

But You Look
So Good!



MS[®]

National
Multiple Sclerosis
Society

**FOTINI (CENTER)
DIAGNOSED IN 2007**

“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, online chat group participant

Many people living with MS experience “invisible” (or not outwardly visible) MS symptoms. This can create a unique set of issues. 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, “But you look so **good!**” — which means that you need to be

prepared to educate the important people in your life about your MS and the symptoms you are experiencing. This booklet will help you feel more prepared for those conversations.

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, balance/coordination problems, and bladder or bowel problems.

It's important to recognize that there are medications, therapies, coping strategies, self-help techniques and self-help groups to help address these problems. Speak with your physician, nurse or call the National MS Society at 1-800-344-4867.

“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 sometimes, but people living with MS are hit hard by a kind of fatigue that sometimes feels totally 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 living with MS may have memory lapses that signal cognitive impairment, one of the most challenging hidden symptoms of MS. Neurologists in the MS community now recognize that cognitive impairment affects up to 60% 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.

“I get anxious and nervous about going out — even to the grocery store — because I have bladder problems that are unpredictable.”

— Person with MS, MS Navigator® phone call

Many people with MS experience bladder and/or bowel problems. Embarrassment and anxiety associated with these symptoms can cause people to cut off their social, sexual and public activities, leading to isolation and depression. In addition, these symptoms, if untreated, can 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 right away. See our website for information and resources about handling bladder or bowel problems.

Self-esteem

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

— Anne, living with MS, Georgia

A diagnosis of MS may change the way you think about yourself. Who we are and how we define ourselves is

oftentimes associated with the jobs we hold, the marriage we are in, or the way we look and feel. It's understandable then that MS can impact self-esteem and confidence.

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

— Dr. Mary E. Siegel, a psychologist with MS, author of 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 and even doctors may doubt the validity or intensity 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. Talking with an understanding confidante, mental health counselor or a self-help group helps many people keep their self-esteem intact.

All in the family

When one member of a family is living with MS, everyone in the family is affected. This is true whether the MS is visible or invisible. Dr. Deborah M. Miller at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic shared this story to illustrate how hidden symptoms can discourage communication 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 thinks Anna is lazy, ‘giving in’ to MS, and at the same time, they stop her from doing

things for herself, even becoming overly protective at times.”

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 National MS Society offers programs and literature for everyone and can help the person with MS start a conversation about what their MS feels like. 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 their healthcare providers about invisible symptoms. 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. An intentional, meaningful relationship with your healthcare provider can improve your ability to cope.

Most doctors don't just want to know what symptoms you have; they also want to know how the symptoms have impacted your life. Some of the most important treatment goals are constructed around what it is that matters to **you** the most and then helping you achieve those things with medication and/or rehabilitation.

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

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, living with MS, North Carolina

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 living with MS. But communication can and should be selective. Take time to think through who needs to know this important information about you and how you choose to share it with them.

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. However, 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.

Self-help groups for people who have less visible MS symptoms have sprung up around the country. Contact the Society about finding or starting a group that addresses this need. 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 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!”

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 prescriptions. For specific information and advice, consult your physician.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at [nationalMSSociety.org](https://www.nationalmssociety.org) or 1-800-344-4867.

The Society publishes many other resources about various aspects of MS. Visit [nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures) or call 1-800-344-4867.

Other popular resources include:

- Fatigue: What You Should Know
- Pain: The Basic Facts
- Managing Cognitive Problems
- Urinary Dysfunction and MS

The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.



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