

Multiple Sclerosis

Also known as Disseminated Sclerosis and Insular Sclerosis

Description of the Disability

Muscular Sclerosis (MS) is a progressive central nervous system disease that damages the protective coating of the nerves. This coating, called myelin, acts as an insulator, allowing nerve signals to move quickly and reliably between the body and the brain. When MS damages the myelin on part of a nerve, a scar or thickening of the nerve forms at the spot. Physicians call this kind of thickening "Sclerosis" (as in Arteriosclerosis - hardening of the arteries). In MS, these "demyelination" scars (also called Plaques or Lesions) happen in many places in the nervous system, thus the name Multiple Sclerosis. The effect of the sclerosis of the different nerves is disruption of the nerve signals to and from the body, resulting in tremors, possible paralysis, and various sensory problems. Sometimes the nerves themselves break down at the site of the damage.

Researchers think MS is an autoimmune disease like Rheumatoid Arthritis and Lupus (see entry on Autoimmune Disorders). In MS, the immune system attacks myelin coverings of the nerves, but no one knows why. It is not directly inherited, but a tendency to get MS can run in families, so there may be a genetic component.

Normally, the body can repair occasional minor damage to the myelin, but in MS the body's repair systems can't keep up. The specific symptoms a particular person experiences depend on where the damage is happening in their body and how fast it is happening. Most people with MS first experience significant symptoms between age 20 and 40. In the early stages, they may experience long periods (possibly years) of remission in between "exacerbations" (also called flare-ups, relapses or attacks). However, MRI studies show that even during remission lesions often continue to form, a process some people call "silent MS." For many people, the time between exacerbations gradually gets shorter and overall function gradually decreases. Also, the symptoms the person experiences may change from exacerbation to exacerbation. Several things seem to trigger an exacerbation or make it worse, including fever, hot baths, and sun exposure.

MS is not fatal and it does not shorten a person's lifespan. Its course and severity vary widely from person to person. In some people it never becomes a significant disability.

Because it affects nerves in both the brain and the rest of the body, MS has many different possible symptoms. A person with MS may experience weakness, tremor, spasticity, stiffness, fatigue, partial paralysis, or complete paralysis in parts of their body, including the face, hands, and arms. They may experience tingling, prickling, numbness, or even hypersensitivity in parts of their body. They may have trouble breathing, difficulty with balance, and difficulty with speech. They may experience incontinence or excessive urination. They may experience emotional problems, memory problems, and difficulty problem solving. And they may experience **Optic Neuritis** - an inflammation of the optic nerve causing difficulty adapting the eye to bright light, double vision, loss of color vision, loss of all vision, pain when moving the eye, or an uncontrollable rapid back-and-forth motion of the eyes. Intense fatigue is a very

common symptom of MS. Not surprisingly, people with MS are at risk for depression and anxiety.

It is very common for someone with MS to look "normal" and "healthy," especially in the early stages of the disease. This can make it difficult for other people to realize how profoundly the disease impacts the person's life. This, in turn, can make it difficult for the person to ask for accommodations for fear of seeming "lazy" or "selfish."

Types of MS

Physicians identify four types of MS:

- Relapsing-Remitting - This is the most common form of MS, especially at the time of first diagnosis. In this form there are distinct periods of flare-up of symptoms and distinct periods of remission, during which the individual has partial or complete recovery from symptoms.
- Primary-Progressive - This is a relatively rare form of MS in which there are no periods of remission. Symptoms are present all the time and progressively increase, although the person may have peaks and plateaus in the rate of progression.
- Secondary-Progressive - This is a combination of the first two forms of MS. It begins with distinct periods of relapse and remission, and later transitions into the continual presence of symptoms. Even during the continual symptoms phase, there may be flare-ups of symptoms and minor recoveries of function. Without treatment, approximately half the people with Relapsing-Remitting MS will eventually develop Secondary-Progressive MS.
- Progressive-Relapsing - This form of MS is also like the combination of the first two. It begins with the continual presence of symptoms and gradual progression, but the person also experiences occasional flare-ups, from which the person may or may not recover. This form is more rare than Primary-Progressive.

Incidence Statistics

- There is a higher incidence of MS in people who have lived in temperate (cold) climates compared to those living in tropical climates. Moving to a tropical climate after the age of about 15 does not decrease the possibility of developing MS
- Twice as many women are diagnosed with MS than men.
- Approximately 35% of people with MS are employed
- More Caucasians are diagnosed with MS than other races
- Approximately 250,000-350,000 people experience MS in the United States
- Approximately 2.5 million people worldwide experience MS
- 85% of people with MS have Relapsing-Remitting MS at first diagnosis. 50% of those later develop Secondary Progressive MS. 10% of people with MS have Primary-Progressive MS, 5% have Progressive-Relapsing
- Optic neuritis occurs in about 55% of people with MS

Common Treatments, Medications, and Side Effects

Physicians use several types of "disease modifying" or "immunomodulator" drugs to reduce the frequency and severity of MS exacerbations and slow down its progression. These include Beta Interferons, Copaxone, and Mitoxantrone, all discussed below. It is important to note that these drugs are very expensive. On the other hand, although they do not cure MS, they slow its progression by nearly half. Experts recommend that people begin taking one of these drugs as soon as they get an MS diagnosis, no matter how mild their symptoms may be, and continuing taking them the rest of their lives. To help with the expense, the drug companies making the 4 drugs have instituted subsidy programs for low-income individuals with MS.

- Beta Interferons - Avonex, Rebif, and Betaseron. These drugs seem to reduce the activity of a specific group of immune cells, but they may also slow down the reproduction of a virus (see Drug entry on MS Drugs - Beta Interferon for side effects).
- Copaxone - this drug seems to work by binding some of the molecules your body uses to mark invaders for destruction by the immune system, but it may also act as a decoy to the immune system as well (see Drug entry on MS Drugs - Copaxone for side effects).
- Mitoxantrone - Mitoxantrone is a more powerful drug, originally developed for cancer treatment. It is only used for people with rapidly progressing cases of relapsing-remitting MS and people with secondary MS. It appears to shut down specific parts of the immune system that attack the myelin sheath (see Drug entry on MS-Drugs - Mitoxantrone for side effects).
- Immunosuppressants - Imuran, Cytosan, Neosar - these powerful drugs are no longer the first choice of physicians for treatment of MS, because they suppress the entire immune system. However, if a person's MS does not respond well to any of the drugs above, their physician may use one of these drugs (see Drug entry for side effects).
- Steroids - reduce severity of symptoms (see Drug entry on Steroids for side effects)

Other possible treatments focus on controlling the particular symptoms of the person. As the disease progresses, the person may need to use an electric wheelchair, among other types of assistive technology.

Possible Functional Issues

Possible functional issues for MS include:

- Fatigue and weakness
- Difficulty with gross motor control and coordination
- Difficulty with fine motor control
- Difficulty walking or moving
- Difficulty standing for long periods of time
- Difficulty with memory
- Difficulty with problems solving and learning

- Difficulty speaking
- Difficulty seeing, or blindness
- Difficulty reading
- Difficulty writing
- Need to avoid heat
- Hypersensitivity to touch

Initial Interview Considerations

Initial Questions

- When (if ever) was their last exacerbation (flare-up)?
- What are exacerbations (flare-ups) like for them? How long do they last? What symptoms do they usually experience? What symptoms seem to change or only show up occasionally?
- What triggers, if any, have they noticed for the exacerbations?
- How long are the remission periods (if any)?
- How steady has the pattern of remissions and relapses/exacerbations been? Has it been speeding up or staying about the same?
- What is life like between exacerbations? What symptoms do they experience during remission?
- What is their energy level like during the day? Are there times of the day that are better than others?
- What is their vision like? Do they have any problems with double vision or loss of vision?
- What accommodations or devices help them? Are there any assistive devices that they would like to have?
- At what rate are their symptoms progressing? Where do they expect their symptoms to be in five years?
- What is a typical day like for them?
- What do they do for fun? What hobbies do they have?
- What, if anything, helps them deal emotionally with the MS during exacerbations/flare-ups?
- What social groups do they belong to? What church (if any) do they attend?
- How are they paying for any MS drugs they are taking? If they have alternative coverage beside insurance, are there income limits that might cause problems?

Initial Observations

- Does the person use mobility equipment?

- Does the person show awareness of his/her symptoms and how they might impact employment?
- Does the person show any signs of memory lapses or other cognitive issues?
- Does the person seem to have any problems with vision? Are they able to read text?
- Does the person seem to have any problems with fine motor control?
- How legible is the person's handwriting?

Interview Accommodations (if any)

- If the person has any memory problems, provide a written summary of the meeting and the next steps the counselor and the person will take.
- If the person has any vision problems, offer to provide printed material in a large print, electronic, or audio (taped) format.

Possible Accommodations and Assistive Technology

- Alternative computer access (voice controlled mouse, other alternative mouse, voice recognition software, etc.)
- Arm rests for computer work
- Large button phone
- Grip aids for writing and other tasks
- Tape recorder for taking notes
- Book holder / page holder
- Share notes from co-worker
- Adjustable workstation to accommodate mobility equipment
- Workstation close to frequently used facilities (copier, mailboxes, etc.)
- Flexible schedule; flexible, frequent breaks
- Work from home, telecommuting
- Personal attendant
- Written instructions and written job aids (to help with memory)
- Calendar and organizer
- Speech enhancement tools (amplification, etc.)
- Adjustable office lighting (for vision issues)
- Flexible schedule during hot weather
- Climate controlled workspace

- Cooling vest
- Fan or air conditioner

Career Planning Issues

- The most common MS drugs are very expensive. It is important to find out how the person is paying for the drugs and, if it involves Medicaid or a drug company-sponsored benefit, consider how employment might effect that payment.
- Fatigue is one of the most common symptoms of MS and often hits in the afternoon. At that time of day the person may feel sleepy, have muscle weakness, and feel mentally tired. Even if the person can walk, it might be helpful think about using mobility equipment to help conserve energy for other later in the day.
- Heat can trigger exacerbations or make symptoms worse. Careers that involve long periods outdoors or near hot equipment could be a challenge.
- Educate coworkers about MS. Because many of the symptoms of MS are not obvious to others, sometimes others may think that an individual with MS is just being lazy or overly dramatic. If the person is comfortable disclosing their disability, it may be helpful to provide some work-place education about MS.
- Plan for exacerbations. Exacerbations can be difficult and demoralizing times for the person, especially in the context of work. Positions that allow paid leave, short-term disability leave, or family medical leave may be better. Alternatively, talk with the employer about these options.
- Plan for change. Because of the progressive nature of MS, the person's needs may change over time. It is important to plan ahead and not wait until symptom changes lead to a crisis. Discuss how the person can adjust his or her level of accommodations in the future and what role VR can play in that.

Emerging Issues

- Treatments to encourage myelin re-growth and repair, and to discourage initial demyelination.

Additional Information Resources

- National MS Society - www.nmss.org
- MS Association of America - www.msaa.com
- MS People Helping People - www.msphp.org
- MS Watch - an MS site funded by a drug company, but with good resources: www.mswatch.com
- MS Active Source - another MS site funded by a drug company, but with good resources: www.msactivesource.com

- MS Lifelines - another MS site funded by a drug company, but with good resources:
www.msllifelines.com

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