Most Frequently Asked Questions

1. What is Multiple Sclerosis?

Multiple sclerosis is an unpredictable neurological disease that affects an estimated 400,000 people in the United States. It stops people from moving. A new case is diagnosed every hour. It can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue and even paralysis and blindness. These problems might be permanent, or they might come and go.

2. Who gets MS?

Two-thirds of those who have MS are women, with the onset of symptoms occurring in the prime of life years, ages 20 – 50, though there are estimated 8,000 - 10,000 children under the age of 18 who also have MS. Studies indicate that genetic factors may make certain individuals more susceptible to the disease, but there is no evidence that MS is directly inherited. It occurs more commonly among Caucasians, especially those of northern European ancestry, but people of African, Asian and Hispanic backgrounds are not immune.

3. How many people have MS?

There are at least 400,000 Americans with MS, and every week about 200 new people are diagnosed with the disease – more than one person an hour.

4. What are the typical symptoms of MS?

Symptoms of MS are unpredictable and vary greatly from person to person and from time to time in the same person. For instance: one person may experience abnormal fatigue, another might have severe vision problems or another could develop attention and memory issues. Even severe symptoms may disappear completely and the person will regain lost functions. In the worst cases, however, people can have partial or complete paralysis.

5. What causes MS symptoms?

In MS, symptoms result when inflammation and breakdown occur in myelin, the protective insulation surrounding the nerve fibers of the central nervous system (brain and spinal cord). The nerve fibers themselves are also damaged. Myelin is destroyed and replaced by scars of hardened “sclerotic” patches of tissue. Such lesions are called “plaques,” and appear in “multiple” places within the central nervous system. This can be compared to a loss of insulating material around an electrical wire, which interferes with the transmission of signals. MS Ambassador Manual

6. Is MS fatal?

No. MS is not a fatal disease, except in rare cases. People who have MS can be expected to have a normal or near-normal life expectancy.

7. Does MS always cause paralysis?

No. The majority of people with MS do not become severely disabled. Two-thirds of people who have MS remain able to walk, though many will need an aid, such as a cane or crutches.

8. Is MS contagious or inherited?

No. MS is neither contagious nor directly inherited; although studies indicate that genetic factors may make certain individuals more susceptible to the disease.

9. Can MS be cured?

Not yet. However, advances in treating and understanding MS are being achieved daily and the progress in research to find a cure is very encouraging. In addition, many therapeutic and technological advances are helping people manage symptoms and lead more productive lives. There are now several FDA-approved medications that have been shown to affect the underlying course of MS.

10. I heard there a new drug that means no more injections. I want it right away.

The first treatments for MS didn't hit the market until the early 90‟s. Many patients have been looking forward to a pill for MS for the past two decades, and can't wait to throw out their syringes. The first oral disease-modifying MS drug, Gilenya, was approved by the FDA in September 2010.

At the MS Society, we believe that the more options that doctors have at their disposal in treating MS, the better off patients will be.

Like any medicine, though, this will work well for some people and not for others, so we encourage people to talk directly to their neurologists about their treatment..

11. What medications and treatments are available for MS?

The National Multiple Sclerosis Society recommends that you talk to your doctor about your treatment options. You doctor will likely recommend that you begin treatment with one of the disease modifying drugs, Avonex®, Betaseron®, Copaxone® , or Rebif® as soon as you are diagnosed with a relapsing form (the most common kind) of MS. These drugs help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions in the brain, and slow progression of disability.

Novantrone® (mitoxantrone) is approved for reducing disability and/or frequency of relapses in patients with worsening relapsing MS. This is the first therapy approved in the U.S. for individuals with secondary progressive MS or who are experiencing a rapid worsening of the disease. In addition, approved by the FDA for return to market, is Tysabri®, which is generally recommended for patients who have had inadequate response to, or are unable to tolerate, other approved disease modifying MS therapies for relapsing forms of MS.

There are many therapies available to treat symptoms such as spasticity, pain, bladder problems, fatigue and weakness. People should consult with a knowledgeable physician to develop the most comprehensive approach to managing their MS.

12. Why is MS so difficult to diagnose?

In early MS, elusive symptoms that come and go might indicate any number of possible disorders. Some people have symptoms that are very difficult for physicians to interpret, and these people must "wait and see." While no single laboratory test is yet available to prove or rule out MS, magnetic resonance imaging (MRI) is a great help in reaching a definitive diagnosis.

13. What is the difference between MS and MD?

The short answer: MD is Jerry‟s kids; we're not. Seriously, muscular dystrophy (MD) is a disease of the muscles, while multiple sclerosis (MS) is a disease of the central nervous system that can cause symptoms in many parts of the body, including the muscles.

14. How do you treat your MS?

If you have MS and someone asks about your medications, treatments or therapies, it is up to you how much information you share; however, remember that you are perceived to be a spokesperson for the MS Society and that if you do share any of your personal experiences, you must specify that they are just that: personal experiences. Always emphasize that MS is unpredictable and different for everyone. Encourage people to get more information and talk to a doctor before making decisions.

15. What are the different types of MS?

In an effort to develop a common language when discussing, evaluating and treating MS, the Society conducted an international survey among scientists who specialize in MS research and patient care. Analysis of the responses has resulted in the following four (4) definitions of disease categories, introduced in 1996.

i. RELAPSING-REMITTING

Characteristics: People with this type of disease experience clearly defined flare-ups (relapses) or episodes of acute worsening of neurologic function. These are followed by partial or complete recovery periods (remissions) between attacks that are free of disease progression.

Frequency: Most common form of MS at time of initial diagnosis. Approximately 85% at onset.

ii. PRIMARY-PROGRESSIVE

Characteristics: People with this type of MS experience a nearly continuous worsening of their disease from the onset, with no distinct relapses or remissions. However, there are variations in rate of progression over time, occasional plateaus, and temporary minor improvements.

Frequency: Relatively rare. Approximately 10% at onset.

iii. SECONDARY-PROGRESSIVE

Characteristics: People with this type of MS experience an initial period of relapsing-remitting disease (see above) followed by a steady worsening disease course with or without occasional flare-ups, minor remissions (recoveries) or plateaus.

Frequency: If left untreated, 50% of people with relapsing-remitting MS develop this form of the disease within 10 years of initial diagnosis.

iv. PROGRESSIVE-RELAPSING

Characteristics: People with this type of MS experience a steady worsening disease from the onset but also have clear acute flare-ups (relapses), with or without recovery. In contrast to relapsing-remitting MS, the periods between relapses are characterized by continuing disease progression.

Frequency: Relatively rare. Approximately 5% at onset.

16. A question you don't know the answer to…

You can't know everything about MS. If you don't know an answer to a question, don't just "wing it." If a visitor has a question, direct him/her to the Gateway Area Chapter phone number or Web site. Give the person a bookmark or other piece of literature that lists the contact information or offer to take the person's name and pass the question on to an appropriate resource in the Chapter office.