



InsideMS

THE MAGAZINE FOR MEMBERS OF THE NATIONAL MS SOCIETY

A SPECIAL REPRINT

MS *and the* Mind

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*Readers share experiences
and coping tips.*

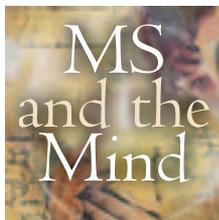
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MS *and the* Mind

ILLUSTRATIONS BY DAVID HOLLENBACH

MS is not a disease that plays fair. It takes unexpected turns at unexpected times. No one, not the person who has MS nor the most experienced MS specialist in the land, can predict with certainty what any one person's MS may do. This special section deals with things MS may do to a person's mind—the “thinking” or cognitive functions, and the emotions.

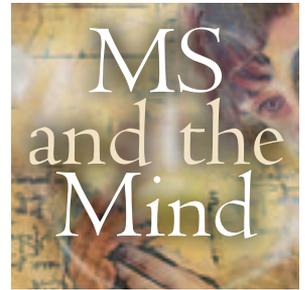
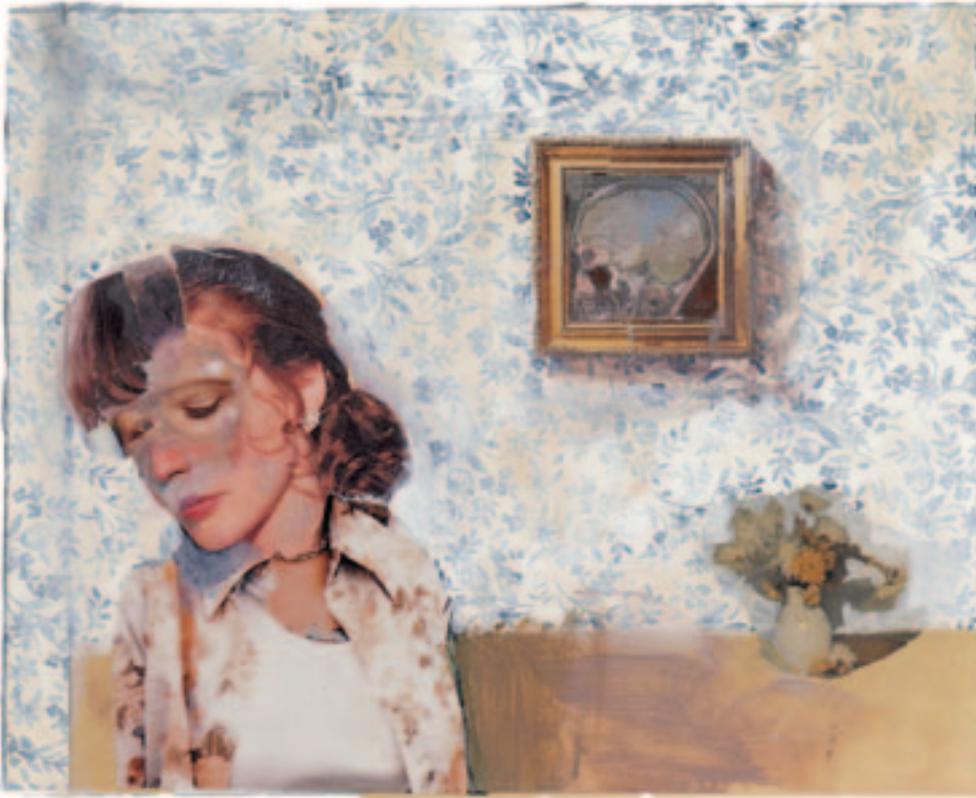
May do—or may not do. No article in this section will speak to all personal experiences of MS. But all have been prepared in the belief that knowledge is power.

The illustrations have been created by David Hollenbach, a professional commercial artist, as a gift to **InsideMS**. David

lives with MS himself. The woman in David's picture on the opposite page finds her thinking dimmed. She has lit a candle to compensate.

Experts and people living with MS agree that there are many ways to compensate for mental symptoms. A sense of humor and a bit of patience were mentioned by everyone. These are not hopeless problems.

Still, we know this subject is not an easy one. If anything you read here leaves you concerned or distressed—please tell someone you trust. Get support for how you feel and what you think. Get help with your next decisions. Light a candle for yourself and others.



About MS and My Mind

Readers sent a flood of letters on the subject of MS and their minds. Here are some highlights, reflecting many different experiences and many common themes.

“I’ve had episodes of almost total disorientation. I didn’t mention these lapses to my neurologist during my diagnosis interview because I had no idea they could be MS-related and my neurologist never asked me about mental symptoms.”

—Howard Bell, *Minnesota*

“I spread my company benefits package

out on the kitchen table and stared. It was so beyond what I could deal with I sat there and cried. Eventually I was able to make heads and tails of it but this sort of thing happens more frequently than I like.”

—Sandra Elkins,
via e-mail

“I am much more emotional than I used to be, espe-

cially right before my period. My neurologist prescribed Wellbutrin. I don’t feel any different, but my coworkers say they notice improvement.”

—Lisa Roesner, *New Jersey*

“There are times when I cry at a commercial and yet I have to remember to act excited when other people think that’s appropriate. These are signs of depression, but I am not at all depressed. There are times when even simple everyday things can throw me completely. I use self-hypnosis, meditation, and just plain faking

to keep a positive attitude—and it works (most days).”

—*Eileen Tolan, via e-mail*

“I can go from happy to depressed to angry in the snap of a finger. My neurologist prescribed antidepressants, which have helped, but I find I also need to notice and adjust my attitude constantly.”

—*Ann Stauffer, Ohio*

“My first neurologist said this was all in my head, that I would have to have severe MS and I only had mild. When I switched to a new neurologist I learned that a majority of people with MS have some form of cognitive problem. Hearing that alone helped because I no longer had the stress of thinking I was just imagining things.

“Change doctors if you are told these mental problems aren’t real symptoms of MS!”

—*Kathy Abbott, North Carolina*

“What saves me is my warped sense of humor. I talk to my disease. I tell it to beat up on the 90% of my brain that I’m not currently using. The honest part of me admits that I was once very arrogant about my mental abilities. Everything came almost too easily. MS has taught me patience and humility.”

—*Julie Bushinski, Pennsylvania*

“I kept feeling I was having trouble with my memory and it took me a year and a half to remember to ask my doctor about it!”

—*Jean Evans, via e-mail*

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Practical Tips

All these suggestions are excerpted from letters and e-mails sent to InsideMS by people who are using them to handle their problems. For the viewpoint of professionals, see page 18.

- **The kitchen timer** (“for everything from taking the clothes out of the dryer to the time of my favorite TV show”).
- **Computer calendars**, especially ones that ping.
- **Calling your answering machine** to record a reminder if you are away from home.
- **Lists, lists, and more lists.** (“A pad and pencil hanging around my neck would help.”)
- **Keeping a sense of humor.**
- **Post-it Notes**—especially on the front door. (Although many people report using them, our experts think sticky notes can cause confusion. They suggest 1 notebook or electronic gadget to be carried with you everywhere.)
- **Having a routine.**
- **Being as organized as possible.**
- **Breaking projects down into small segments.**
- **Writing down instructions.**
- **Taking a break when you feel overwhelmed.**
- **Stretching your brain with puzzles, games, reading.**
- **Planning.**
- **Enlisting friends, family, coworkers (even your students, a college teacher suggested):** Let them remind you and tell them it’s OK to correct you.
- **Having a specific place for things and putting things back in their place immediately after use.**
- **Having a calm corner to go to, in your imagination and in your home.**

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“The thought of asking for help just tears me apart. I’ll do it if I have to crawl to get it done. My most embarrassing moment was a Thanksgiving Day when I forgot how to cook the turkey. I took the easy way out and ordered dinner from Safeway. Hey, I didn’t even have to admit I had forgotten. Did somebody say **attitude check?**”

—*Name withheld, Washington*

“I struggle with things like T-shirts because I can’t figure out which is the front and which is the back. I brought up some of the difficulties I was having in my small MS support group. It turned out to be a very tearful meeting as 3 out of the 5 of us have these same weird problems. We all felt such a release to discover we weren’t crazy.”

—*Name withheld, California*

“I was in the chess club in high school. In seminary I continued to play and win, but while serving in my first church I noticed my power of concentration starting to wane. This coincided with the onset of my MS. Still, I love crossword puzzles and during baseball season I mentally calculate percentages from reports on the radio and check the sports page to see if I get it right. I do. My conclusion? I’m still a math wizard but when it comes to solving the deeper problems in life, I think I will call in the experts.”

—*Milton Lentz, pastor emeritus, United Methodist Church, Minnesota*





Depression: My Story

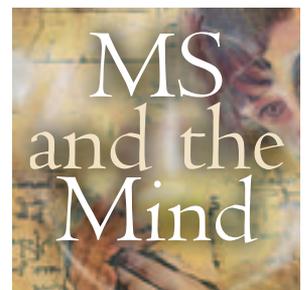
BY SHELLEY PETERMAN SCHWARZ

The author looks back at 20 years of living with MS, in which clinical depression has periodically reared its head.

“**D**epression Deadly as Cancer” was a headline in my local newspaper the other day. Those words were a haunting reminder of the dark place that held me for many years after I was diagnosed with MS.

I took the news calmly at first and was determined not to let it change my life. I quietly made little changes to accommodate minor yet ever-present difficulties. But the progressive nature of my illness meant continually readjusting my life to deal with increasing disability.

It wasn't long before I stopped going out at night. Then I stopped going to the mall and did my shopping at stores where I could park directly outside the door. I stopped knitting and needlepointing. When I went to restaurants, I ordered finger food like fried shrimp so I





Shelley Peterman Schwarz with Andy, Jamie, and Dave

wouldn't need someone to cut up my meal. I kept trying to pass as normal, but the sadness I felt kept growing.

Within 2 years of my diagnosis, I had given up everything extra

in my life. I only did the things that had to be done. I saved whatever energy I had for my husband, Dave, and our 2 children.

That year I had to quit working. It was the saddest day of my life. Ever since I was a sophomore in high school, I had wanted to be a teacher of the deaf. But I had lost the ability to finger-spell and sign. I knew I'd never teach deaf children again. My wonderful work friends tried to keep me involved by inviting me to professional gatherings, but I felt I no longer had a purpose in life. I went into a deep depression.

I was 35 years old. What would I do with the rest of my life? My perceptive daughter, Jamie, was 7 years old when I retired, and she had her own questions: Who would help Mom when Dad couldn't help her anymore? Would Mom have to live in a nursing home like Great-Grandma?

I couldn't get over the sadness I felt, nor could I stop worrying about the future. What scared me the most was that the disease showed no sign of letting up. I cried all the time.

I shared my feelings of despair with my

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Depression: *The Doctors Are In*

BY HENRY HAMPLE

Depression is a medical issue as much as a spiritual one.

If you are feeling depressed, you are clearly not alone—depression is a major symptom of MS, one that is frequently misunderstood and, worse, frequently under-diagnosed and under-treated.

To learn more, InsideMS spoke with David C. Mohr, PhD, assistant clinical professor and director of medical psychology at the Mt. Zion MS Center of UC San Francisco, and Sarah Minden, MD, assistant profes-



David C. Mohr, PhD

sor of psychiatry at Harvard Medical School, senior scientist at Abt Associates in Cambridge, and practicing psychiatrist at Boston's Brigham and Women's Hospital.



Sarah Minden, MD

“The rate of depression in people with MS is very high,” Dr. Minden said. “About 14% of the MS population is currently experiencing a major clinical depression, and we estimate that 42% of all people with MS will endure a major depressive



disorder at some point during their lives. This clearly signals a research direction, because we don't yet know what makes this so in MS. We don't have the tools we need to sort out the interactions between dysfunctions in the brain and individual reactions to life circumstances. We do know they link together in a vicious circle. They feed each other. And we do know that medication can positively affect the brain chemicals, which lifts the burden and then gives people a chance to work

through their life problems with a therapist.”

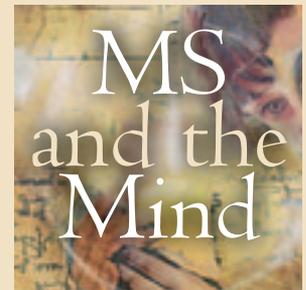
Dr. Mohr sees patients in individual

and family therapy, does neuropsychological evaluations, and teaches graduate-level psychology courses. He is currently conducting research on the relationship between stress, depression, and MS; the treatment of MS depression; and helping people with a fear of needles learn how to self-inject medications.

Dr. Mohr believes there is evidence that depression is related to immune system dysfunction. “When the immune system is activated—like when you get a cold or have the flu—behaviors are activated that look like depression,” he said. “For example, one of the things that most people experience is feeling they don't want to be around other people. They want to curl up under the covers. Often they have a loss of appetite. These

illness behaviors look like depression. And MS is a disease where the immune system is overly active, especially when a person is having an attack or exacerbation. I believe in some cases depression may actually be a symptom of MS—a symptom of the immune-system dysregulation.”

The interferon-based disease-modifying drugs have been associated with depression in the FDA-required patient information labels of Avonex, Betaseron, and Rebif. There is a great deal of con-



troversty about this association and no definitive scientific data.

As Dr. Mohr points out, depression and MS are common companions, and the disease-modifying drugs have clear benefits for many people.

Medication...and the couch

“Anyone with MS who feels symptoms of depression that last more than 2 weeks without lifting should be evaluated,” Dr. Minden said. “The symptoms aren’t always feeling sad or crying all the time. Some people simply lose their ability to enjoy things. They are tired and listless, or prone to outbursts of anger. It’s common for family members to accept this as part of MS, or MS fatigue. It is not.”

There are a number of medications used to treat depression. “Finding the right drug and the right dose can take some time,” mused Dr. Mohr, but the picture is much brighter today since the development of a class of antidepressants called SRIs (or serotonin re-uptake inhibitors). These drugs have a very low side-effect profile. Even so, it takes 6 to 8 weeks for any antidepressant to reach full effect.

Both Dr. Mohr and Dr. Minden stress that psychotherapy is an important part of treating depression in people with MS. More than ever, Dr. Mohr said, modern psychotherapy is oriented toward helping people learn what he calls “coping

skills”: adopting new patterns of thinking, managing one’s fatigue, compensating for cognitive problems, improving one’s ability to interact with other people, and learning assertiveness techniques.

“Our society’s not very kind to people with disabilities. It’s easy to get angry, frustrated, or feel hopeless—but these feelings don’t get you what you want,” Dr. Mohr said. “Therapy helps people be more assertive, so they get the things they need without getting angry or giving up. We also know that psychotherapy and medication together are more effective for depression than either of them alone,” he concluded.

Dr. Mohr is currently researching a new thesis—that in addition to MS causing depression, depression may have an effect on MS: “There’s some early evidence that depression can increase the immune dysregulation associated with MS. So getting treatment for depression may be even more important for people

with MS than it is for the general population.”

By and large, he said, “the immune system is still a mystery.” While researchers concentrate on the puzzle, medication and counseling really work for people with depression, both doctors emphasized.

“There’s some early evidence that depression can increase immune dysregulation. So getting treatment for depression may be even more important for people with MS than it is for the general population.”
—Dr. David Mohr

Henry Hample was managing editor of InsideMS in 2000.

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doctor, who prescribed an antidepressant. I thought this would be a quick fix—but it wasn't. It took months to find the right medication and to adjust the dosage. I also started seeing a counselor. I remember walking down the hall to his office as if 100-pound weights were attached to my legs. I sat down on his couch, reached for a tissue, and cried for the next hour. I returned each week and unleashed my feelings.

The combination of medication and counseling helped me regain some control in my life and begin accepting my new reality. I didn't want to alienate my friends and



Shelley Peterman Schwarz and husband Dave

family by always being self-absorbed and down. At 39, I wanted to be happy again.

I wasn't the only one in the family who had been dealing with the effects of MS. Dave wasn't mad at me or my MS—he just threw himself into overdrive, did more and more around the house. Four years after my diagnosis, he had lost 20 pounds and his great sense of humor. He was diagnosed with clinical depression and was put on an antidepressant. The medication

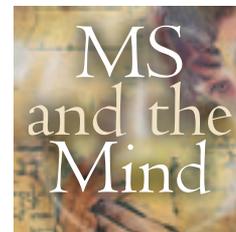
worked and he returned to his old self.

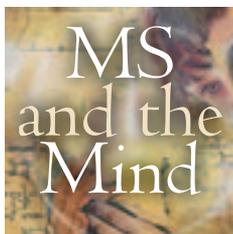
When Jamie was 9, she became withdrawn and didn't want to leave the house. She too was diagnosed with clinical depression. Thankfully, medication and family counseling helped her recover as well. Andy seemed to be the only one whose emotional stability stayed intact through the years. His temperament has always been very laid-back.

Then, 10 years after my diagnosis, the clouds of depression again became too difficult to keep away. Why did the dark come back? I only know the medical studies for which I'd volunteered had not improved my condition. I was tired and scared. Once again, I cried more and slept less. I became convinced that, at the age of 44, I was dying. The middle of the night was the worst because then I was surrounded by darkness inside and out. I began to spend hours each day planning my suicide.

Then something happened that changed everything. Jamie, at age 13, found my suicide letter, which I had hidden in my desk. She confronted me with it, clinging to me as someone would cling to a life preserver. We both sobbed, and I promised her I wouldn't take my life. Her pleas made me realize I did have a purpose I had lost sight of: I was Mom, and I could never be replaced.

A few nights after that, I was again awake in the middle of the night, trying to figure what options were still open to me. For the first time in my life I asked God for help: "I give up! I can't do it alone. I need Your help." The words of a learned rabbi echoed in my mind: "Live each day as if it





were your last, and you will live each day wisely.” If now was to be the best moment I was going to have, and tomorrow would be worse, I would make the best of this moment. I would try to accept each day as a gift.

I returned to the doctor, who adjusted my medications, and I began seeing a counselor again. I chose a path for living, not dying.

Now that our children are adults, I’ve had to refocus and find a new purpose for my life. I want to stay on a path for living. I no longer cut everything out. Dave and I travel, entertain, go to restaurants and movies. I’m volunteering again and raising money for the National MS Society. I’m playing bridge with my girlfriends. And I write and speak professionally about the challenges of living with MS. Life is good.

Yes, I still have days when my spirits sag and I question what the future will bring, but I live in hope. It wasn’t easy to write this story, but I’m glad I did. It reminded me that I won’t give up. I hope my story has in some way helped you in your journey.

Shelley Peterman Schwarz is a nationally recognized motivational speaker and author of 300 Tips for Making Life with Multiple Sclerosis Easier, a book based on her syndicated advice column, Making Life Easier. Her other books include Blooming Where You’re Planted: Stories from the Heart. You can visit her web site at <www.MakingLifeEasier.com>.

Memory Problem

These are the two areas where MS most often creates glitches.

The MS symptoms that usually grab the spotlight are the physical ones—balance, gait, muscle control, bladder control, vision, numbness. But in the last decade, light has also come up on how MS may affect cognition—the mind’s ability to store, organize, and recall information. Memory deficits, a slower response to problem solving, or a shorter attention span have always been part of the disease for some people, but these symptoms were often misunderstood or downplayed.

“Before 1990, many physicians assumed MS caused **physical** disability but left the mind intact,” said Dr. Stephen M. Rao, who has been researching cognitive aspects of MS since 1981. He is currently a professor of neurology and a clinical neuropsychologist at the Medical College of Wisconsin in Milwaukee. “When people complained to their doctors about memory problems, they’d hear, ‘You’re not really forgetful. You’re just depressed or tired,’ ” Dr. Rao said. Other neurologists chalked the problems up to the person’s attitude: “If only he’d try harder, he’d remember...”

and Solving

BY MARTHA JABLOW

“Until the late 1980s, gait was seen as the primary MS problem,” said Dr. Nicholas LaRocca, a clinical psychologist who is currently the Society’s director of Health Care Delivery and Policy Research. “Cognition wasn’t studied in any great detail in large clinical trials, and many neurologists said MS doesn’t affect memory, period. But now we know that isn’t so.”

Experts now know mild problems are common

Recent research shows that from 40% to 60% of people with MS develop some degree of “cognitive dysfunction”. Most people who are affected have mild problems. Moreover, there is little correlation between physical and cognitive symptoms. For example, one person might progress swiftly to total inability to walk but never develop any cognitive problems, while another might have poor memory as one of the very first signs of MS, and never develop severe physical symptoms.

Cognitive problems are not inevitably progressive. They are not destined to



worsen steadily once they start. Like motor or sensory problems, cognitive difficulties may improve, or become worse, or stay about the same. As all MS experts agree, variability is the hallmark of this disease.

Serious problems are far less common. Although solid data are not really available, experts guesstimate that 5% to 7% of people with MS have cognitive problems that can be called serious. These include moderate to severe impairment in thinking, reasoning, or judgment, major personality changes, or a lack of self-awareness leading to inappropriate behavior.

Causes

Cognitive dysfunctions arise when lesions (or areas of MS damage) occur in certain locations in the brain. In MS, **myelin**, the material that sheathes nerve fibers (or

axons) in the brain and spinal cord, is attacked or worn away; scarring is often left in place of the healthy myelin. Scientists recently learned that the underlying nerve can also be damaged, even severed. MS lesions may develop anywhere in the brain or spinal cord, but when they appear in the cerebral hemispheres, the “thinking” part of the brain, some thinking functions can be affected.

Where the glitches are

“The vast majority of people have relatively mild problems, mostly in the area of memory and attention,” Dr. Rao said. “They’re more nuisance problems than seriously disabling ones.” These are the most common symptoms:

- Recent memories are more difficult to recall. A person can’t remember what she ate for breakfast or a phone number that she learned last month, but has no trouble remembering phone numbers of childhood friends or the Social Security number that she’s had for 20 years. Most people with this symptom can still learn and remember new information, but recall will take a little longer.
- Fluency with words may be diminished. The person searches for a word. It’s on the tip of the tongue, but he just can’t think of it. This too is a recall problem. It is not the same as the changes in voice quality or a slower rate of speech, which are associated with physical changes caused by MS.
- When a lot of information is coming all at once, processing may take longer. If several people talk at once, or the television or radio is on, or even if a single

speaker talks too rapidly, the barrage of information can be too overwhelming for the person with MS to sort out. (Eliminating distractions like background noise will help.)

- Judgment and problem solving may be slower or less reliable. Some people with MS-caused cognitive problems have difficulty analyzing a situation, coming up with a solution, and carrying it out.

Sylvia White, a 42-year-old Philadelphia woman, related a common example of this problem and how she dealt with it: “I wear a different jacket depending on the weather. One morning I’d pulled the door closed behind me, and it locked just as I realized my keys were in my other jacket pocket. No one else had an extra set of keys. My son’s set doesn’t include the key to the top lock.

“I worried that he wouldn’t be able to get in when he got home from school,” said Ms. White, who has had MS since 1985. “When I have a problem like that, I can get frustrated because I **know** I can solve it



but I just can't figure out the steps at the moment. I've learned that I have to stop saying 'I can't do this; I can't do this.' I have to slow down my thinking, and then my brain will work. I can find a solution if I say to myself, 'I think I can do this.' But I need some time to get past the frustration."

Once she took time to calm herself down, Ms. White asked a neighbor for help. He had a ladder. He climbed through an unlocked second floor window and opened the front door from inside.

Common misunderstandings

Some common misunderstandings about cognitive problems and MS need to be clarified. One is the confusion with Alzheimer's disease.

◆ *Not Alzheimer's*

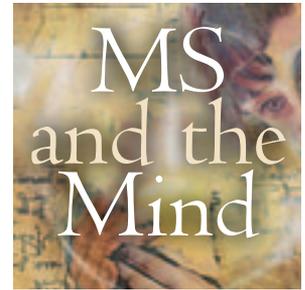
Alzheimer's is an entirely different disease from multiple sclerosis. Dr. Rao illustrated: "People with Alzheimer's have difficulty storing information from moment to moment. They can't use a notebook as a memory aid, because they won't be able to remember why they're even carrying it. MS-related problems tend to involve retrieving information. For a person with MS-related problems, a notebook or other gadget really works to make up for poor memory. The person with MS is able to store and retrieve information but may require more time to do so or may be somewhat less accurate in the recollection."

◆ *Not loss of intellect*

Another misunderstanding centers on intellectual ability. MS-caused cognitive prob-

lems don't mean that intelligence has declined. However, some people may not be able to think as flexibly as they once did.

They may be less responsive to feedback from other people and find it harder to adapt to changes in routines or environments. They may need time and a supportive atmosphere to solve challenges.



◆ *Not mental illness*

Cognitive problems are sometimes confused with mental illness or emotional problems. Cognitive difficulties involve specific thinking processes. Unruly emotions may arise as a psychological response to having a frustrating chronic illness—especially if cognitive symptoms are present—or they may result from MS lesions in a specific part of the brain.

Role of MRI

Magnetic resonance imaging (MRI), which takes pictures of internal organs without X-rays, is the definitive way to determine

where MS lesions are, but most experts say that an MRI scan isn't all that helpful for cognitive issues. If problems like forgetfulness or poor concentration are interfering with work or family life, neuropsychological tests may be a better approach to effective management. These tests measure "cognitive performance" such as recall and attention. They are far more extensive than the 5-minute "bedside" assessment neurologists use, as they are designed to uncover the subtle problems typically caused by MS. A full assessment may require 2–5 hours, and it is considered the most accurate way to evaluate cognitive strengths and weaknesses. However, there are other avenues to explore with a referring physician if neuropsychological testing is impractical.



Three kinds of specialists can help

According to Dr. Rosalind Kalb, a clinical psychologist who has specialized in MS for some 20 years, 3 different kinds of specialists can evaluate cognitive dysfunction: a neuropsychologist, a speech/language pathologist, or an occupational therapist. "Although these 3 specialists use somewhat different assessment tools, they share the ability to identify cognitive changes that are affecting a person's daily life," she explained. "Sometimes the professional who tests you is determined by who is available in your part of the country."

Retrain or compensate?

Rehabilitation techniques long used for people who've had head trauma or stroke may enhance cognitive functions for people with MS. These techniques are as sophisticated as computer-based training in which a person follows a repetitive on-screen task, or as simple as exercises using illustrated cards as memory joggers. The principle involves retraining to improve function by strengthening mental patterns.

The most useful approach is compensation, which means making adjustments for specific losses. "For coping with mild to moderate cognitive problems, try compensation strategies first," said Dr. Kevin Riley, a psychologist in the MS program

at Temple University Health Sciences Center in Philadelphia. **InsideMS** readers sent many suggestions for handling everyday cognitive problems, and most of them involve compensation. (See page 5. The sidebar on page 18 presents compensatory techniques suggested by the experts.)

A solid rehab program usually mixes retraining and compensation, and will be tailored to the needs and the strengths revealed in an individual's evaluation, according to Dr. Kalb.

No medications have yet demonstrated long-term success in reducing cognitive problems, although a recent, small study of Aricept (donepezil hydrochloride), a drug that improves memory in people

with Alzheimer's, has shown some promise in people with MS. Drugs do play a role in treating depression, mood swings, and fatigue—all symptoms that can complicate cognitive issues.

An ounce of prevention

Can cognitive problems be prevented? The question is still open. But research involving the disease-modifying drugs (Avonex, Betaseron, Rebif, and Copaxone) indicates that all 4 slow down the rate at which new lesions develop in the central nervous system. If fewer lesions develop, fewer may occur in the critical parts of the brain that affect cognition.

Dr. Jill Fischer of the Mellen Center for MS Treatment and Research at the Cleveland Clinic Foundation reported that some disease-modifying medications have been shown to affect cognitive functions the way they affect physical functions. "They do not reverse cognitive problems," she said, "but they can slow the rate of progression, and that's reassuring." And for people with progressive forms of MS, she noted, oral methotrexate may provide "a modest beneficial effect" on cognitive problems, as was indicated by Dr. Donald E. Goodkin in his recent research.

Family matters

Psychologists, physicians, and people with MS all agree that understanding and support by family members are essential. Fam-

ily members shouldn't assume that the person with MS isn't trying hard enough or doesn't listen or pay attention.

"Family members need to recognize that these problems are not under the person's control," Dr. Rao said. "You wouldn't blame a person for having problems walking because of MS, so don't blame him or her for forgetfulness. A person who's

experiencing memory loss often feels guilty about it. That's another reason family members need to be as tolerant and supportive as possible," he added.

Taking action at work

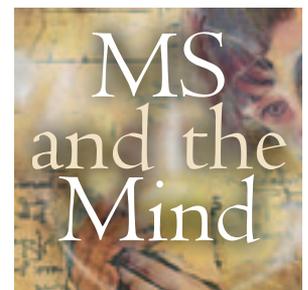
"Most people wait until there's a crisis to talk to their employer about their cognitive problems," said Dr. LaRocca. "That's probably a mistake. It may be

wiser to try to open a dialogue with your supervisor before your performance is affected. You will have to educate your employer about the nature of the problem. First, an employer may assume the problem's going to get worse, and it doesn't for many people. Second, this disability is covered under the Americans with Disabilities Act, so if you need an accommodation to remain productive in your job, you will need to take some action.

"The Society recommends that you get advice on workable solutions and some

"The person with MS is able to store and retrieve information but may require more time to do so or may be somewhat less accurate."

—Dr. Stephen Rao



Palm Pilots and Post-it Notes: *What the experts say*

“What you’re trying to do is replace memory with organization.”

—Dr. Nicholas LaRocca

- **Keep a daily diary or notebook.** Write down all appointments, reminders, and lists of things to do in one place. When you make or receive a phone call, note the date, time, whom you spoke with, and a short reminder about what was said. Get in the habit of referring to this diary routinely, perhaps at the same time each morning and again in the evening for tomorrow’s schedule.
- **Post a large family calendar in a prominent place**—maybe the refrigerator door—where everyone in the household writes down their activities and schedules. Think of this calendar as “communications central” and refer to it daily. Check things off as they are completed.
- **Use a wristwatch with a beeper,** and set it to remind you of events. People who must take medication at certain intervals find this especially useful.
- **Electronic gadgets like the Palm Pilot** are effective for lists, agendas, important phone numbers, and addresses. Or try other organizational gizmos such as a Day Runner, Filofax, or laptop computer—whatever works for you. Post-it Notes are useful, but they can get unstuck. Moreover, the habit may get out of hand. “I stick them up everywhere, but I may forget to throw them away once I’ve com-

pleted whatever I’ve written on them,” said Sylvia White.

“If I don’t toss them, I wonder later, ‘Did I do that already?’”

- **Keep important things in a designated place.** Keep your daily diary on your night table or next to the phone, your keys in a particular drawer or on a hook near the door. Consistency and routine make it easier to remember where things are.
- **Design a master grocery list,** with all the items you normally need, and make multiple copies. Before going out to shop, review the list and check off the items you’ve run out of. Try to stay calm when memory fails. “It’s normal to tense up or feel frustrated if you are forgetting or losing something, but when you do, you switch out of the problem-solving mode and into the angst mode,” Dr. LaRocca noted. “So take a few moments to calm down. Do slow breathing or other relaxation exercise. Your memory will usually clear.”



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help preparing for negotiation before you speak to your employer. The Society has information on job retention techniques and the protections the ADA provides. Call our 800 number first.”

A vocational counselor or occupational therapist may be your best resource if you need help minimizing a job problem. Dr. Rao cited this example: Workers at a Milwaukee brewery are trained in many different skills and are switched from task to task to avoid boredom. The brewery likes this policy because any one worker can fill in for another. But switching tasks frequently became frustrating and counterproductive for a worker with MS-caused cognitive problems. He'd been trained in 7 different tasks, but he began to forget them when he was moved from one to another. His union, a vocational counselor, and his employer worked with him to find a simple solution. They stopped the musical chairs, kept him at one task, and he performed it well.

In addition to family and employment support, the Society offers peer support, educational programs, and self-help groups where people can find understanding and practical advice. Talking with a psychotherapist may help control anxiety or other problems that so easily boil up along with cognitive difficulties.

The bottom line is that MS **can** affect the mind. Anyone affected by such symptoms needs to learn the facts about them and the ways to handle them effectively.

Martha Jablow is a frequent contributor to InsideMS.

An Ocean of Emotion: *Mood Swings, Anger, and Uncontrollable Laughing and Crying*

BY CYNTHIA ARNOLD

Some people call these MS symptoms “emotional incontinence”. Joella Vreeland calls them embarrassing:

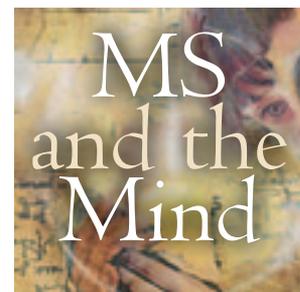
“At lunch hour a colleague was telling us that he was very disappointed as he had applied to the reserves and been rejected because of a heart condition. I laughed.

“ ‘It’s **not funny!**’ he said—and I apologized. But why had I laughed? I was as puzzled as he was.

“I do a lot of speaking—often from the podium—at my church. I was telling a story about a pine tree that had died. And I started



Joella Vreeland



crying—could not control it—and sat down.

“ ‘Well,’ said my friend later. ‘It **was** a sad story.’

“ ‘Not that sad!’ I replied. I have MS, and I was experiencing a problem. I could no longer speak about my mother, my son, or even myself, without getting so choked up that I couldn’t continue. Though this was new for me, I had read about it in an MS publication. Someone had referred to it as ‘emotional incontinence’. I remembered that it meant overreaction: laughing when it wasn’t that funny and crying when it wasn’t that sad.”

“ ‘Emotional incontinence’ is not a great term, even though it captures the issue,” said Dr. Sarah Minden, assistant professor of psychiatry at Harvard Medical School, who sees people with MS at Brigham and Women’s Hospital in Boston. “It’s embarrassing, distressing, and stressful for people with MS to lack control over their emotions.”

For best treatment, determine the cause

According to Dr. Minden, it’s difficult to know what causes these emotional symptoms—uncontrollable laughing and crying, angry outbursts, or rapid mood swings. They could be the result of lesions in the brain and abnormalities in the brain chemicals directly caused by



MS. They could just as easily be due to emotional disorders or situational problems. Dr. Minden believes it is very important that the cause of an emotional problem be clarified, because a diagnosis will determine which treatment approach should be most effective. A correct diagnosis can be made by a neurologist or psychiatrist who is familiar with these kinds of MS symptoms. Only then can the right combination of medications, counseling, and, possibly, behavioral therapy be prescribed.

Dr. David Mohr is assistant clinical professor and director of medical psychology at UC San Francisco’s Mt. Zion MS Center. Dr. Mohr believes that some people may be predisposed to developing these kinds of problems because they have certain genes.

Blame and shame

Dr. Randolph Schiffer has a lifelong professional interest in the behavioral aspects of MS. He is chair of the department of Neuropsychiatry at Texas Tech University. “Any cognitive loss is anxiety-producing,” he said. “People may not understand why they’re having trouble functioning at work or at home. The pattern can be subtle. It’s easy to blame yourself for not doing things as well as you formerly did.

“Our culture is more tolerant of physical disability than of mental impairment, in many situations,” Dr. Schiffer added. Both the person with mental or emotional symptoms and the people around her or him may be struggling with a sense of shame.

“We tend to see emotions as separate from our bodies, but they are not. It’s important to acknowledge that emotions are biological processes,” Dr. Mohr said. “How you think about things influences neurotransmitters in the brain. There is increasing evidence that how people feel may affect their MS directly. The good news is that people can learn to cope with emotions. You may need a mental health counselor to help you identify the pattern of your thoughts and behaviors and learn how to change the ones that contribute to stress or depression.”



Cynthia Arnold, who herself has MS, is a freelance writer and an English professor at a college in Western Massachusetts.

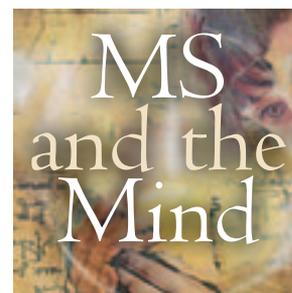
The Devil of Denial

MS-related cognitive problems can be hard to detect and even harder to admit. Denial can be a real devil for people with MS, their friends, family members, and their employers.

BY KAREN J. ZIELINSKI

“Oh my gosh, I lost my car keys!” Maureen panicked. Then she realized that she’d given them to her friend who was presently driving her car. Maureen was sitting in the passenger seat. Forgetting things happens a lot to her. Everybody forgets things, she thought. She did not believe she had cognitive problems.

Maureen was an elementary school teacher before she was diagnosed with MS in 1988. She left teaching because she was “tired of writing lesson plans and tired of trying to handle 30 students.” She went to work doing light filing for a law firm. Eventually, she had to resign. She said the reasons were a few falls, the fatigue of a 9-to-5 routine, and the long distances she needed



to walk. “I guess my physical limitations probably affected my work quality,” she said.

But her boss at the law firm saw it differently: “Maureen’s cognitive ability has gradually decreased in the past 2 years. Her short-term memory is the most obvious area. When giving her instructions...each word has to be written out in order for her to complete the job. She does not have the ability to recall details of a conversation that just took place. This has affected not only her work tasks but daily personal tasks as well.”

Maureen’s boss helped her file her Social Security disability claims and find housing, and got her started on a regimen for completing financial tasks like paying bills. Even so, she did not believe she had cognitive problems—until she read an evaluation of her work at the law firm.

Why is it hard to admit to having cognitive problems?

“People are reluctant to admit to cognitive problems because they often feel these problems make them less of a person, almost as if these problems separate them from others. They often feel helpless,” said Dr. Jaclynn Faffer, who is executive director of Ruth Rales Jewish Family Service of South Palm Beach County, Florida. “We accept and know how to respond to the elderly who have cognitive problems, but when a person is young or middle-aged, we feel less comfortable.” Dr. Faffer said that today’s society has



begun to accept physical disability, but there is more stigma when the mind fails to process information well. This only adds to the difficulty of accepting that a problem with the mind is real.

Research indicates that cognitive impairment may be the most significant factor in the high unemployment rate among people with MS. Even more than

problems with walking or fatigue, changes in intellectual functioning can result in premature departure from the workforce.

Is there hope?

Yes—if the person is able to face the problem and take some action. “Take a deep breath, and see a specialist who can give you tools to help you cope in your life,” Dr. Faffer advised. “It’s important to know that there are techniques one can use to enhance cognitive function and develop positive thinking habits,” she emphasized. “Remember that knowledge is power. With more self-awareness, coping can improve.”

How do I know I need help?

“Do you find activities such as keeping track of appointments, remembering conversations, balancing a checkbook, or staying focused on a task without getting distracted becoming more difficult? These are some common MS-related problems,” said Dr. Rosalind Kalb, a clinical psychologist and director of the National MS Society’s Professional Resource Center. Dr. Kalb added: “It is important to talk with your neurologist. However, a person with MS may know that something is wrong long before a neurologist is able to detect any significant problems in a standard neurological exam. The person who is concerned about intellectual functioning needs to be proactive and request an in-depth evaluation. Ask for a referral to a specialist who can carry out this evaluation.”

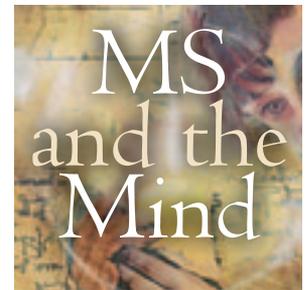
Dr. Kalb always encourages people not to panic: “From what we know, cognitive

problems tend to progress very slowly, and are relatively manageable with remedial interventions. It is important to prepare for the future with habits and techniques that can be learned in rehabilitation,” she said.

Life goes on

Maureen was able to admit her cognitive problems when her boss helped her do so, but neither of them realized that she might have benefited from testing and targeted rehabilitation. Even so, Maureen lives independently, is active in a church program, enjoys gardening, and reads extensively. She has found that sharing her memory problems with her family and friends, keeping a daily planner, writing lists, and using her wry sense of humor help her manage.

“Don’t forget the resources the National MS Society has to offer!” she reminded us. To people who think they have some cognitive problems, Maureen said: “See your neurologist and talk honestly. Give all the details.” ■



Karen J. Zielinski is a Franciscan sister and heads the communications office for



the Sisters of St. Francis of Sylvania, Ohio. Sister Karen writes 2 different monthly advice columns and serves the Society as an active volunteer.

- The National Multiple Sclerosis Society is dedicated to ending the devastating effects of multiple sclerosis.
- For information
1-800-FIGHT-MS (1-800-344-4867)
Web site: www.nationalmssociety.org

