the spectrum of symptoms of MS.

Over the past few years physicians have come to realize that pain is not only possible as a symptom of MS, but that in some patients, pain is a key symptom. It can be a major cause of reduced function, decreased sense of well-being, and an important target for treatment. In some studies, up to one in four people with MS have ongoing pain which in some way affects their function.

“Pain is an emotional and sensory experience...” (IASP, 1973). Psychosocial variables have long been shown to have a significant impact on pain perception, and in turn disability due to pain. Specifically, the intensity of the pain, the degree to which it interferes with activities, and the extent to which it disrupts mood, predict chronicity of pain. Identification of the presence of such possible co-morbid problems can guide appropriate early intervention.

Today we know that the pathophysiology of pain is complex, with messages being sent from the periphery to the brain, from the brain down and strongly influenced by emotions. Context, catastrophizing, acceptance, central sensitization, opioid-induced hyperalgesia, emotions, expectations for future pain, prior experience, repeated exposure to painful stimuli, past exposure to trauma all have an effect on the perception of pain.

The emotional component of pain or the suffering endured by patients is equally important as the somatosensory component.

WHAT KIND OF PAIN CAN OCCUR WITH MULTIPLE SCLEROSIS?

There are a variety of types of pain types that may occur with MS, including:

- **Trigeminal neuralgia** — There is a facial pain syndrome known as trigeminal neuralgia which is more common in people with MS than in the general population. It is a sharp, electrical jabbing pain on one side of the face, usually in the cheek. It can be very severe, and lasts a few seconds. It may occur many times a day. It may be triggered by touching the face, feeling a breeze on the face, or even chewing. Treatment of trigeminal neuralgia includes medications that alter nerve function such as carbamazepine, phenytoin, lamotrigine, Neurontin®, Lyrica®, and so on. Sometimes, surgical procedures may be useful (for example, using a balloon catheter to put pressure on the nerve to numb it, or heating the nerve up electrically). Some patients may benefit from a focused radiation beam directed at the nerve.
- **Burning limb pain** — A second type of pain is a burning pain that often involves the legs but may occur anywhere in the body. This may be worse at night and is often constant. There may be sensitivity to the touch, and sometimes the affected limb feels cold. This is likely due to altered sensory signals to the spinal cord and brain due to demyelination.

Medications that are used to treat burning limb pain include some antidepressants such as nortriptyline which are effective in nerve pain, and some anti-seizure medications such as carbamazepine, gabapentin, and others. Duloxetine hydrochloride has been approved for peripheral nerve pain and may also be used for the pain related to MS. Tramadol may be useful for such pain. Sometimes long-acting pain medications may have to be used. Physical measures such as exercise and stretching may be useful. Lidocaine patches may provide relief at more severely affected locations.

- **Neck and back pain** — Some people with MS can experience neck and back pain. This may be due to immobility, or to the same type of wear and tear that many people without MS experience. This type of pain is often an aching, stiff sensation that can be moderately severe. At times, imaging to rule out other causes of pain such as lumbar disc disease may be important. Trials of anti-inflammatory medications may be beneficial. Therapy, stretching, aquasize, and other physical measures may be useful.
- **Other sources of pain** — Finally, there are occasional patients who have hip or shoulder disease related to prior steroid therapy. On occasion, repeated steroid use causes an alteration of blood supply to the hip or shoulder joint, and this may cause injury to the hip. Imaging with X-ray or MRI scanning may show damage if this is the case. If the damage is severe enough, the patient may require joint replacement surgery. Since many other disorders can cause pain, it's important to consider other sources of pain and not just 'pin it on MS'.

WHAT ELSE CAN I DO?

Regular exercise and stretching do reduce certain kinds of pain, particularly back pain and muscular pain. Such activities also help with fatigue and increase a sense of well-being. Trying to get restful sleep is also important when fighting pain. Some people find that alternative pain management strategies such as acupuncture, cognitive behavioral therapy, and psychophysiological pain and stress management techniques such as biofeedback, relaxation training and self-hypnosis are useful.

If pain is hard to control, a formal pain management program may be useful. If you are on pain medications, make sure you have a good bowel regimen as constipation is common and will only increase the discomfort you are feeling.

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WHAT IS RELAPSING-REMITTING MULTIPLE SCLEROSIS?

In 1999, an international panel published a classification of multiple sclerosis (MS) that defined different forms of MS. One of these, the most common form, was relapsing-remitting MS (or RRMS). Relapsing-remitting MS is defined as MS in which patients have relapses of MS and periods of stability in between relapses. Relapses are episodes of new or worsening symptoms not caused by fever or infection and that last more than 48 hours. In other words, a stable course is punctuated by episodes of new or worse symptoms.

Relapsing-remitting MS is the most common initial form of MS. Younger patients are more likely to have this form of MS than older patients.

WHAT ARE THE SYMPTOMS OF RELAPSING-REMITTING MULTIPLE SCLEROSIS?

The symptoms of RRMS vary widely. Frequent early symptoms include:

- episodes of visual loss in one or the other eye
- tingling or numbness
- double vision, fatigue
- urinary urgency
- balance problems
- weakness

No two patients have the same symptoms. Some people are sensitive to heat. Some people get a tingling feeling when they bend their neck forward (Lhermitte's symptom). Some patients will have problems with weakness or unsteadiness of walking. Some combination of symptoms is common, and symptoms may vary over time in an individual.

HOW DO I KNOW I HAVE THIS FORM OF MULTIPLE SCLEROSIS?

As long as you have had two or more attacks of MS, and are otherwise stable, you have relapsing-remitting MS.

There is no specific test for this, and the MRI scan or spinal fluid test does not tell this form of MS apart from any other form.

HOW IS RELAPSING-REMITTING MULTIPLE SCLEROSIS TREATED?

In general, all of the standard disease-modifying agents for MS have been tested in patients with relapsing remitting MS. All of these medications reduce the number of relapses, reduce MRI activity, and may reduce disability. They differ in their side effect profiles and in how often and the way in which they are given.

Administration of these medications ranges from once weekly to daily, either under the skin or in the muscle. There is also a new oral medication.

WHAT IS THE PROGNOSIS FOR RELAPSING-REMITTING MULTIPLE SCLEROSIS?

The prognosis varies widely for RRMS. Some patients rarely have attacks and go years without having new clinical problems. Others have frequent attacks and require extensive medication treatment. There is no predictable pattern for RRMS. There is no test that predicts specifically what will happen in RRMS. Prognosis for all forms of MS tends to be much better than people suspect.

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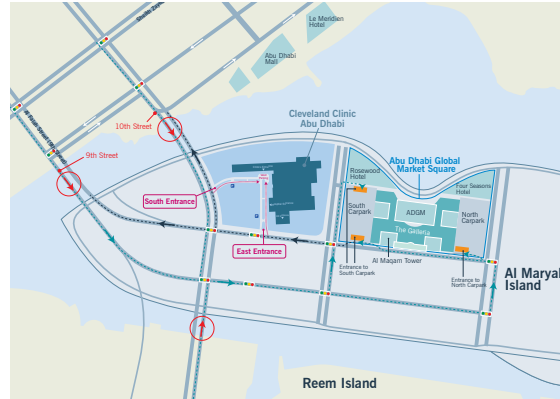
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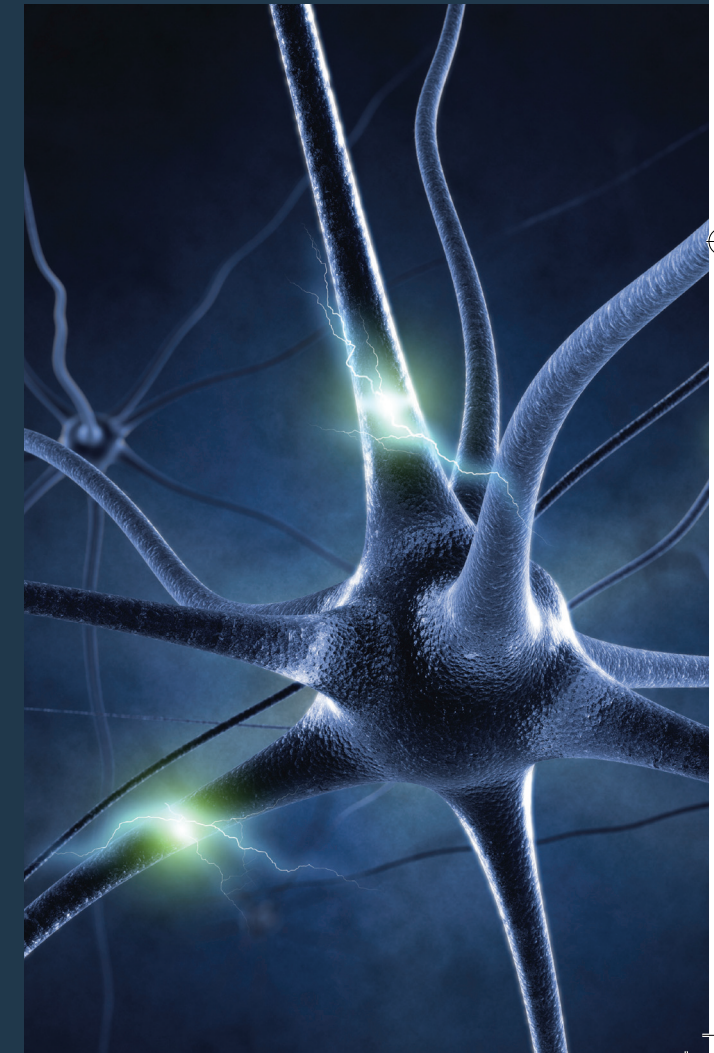
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INTRATHECAL BACLOFEN THERAPY (FOR MS)

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NOTES





WHAT IS SPASTICITY?

Spasticity is a movement disorder that can occur in conditions which affect the brain or the spinal cord, such as multiple sclerosis, stroke, cerebral palsy, spinal cord injury, or brain injury. Spasticity is caused by an imbalance between signals that inhibit or stimulate the spinal cord. This results in hyperexcitable stretch reflexes, increased muscle tone, and involuntary movements.

WHAT ARE THE SYMPTOMS OF SPASTICITY?

Spasticity causes muscle stiffness and tightness which interferes with voluntary movements. Spasticity can also cause muscle spasms (jerky involuntary movements) or clonus (repetitive involuntary movement).

Stiffness and spasms are often bothersome and sometimes painful, and they interfere with the ability to carry out daily activities. Spasms may also disrupt sleep and increase daytime fatigue. When spasticity is severe, contractures (fixed limitations of range of motion) may develop.

HOW CAN SPASTICITY BE TREATED?

Stretching, exercise, and rehabilitation are the first line of interventions for spasticity. Oral medications are often effective, but may cause side effects such as drowsiness. When spasticity affects only a few muscles, local injections of botulinum toxin can be helpful. When spasticity is diffuse and severe, intrathecal baclofen (Lioresal®) (ITB) may be a good treatment option.

WHAT IS BACLOFEN?

Baclofen is one of the medications most commonly used to treat spasticity. Baclofen acts in the spinal cord, and improves hyperactive reflexes and excessive muscle tone.

Some of the side effects of baclofen are:

- Drowsiness
- Dizziness
- Weakness
- Nausea
- Headache

Stopping baclofen suddenly may cause withdrawal symptoms that include seizures. You should avoid suddenly stopping this medication.

WHAT IS INTRATHECAL BACLOFEN THERAPY?

Baclofen is usually taken by mouth several times per day. Intrathecal baclofen therapy (ITB) consists of delivering a liquid form of baclofen into the spinal fluid, using a device called a baclofen pump. ITB is approved for the treatment of severe spasticity.

WHAT IS A BACLOFEN PUMP?

The baclofen pump system consists of a pump and a catheter that brings the medication from the pump into the spinal fluid. The pump is a round metallic disc (about 2.5 cm thick and 7.5 cm in diameter), which is surgically implanted under the skin of the abdomen.

The pump contains a battery, which usually lasts between 5 and 7 years, a reservoir for the medication, and a microprocessor. The pump can be programmed with a small computer which communicates with the pump via a wand placed over the skin. The catheter is a thin flexible tube implanted under the skin. One end of the catheter is connected to the pump, and the other end is inserted into the spine at various levels.

WHAT ARE THE ADVANTAGES OF ITB COMPARED TO TAKING BACLOFEN BY MOUTH?

- ITB is usually much more effective in controlling the symptoms of spasticity, because the medication is brought directly in contact with the spinal cord.
- With ITB, the medication is delivered continuously, day and night, giving a more steady relief of symptoms.
- ITB, in most cases, causes less side effects than oral baclofen, particularly when high doses are needed to treat severe spasticity.
- ITB programming is very flexible, allows more precise dosing of baclofen, and gives the ability to deliver different doses at different times of the day.
- Compared to other surgical treatments, ITB is reversible, as the pump can be stopped and removed if needed.

WHAT ARE THE POTENTIAL RISKS AND ADVERSE EFFECTS OF ITB?

The baclofen pump system needs to be surgically implanted under anesthesia, leading to the usual risks of surgery. Complications more specific to ITB include the risk of infection around the device, and the risk of device malfunction. Baclofen withdrawal (from abrupt interruption of the delivery of baclofen via the pump) and baclofen overdose (usually as a result of human error) have also occurred with ITB. Serious complications from ITB are infrequent, and in most cases reversible as long as they are diagnosed and treated in a timely fashion. Even without complications, ITB can cause increased weakness, because it is very potent.

WHAT IS INVOLVED IN THE MANAGEMENT OF A BACLOFEN PUMP?

The pump needs to be refilled at regular intervals (usually every 1 to 6 months) by a trained health care professional who possesses the equipment needed. The pump is refilled by inserting a needle through the skin into a refill port on the pump. In some cases the refills can be done at home,

but follow-up visits are needed one to two times per year to ensure that the therapy is working appropriately. The dose of baclofen can be adjusted at any time, but the adjustment must be done by a trained professional. When the battery approaches the end of its life, the pump needs to be replaced (but not the catheter). When a problem with the baclofen pump is suspected, medical attention should be sought as soon as possible.

HOW DO I KNOW THAT I AM A GOOD CANDIDATE FOR ITB?

If you have severe spasticity, and oral medications are not helpful, your treating physician may refer you for a consultation to evaluate if ITB could be a good option for you. Detailed clinical assessments are performed, usually by a physician and physical / occupational therapists. These professionals provide information about ITB for discussion.

A test injection is then performed to further evaluate the appropriateness of ITB. The test consists of a spinal tap, with a small dose of baclofen injected into the spinal fluid. A few hours later, the effects of the medication are evaluated. These effects are temporary, but provide very useful information that help with the decision process.

WHAT HAPPENS IF THE TEST IS SUCCESSFUL?

If the test is successful, you will be referred to a neurosurgeon who will implant the baclofen pump system. After the surgery, you will stay in the hospital for a short time. In some cases, inpatient rehabilitation is needed to adjust the pump and perform functional training before returning home. In all cases, outpatient or home rehabilitation is needed to optimize the benefits of ITB.

DOES INSURANCE COVER ITB THERAPY?

Since coverage varies greatly between individual insurance plans, we encourage you to check with your insurance ahead of time.

In summary:

- ITB can be very effective on severe spasticity and can markedly improve quality of life.
- Because ITB is a surgical treatment with known risks, thorough testing and education are needed before starting this therapy.
- Compliance with follow-up visits, and with rehabilitation and home exercise, are essential to maximize the chances of success and to minimize the risk of adverse effects with ITB.

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