

MS STOPS PEOPLE FROM MOVING.

**WE EXIST TO MAKE
SURE IT DOESN'T.**

JOIN THE MOVEMENT.



**National
Multiple Sclerosis
Society**

700 Broadway Suite 810

Denver CO 80203

tel 303 813 1052

fax 303 813 1513

nationalMSsociety.org

For Information: 1 800 344 4867

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**"But You Look
So Good!"**

Managing Specific Issues



**National
Multiple Sclerosis
Society**

“My neurologist, my family doctor, even my aunt’s visiting nurse—they all say ‘but you look so good for someone who has MS.’...

“My family seems to assume that if they can’t see it, there really isn’t anything wrong with me.

“They should see my MRIs for the past 10 years. Should we all start carrying wallet-size copies of our MRIs? This is my niece ... and this is my son ... and this is my MS.”

— Carolyn Doss, online chat group participant

People who have “invisible” MS symptoms have a unique set of problems. Some people assume that you don’t **really** have a disease. This can undermine your confidence and your relationships, and discourage you from seeking treatment or help for problems. Add in living with all the other things that other people can’t see—your feelings of anger, uncertainty, frustration, and fear. Still, people will look right at you and say, “You look so **good!**”

Common “invisible” MS symptoms

MS symptoms that are hard to see include fatigue, pain, cognitive problems like memory loss or trouble solving problems, weakness, blurred vision, numbness, prickly or tingling sensations, heat sensitivity, dizziness, and bladder or bowel problems.

It’s important to recognize that there are medications, therapies, coping strategies, self-help techniques, and self-help groups for these problems. Speak with your physician, or call your local Society chapter.

“It can be frustrating when you tell someone you’re tired and they say they know the feeling, they had a big night last night, too.”

— A member of a “But You Look So Good” self-help group

Everyone experiences fatigue, but people with MS are hit hard by a kind of fatigue that can be overwhelming. This can be hard to explain to outsiders. People with MS often expend extra effort on

activities—such as lifting legs to walk—which once were second nature. These efforts add to the burden of MS fatigue.

“My wife wanted to meet me at a restaurant and I forgot and came home. She’s insisting I don’t love her anymore.”

— *Person with MS, online chat group*

While everyone is forgetful sometimes, people with MS may have memory lapses that signal cognitive impairment, one of the most disturbing hidden symptoms of MS. Neurologists in the MS community now recognize that cognitive impairment affects up to half of all people with MS. The problems are usually subtle and are termed “mild”, but they can have a major impact on a person’s life.

At some time, most people with MS experience bladder or bowel problems. The embarrassment can cause people to cut off their social, sexual, and public activities. These problems, if untreated, can also develop into serious medical problems. New medications and changes in diet and behavior can do a lot to keep these symptoms invisible—and under control. Talk to your nurse or doctor.

Self-esteem

“I think the most difficult thing to cope with is the absolute dichotomy between how you look and how you feel.”

— *Anne C. Huss, Atlanta, GA*

A diagnosis of MS changes the way you think about yourself.

“It’s difficult to feel powerful, competent, assertive, beautiful, or handsome when you just don’t feel well.”

— *Dr. Mary E. Siegel*

Dr. Siegel, a psychologist with MS, co-authored the book, **Sick and Tired of Feeling Sick and Tired.**

People with invisible symptoms must constantly adjust to the differences between how they feel “inside” and how the world reacts to them when they “look so good.” Family members, friends, employers, even doctors may doubt the validity of invisible symptoms. When people question you often enough, you may begin to doubt your own perceptions. MS is different for every person, and it’s important

to learn to recognize what **your** MS is like. Some people keep a journal or diary of symptoms. An understanding confidante, mental-health counselor, or a self-help group help many people keep their self-esteem intact.

All in the family

When one member of a family has MS, everyone in the family is affected. This is true whether the MS is visible or invisible.

Dr. Deborah M. Miller at the Mellen MS Center at the Cleveland Clinic, told this story to illustrate how hidden symptoms can create a conspiracy of silence within a family, despite everyone's best intentions:

"Anna has problems with weakness and balance, and she is concerned about managing a set of steps going into someone's house. Instead of admitting the fears, she just says she doesn't want to visit. It's a shorter explanation. The family gets frustrated because they see her giving up on life. The fact is, Anna is just concerned about one specific part of the outing. But nobody in the family says anything more about it. Soon everyone in the family chalks up the

episode to laziness because, strangely, that's easier than admitting that Anna, their wonderful mom, sister, or wife has this unpredictable disease.

"The consequence of everyone's silence builds," Dr. Miller continued. "The family knows Anna has MS, and becomes watchful and overly protective. They think she is lazy, 'giving in' to MS, and, at the same time, they stop her from doing things for herself."

Once the silence is broken, family members can work together to modify activities and responsibilities. Everyone in the family needs to learn about MS. The Society offers programs and literature for everyone. With education, family members won't question whether or not invisible MS symptoms are real.

A supportive family won't allow the person with MS to withdraw and give up, but won't push in situations where pain, fatigue, or other problems are overwhelming.

The doctor/patient relationship

People with MS sometimes feel reluctant or unprepared to talk with a doctor

about invisible symptoms such as memory lapses, weakness, fatigue, or bowel and bladder problems. Or, they may not realize that these problems are related to MS. Since not all doctors routinely ask about such symptoms, the person with MS is left to face them alone, without a thorough evaluation or the medication or rehabilitation strategies that could help make them better.

Learning how to describe clearly what is happening and how it feels is vital to creating an effective working partnership with your doctor. Keep a list of problems and symptoms—perhaps a simple health diary—to improve communication with your doctor. Write down questions you want to ask—making sure that your most important questions are at the top of the list.

If your doctor seems to brush off your invisible symptoms, call your Society office for information, support, and perhaps, referrals to other physicians.

The need for support

“Every time I went to a self-help group all the people were using wheelchairs or electric carts. I was embarrassed to talk about my problems because they seemed piddling next to people who could not walk anymore.”

— Allen Godfrey, Raleigh, NC

It’s very important for people not to bottle up their concerns about invisible symptoms. In chat groups and in self-help meetings, the need to confide is repeated again and again by people with MS. But communication can and should be selective.

If your symptoms are hidden, most people won’t know that you have a chronic illness—and many of them probably don’t need to know. Everyone with MS needs a few people who know what is going on, with whom they can openly discuss problems. A good confidante can also help you decide how much—and when—to tell other people.

Over the past decade, self-help groups for people who have the less visible MS symptoms have sprung up around the country. Many are named after the

original article on the subject published in **InsideMS** back in 1983.

Some people attending “But You Look So Good” groups are recently diagnosed; others have been living with invisible MS for 10 or 15 years. Members of these groups say that they understand each other, and this can make all the difference in facing a world that keeps insisting “But you look so good ...”

Additional reading

To learn more about managing specific symptoms, call your chapter or search our Web site. Click “search” and type the name of the symptom or the keyword “Sourcebook.”

The Sourcebook is the Society’s compendium of information on hundreds of MS-related topics.

On the cover
Image courtesy of Jupiterimages Corporation © 2007.

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-344-4867.

All our publications are on our Web site, along with handouts called “Basic Facts” on various topics. For a list, click the bar on our home page called “Library.” If you have no access to the Internet, just call your chapter and ask for a copy of the latest Publications List.

Some of our popular pamphlets include:

- **Fatigue: What You Should Know**
- **Pain: The Basic Facts**
- **Solving Cognitive Problems**