

close friend of mine is planning her wedding. At dinner a few nights ago, while describing the preparations, she became increasingly distraught. Finally she stopped,

looked up at me sadly, and sighed, "I guess I just don't handle stress very well."

My first thought was, who does? Whether getting married, starting a new job or leaving an old one, or dealing with the loss of a loved one, life can sometimes seem overwhelming. And being told we need to reduce our stress often makes us feel even more pressured: taking yoga classes or practicing deep

breathing are just more things to add to our to-do list.

Ironically, even though everyone experiences it, stress is difficult to define objectively. "Different people really mean different

things when they talk about stress," said Nicholas
LaRocca, PhD, the director of Health Care Delivery and Policy Research for the National Multiple Sclerosis Society. "Not just the general public, but scientists, too."

There are many kinds of potentially stressful situations, and each person has his or her own response. One person may be devastated by the loss of a job, while another may find working full-time stressful. There's everyday stress, like being stuck in traffic, or there's traumatic stress, such as divorce or loss of a child. There are even general stresses brought on by war or terrorism.

Multiple sclerosis brings its own kinds of stress. New York City paramedic Maggie Staiger was diagnosed in August 2001, and a month later she worked as a paramedic at the World Trade Center site. "All these things are happening—you have to give yourself shots, your whole life changes—and then everyone tells you to try not to get stressed out. How in the world are you not supposed to get stressed out?" she said.

## **Stressing over stress**

Dr. LaRocca calls it "stress related to worrying about stress." If you think that stress could cause an exacerbation—which has never been definitively proven—then you may stress over managing your stress.

Rosalind Kalb, PhD, director of the Society's Professional Resource Center, agreed. "People can be so worried about anything making their disease worse that it becomes another stress in and of itself." In addition, friends or family members may feel responsible or guilty for causing stress, thinking that they may be worsening a person's MS.

"Issues that need to be discussed sometimes don't come up because a family member is afraid to bring them up," Dr. Kalb said. "Rather than being brought out into the open and resolved, they get swept under the carpet because the person doesn't want to bring up something that might upset the loved one with MS."

"One idea I find incredibly offensive is the idea that I wouldn't have MS if I'd managed my stress better," Staiger said. "There's the implication that if you can affect it with your mind then it was caused by your mind." She adds, "When I first got diagnosed, and then there was the World Trade Center, I was reading all this stuff about MS that emphasized 'try to avoid stress, try to avoid stress.' I thought, this is horrible! But I realized that, while I can't really avoid stress, I can change my reaction to stress."

### The missing link

The first thing to know is that while stress can make us **feel** worse, whether upsetting our stomachs or knotting our neck muscles, no research group has been able to prove any direct cause-and-effect relationship between MS and stress. Many have tried.

"There's no doubt that there is a link in a general sense between stress and other things that happen to the human body," Dr. LaRocca said. "But what they are and how they operate in each case is not so clear." He added, "People get caught up in this question: Is stress making MS worse? I think we need to focus deeper than that and try to define stress in a scientifically rigorous way and then relate it to what's happening to the immune system."

Dr. Kalb agreed. "If people say they feel worse, I believe them, but we just don't know what the mechanism is." It's difficult to separate out the general effects of stress—such as making people feel more tired or jittery—from what actually happens to the immune system when it is under stress. The immune system is made up of many different elements working together, almost like a web. It is a mistake to point to a single factor, like stress, and blame it for everything.

"It's important for people with MS to

know that there have been a lot of studies, but we still don't have conclusive evidence that stress causes exacerbations. I personally doubt that it causes them alone," said David Mohr, PhD, an associate professor in the department of Psychiatry and Neurology at the University of California, San Francisco.

Dr. Mohr recently conducted a "metastudy" of 14 studies on MS and stress, which was published in the March 19, 2004, issue of the **British Medical Journal**. While the data from that study shows an association between stress and exacerbations, Mohr is careful to point out many variables, such as medications, or a

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viral or bacterial infection. Time is also a major factor, in more ways than one.

When people remember a stressful event, they do so through hindsight. Since memory is often kind, small details tend to get erased and large details can become linked in a way they weren't in reality. "Life is full of stress," Dr. LaRocca said. "You can always find some sort of stressful situation in your life." He pointed out that one of the dilemmas scientists face is that it's "very difficult to go back and retrospectively look at this before people developed MS."



#### What is known about stress?

Stress initially acts to protect you, releasing chemicals that make your reactions sharper and your mind move faster. Interestingly, the main hormone released during stress, cortisol, is anti-inflammatory, and derivatives of cortisol, such as prednisone, are often used to treat exacerbations. Dr. Mohr said that one possibility is that it's not stress itself that helps cause problems, but rather the resolution of stress, when levels of anti-inflammatory cortisol drop.

Dr. Mohr also points out that exacerbations may originate **before** stressful events. "Processes are going on that may occur over months, and your body is trying to manage those," he said. "Sometimes those processes get shut down, and sometimes they go on to become full-

blown exacerbations." If you are stressed when no exacerbation is developing, then nothing may happen. However, if you are stressed when an exacerbation is developing, Dr. Mohr said, "it may increase the risk a little bit." In other words, stress alone will not cause an exacerbation, but it might be one factor in a complex set of factors that lead to an exacerbation.

"Saying that stress causes exacerbations is certainly premature," Dr. Mohr said. He is currently enrolling people

with MS in the San Francisco Bay and Seattle areas in a study designed to track whether learning stress management techniques can reduce development of new brain lesions or occurrences of new exacerbations. For information about participating, call 800-923-1033 or visit www.ucsf.edu/bmrc.

# **Eliminating stress?**

Getting rid of stress is not the same as cutting out french fries. "People with MS have at times been told to quit their jobs to avoid job-related stress," Dr. LaRocca said. "However, people find that if they withdraw from significant life activities, it can actually make their stress worse." Instead, he said, the key is to learn how to deal with stress, not try to escape it.

"I think people have to start by acknowledging that stress is normal in everyday life and that families—with or without MS—have issues that they have to work on and resolve as a family," Dr. Kalb said. She suggests family meetings, family counseling, and individual therapy for figuring out "stress triggers" and managing stress. A stress trigger could be external (noise, disturbing news, caffeine) or internal (depression, anxieties about money, etc.). And no two people are affected the same way by any particular event or thought pattern.



## Managing stress the healthy way

After Maggie Staiger was diagnosed, she decided to try hypnosis to help control the pain caused by her MS-related nerve damage. "I was so skeptical because nothing was working," she said, "so why would hypnosis work?" After two sessions, she was convinced—so convinced that she decided to study hypnosis herself and offer hypnosis to other people.

"Through hypnosis you still have all those stresses around you, but you're not responding in a way that is destructive to you," Staiger said. "The stressor of chronic pain is really debilitating, and relieving that stress of always feeling uncomfortable and never getting proper rest was a huge load off me—that made me feel better."

Other people turn to exercise, meditation, prayer groups, or psychotherapy to help with stressful situations, but everyone agrees that whatever you do—or don't do—no one should ever feel guilty about feeling stressed. For better or worse, stress is a normal part of life, and everyone goes through it differently. The person you admire for traveling

alone to Tibet may be the person who is barricaded behind the bedroom door during a family picnic.

The relationship between stress and MS is still so tenuous and little understood, that, as Dr. Kalb said, "Until we can explain it, all we can do is encourage people to try to figure out how to handle stresses that are part of their lives"—which, for anyone, can only be a win-win situation.

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