

The shifting tides of moods in MS



Depression, anxiety, mood shifts and other emotional symptoms are common in MS.

by Alice G. Walton, PhD

For William Pulliam, 30, of Denver, who was diagnosed with multiple sclerosis in 2002, the sometimes-unpredictable mood changes he experiences are one of the hardest parts of living with the disease. Going to bed in a positive, happy mood is no guarantee that he'll wake up that way the next morning.

"I've got experience with all avenues," Pulliam says. "I've been happy, sad, depressed, angry. It can be completely random. Other times there are triggers."

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Some MS-related mood symptoms may be a result of the disease process, some a reaction to it, and some have a complex set of causes.

The psychological changes that can occur with MS can be difficult to live with, for both the person with MS and his or her family. That said, mood changes are also among the most

easily treated aspects of MS, says Deborah Miller, PhD, a social worker at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic.

Depression and anxiety are some of the most common psychological changes. Less frequently, people with MS may have pseudobulbar affect (PBA), a condition that can produce uncontrollable laughing or crying spells that are out of proportion to or disconnected from what people are feeling. And, some people with MS (the number is unknown) experience rapidly shifting moods.

“It’s so important to manage these emotional symptoms,” Dr. Miller says, “because this makes all the difference in how you manage the other symptoms.”

Rosalind Kalb, PhD, vice president of Clinical Care at the National MS Society, and a clinical psychologist, says this is an important point. “People who are very depressed or anxious find it much more difficult to participate actively in their own care.”

Today, treatment for most mood disorders uses a three-pronged approach. “It’s important to recognize that a combination of medication, talk therapy and exercise is most effective,” Dr. Miller says.

If you find yourself experiencing any of these issues, address them with a mental health professional early, so you can arrive at an effective course of treatment—and get on with living and enjoying your life.

Grief is natural

Many people with MS go through a period of grieving after diagnosis—because dealing with the loss of certain capabilities and the uncertainty about the future is a lot to have on anyone’s plate.

“When you’re a young person, starting a career, and your doctor tells you that you have this disease, there are going to be reactive factors,” says Dr. Barbara Giesser, the clinical director of the MS Program at UCLA. “There’s the loss-of-identity factor in the usual family role—perhaps as breadwinner, or caregiver to a child or to an elderly parent. Your self-image changes; some people may have trouble with their body image after an MS diagnosis.” And the unpredictable nature of the disease may be the hardest part to grapple with, she adds.

“Grieving is a normal, healthy process that people need to not squelch,” Dr. Miller stresses.

Many people find it beneficial to meet with a therapist who has experience in this area and who can help you work through grief, whenever it occurs over the course of the disease.

Often, people will grieve not just after diagnosis, but each time they experience significant changes in functional abilities or life roles, says Dr. Kalb. “It may happen over and over, with the ebb and flow of the disease,” she says. “These are losses, just like the loss of a loved one. You feel terribly sad at first, and it gradually lessens.”

The caveat to this, Dr. Miller says, is that in some people, the grieving process can go on for too long, and morph into something else—depression. If you find that you're still experiencing significant grief after six months, it should be addressed.

Shades of depression

Depression is one of the most prevalent mental health disorders in the general population, and for people with MS, it's even more common. Dr. Giesser says that about 50 percent of people who have MS will also experience a major depressive episode over their lifetimes. It can range from mild to severe and may occur as a reaction to the disease, or as a symptom of it.

Dr. Kalb points out that “individuals, family members and even healthcare providers often mistakenly assume that anyone with a chronic, unpredictable illness like MS would be depressed. In other words, they think it's ‘normal’ to feel that way, so it doesn't get reported and it doesn't get treated. This means that many people with MS are living with a lot more emotional pain than necessary—which can be as disabling as the physical aspects of the disease.”

But depression doesn't have to become a part of the MS experience—something Lauren Parrott, 29, of Harper Woods, Mich., discovered after she was diagnosed in 2002. She says depressed moods were triggered each time she became aware of something she could no longer do. “I cry because of my limitations,” she says. “I used to be an avid runner, but it's not possible for me anymore.” Parrott says she's learned that focusing on the things she can do, rather than dwelling on what she can't, helps to reduce her discouragement. “I've developed a passion for going on the elliptical trainer. It's a great cardio workout and I never trip and fall.” What's more, exercise is often a crucial component of managing depression and most other mood changes that occur in MS, Dr. Miller says.

The medical community agrees that it's common for feelings of depression to occur as new symptoms arise, but the causes are not fully understood. One theory is that the lesions that occur in MS may affect the parts of the brain involved in emotional regulation, such as the hippocampus—which is just what UCLA researcher Dr. Nancy Sicotte and her colleagues (including Dr. Giesser) found in research they published in the journal *Brain* in 2008.

“This suggests a structural basis for the depression that people with MS can often experience,” Dr. Giesser says. People who seemed unflappable before their MS diagnosis may be surprised when they experience depressive symptoms.

Elizabeth Pontillo, 31, of Oyster Bay, N.Y., says she began experiencing depressive symptoms before she was officially diagnosed with MS, and thinks that for her, it was associated with the disease. “I do experience definite mood changes—everything in my life seems to be fine, and then I'll bottom out. It seems like the underlying constant is my MS.”

Elizabeth Pontillo shares scenes from her life.

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But Pontillo says she's also experienced a depressed mood during difficult times in her life. "In my most recent round, I was in a job situation I wasn't happy with, and my husband was going through a major health crisis. It just seemed like nothing was easy." She's also become depressed after MS exacerbations. "I start on that downward spiral: 'What happens if it gets worse? What happens if it affects this body part?' One exacerbation affected my ability to focus one of my eyes; that's a problem because I'm a copy editor. I dealt with it, but worried, 'What if I do lose my vision? What if I can't drive?' To be relatively young and have to start thinking about it can be very upsetting."

The interferon-beta medications that are sometimes used to treat MS may be linked to a greater risk of depression, too, particularly for those who have a history of it. These medications include interferon beta-1b (Betaseron® or Extavia®) and interferon beta-1a (Avonex®). If you're on one of these treatments, it's very important to talk to your doctor about any psychological symptoms you're having, especially persistent feelings of sadness, hopelessness, worthlessness or a lack of interest in the activities that you previously enjoyed. It is also important to tell your doctor about past episodes of depression you or family members have had.

The depression toolkit

Dr. Kalb stresses that people shouldn't try to just tough it out, or otherwise let depressive symptoms go untreated or ignored. "The risk of suicide is higher among people with MS," she says, "and the biggest risk factor for suicidal thoughts and actions is untreated depression." Depression is highly responsive to treatment, and mental health professionals have a number of strategies available for treating it.

The word on psychotherapy

Some studies have shown that cognitive behavioral therapy (CBT), a form of talk therapy that helps people identify their negative thought processes and replace them with more positive ones, can be very effective in treating depressive symptoms in people with MS, according to Dr. Sarah Minden, a psychiatrist at Harvard Medical School. Other talk-based forms of psychotherapy are also effective. Psychotherapy in conjunction with antidepressant medication is generally much more effective than either one alone.

"I'm a firm believer in combined treatments, using multiple modalities," says Dr. Sarah Minden, a psychiatrist at Harvard Medical School who treats many people with MS. It's easy to take an antidepressant medication, she says, but it's essential to meet with a mental health professional at the same time to help you work through the feelings you're experiencing. "There are times that are extremely stressful and burdensome to people—diagnosis, relapse, using a cane for the first time, or considering a wheelchair. I really urge people to have someone to talk to." Pontillo has sought treatment—a combination of medications and psychotherapy—each time depressive symptoms showed up for her. Pontillo's therapist taught her how to reframe her thoughts.

"I tend to be very hard on myself and hold myself to standards that no one else ever would," she says. "My therapist helped me see that if I wasn't doing everything 100 percent the way I thought I should, it wasn't the end of the world. In the last year I've learned to give myself a lot more breaks than I used to, and that's done a lot to help me deal with everyday life, and life with an unpredictable disease."

Parrott, too, says reframing her attitude about her limitations helped her cope with the psychological challenges they brought, but she adds that talking to people with MS who are similar to you in age or in personal experiences can also be therapeutic. She was diagnosed right before she went off to college, at age 18, and says hiding it from people rather than reaching out made it worse. "I would definitely talk to someone who has MS already, someone who's similar to you in some way," she says. Parrott recommends joining local support groups, where you can openly discuss the emotional or psychological changes you're experiencing (call an MS Navigator at 1-800-344-4867 to find out what's available near you) or find others with MS facing similar challenges. The Society's online community, [MSconnection.org](https://www.msconnection.org) and its telephone-based support program, MS Friends, are good places to start.

High anxiety

Studies have found that more than 35 percent of people with MS have some type of anxiety disorder, which is higher than the general population. Within this 35 percent, the majority of people have generalized anxiety disorder, though obsessive-compulsive disorder and panic disorder are also well represented. Women are more likely to have anxiety than men; the same is true for depressed mood. Pontillo experienced anxiety along with her depression.

"I was having a lot of panic attacks. One part of my brain was like, 'You're in danger,' and another was telling me to stop freaking out." Like other psychological issues, anxiety can be treated in a number of ways, which will vary from person to person.

Many antidepressant medications effectively treat both depression and anxiety. Specific anti-anxiety medications can work well for short periods of time, but carry the risk of dependence. CBT and other forms of psychotherapy can be very effective for anxiety disorders. And yoga and meditation can help calm the nervous system and reduce activity in the parts of the brain that govern the stress response. Your doctor or mental health professional can help you

find the right combination of treatments for you.

Fickle feelings

Some people with MS may have swift and dramatic shifts in their moods, sometimes called emotional lability. “This is incredibly common,” says Dr. Miller, although no precise figures are available. For some people, this symptom shows up as an increased level of irritability. Other people may experience quick changes in temper, going from happy to angry or upbeat to sad, or almost any other combination. “It’s like when a person is covered with black-and-blue marks—everywhere you touch them, it hurts. Emotionally, they’re raw,” says Dr. Kalb.

Dr. Miller points out that while this kind of emotional lability often happens in response to outside events, it can also happen spontaneously without any apparent triggers. “That’s why family members often say they feel like they’re always walking on eggshells,” she says.

But the brain is complex, and many other psychiatric and medical conditions could lead to such mood symptoms, and the distinction among them can be difficult.

“Frequent and intense changes in mood need a thorough psychiatric evaluation,” says Dr. Minden, “to determine the cause and recommend treatment.”

Medications can also produce changes in mood. For example, high doses of corticosteroids, which may be prescribed to manage MS relapses or optic neuritis, have been associated with significant mood changes in some people. However, this phenomenon can usually be prevented by taking lithium along with the corticosteroid treatment,

Dr. Minden says. Be sure to discuss this with your physician, and to give a complete personal and family history of depressed mood, bipolar disorder and other mental conditions before taking corticosteroids.

Managing mood shifts

After you have a frank discussion with your doctor, he or she may refer you for a psychiatric evaluation to determine whether your symptoms are part of the course of MS, or caused by something else.

Once you understand what is happening and decide on a course of treatment, communicating with family and friends becomes key. That way, they won’t take any episodes of mood change personally, and may help you work through them.

“I recommend that the family talk together about how to manage these mood shifts in advance, when things are calm, and then follow that plan,” says Dr. Miller. In addition, psychotherapy and medication may help, as they do with other MS-related emotional changes. Your doctor can help determine the right approach for you.

PBA: A sea of emotion

When David Diehl, 57, of East Helena, Mont., began to display dramatic emotions that didn’t

match external events, his wife Arlene's radar went up—and this was before David had been diagnosed with MS. Arlene's father had lived with MS, and she had seen this phenomenon—pseudobulbar affect, or PBA—in him. PBA, which occurs in about 10 percent of people with MS (and in certain people with other types of neurological diseases or brain injuries), is a direct result of the changes in the brain.

PBA can exaggerate the emotion you're feeling, or there can be no relationship between your behavior—laughing or crying—and how you feel internally. The key is that the spells are uncontrollable, and can be alarming, both to the person experiencing them and to others.

Arlene was familiar with it, though. "My father would laugh and cry at strange times; we all knew it was part of the disease. I immediately recognized it in David, and very soon after, he was diagnosed with MS."

David says, "I experience it the most with laughing. For instance, when we went to a friend's funeral, someone told a mediocre joke—and I laughed through the whole funeral. I was so ashamed. And the joke wasn't that funny!" With the help of his wife and his physician, though, David eventually figured out what was going on.

Treatments for pseudobulbar affect initially included only antidepressants and levodopa (a medication more commonly used to treat Parkinson's disease), says Dr. Minden. In 2010, the FDA approved Nuedexta® as a medication for treating PBA. It's thought to work by affecting the centers of the brain that control emotion. David has started taking Nuedexta and says it's helped reduce his PBA significantly, and with almost no side effects. As with all medication decisions, you'll want to discuss the best treatment for you with your physician.

It's a family thing

No matter which emotional symptoms you may experience with your MS, remember that your family is part of it, too.

"Family counseling is incredibly important—both for education as well as therapeutically," says Dr. Miller. It can help family members understand that you may go through psychological changes that aren't necessarily "you."

This is essential, especially if you have young kids at home. The Diehls say that it was hard to explain the mood changes to their children, who were 9, 11, and 13 when David first had neurological symptoms.

"They just thought, 'Dad's being ornery,'" says Arlene. "Here, you have a physical disability, but put on top of it the ups and downs, and inappropriate emotional stuff—it can be hard. We all knew that it was not normal, not really who their dad was, but it was still disturbing to them." But talking about it, as a family, with their pastor helped them cope. "We explained that this is part of [what it means to have] the disease," she recalls.

Ultimately it paid off. Arlene says that now that the kids are grown up, they understand and

are very supportive. “Our daughter gave David a Father’s Day card last year,” says Arlene. “It said, ‘I know I put you through the wringer, but you were no piece of cake either!’ We can laugh because now we understand it.”

David’s final piece of advice is for people to really internalize that there’s a difference between them and their MS, especially when it comes to the emotional symptoms. When mood symptoms first pop up, he says, “You think it’s you. You think, ‘I’m angry about something; I need to overcome this.’ But you need to understand it’s not you, it’s [you having] the disease. And there are things you can do to mitigate the symptoms.”

Moving forward

If you’re newly diagnosed and experiencing emotional symptoms, or if you’ve had MS for a while and are experiencing psychological changes for the first time, they can be unnerving. But remember that you’re not alone; these symptoms are incredibly common with MS, and talking to others who are experiencing the same things can be very helpful. Finding a support group that lets you share your experiences with others, and listen to theirs, can feel really good. But if you don’t start to feel better quickly and completely, talk to your doctor and have a psychiatric evaluation. It is simply not “normal” to have persistent feelings of depression and anxiety.

Also keep in mind that you can tailor your treatments to your lifestyle. “Think about what’s going to work best with your life,” says Dr. Minden. Is your support-group or individual therapy meeting going to be accessible, and be a good fit for you? In a group therapy situation, if you have symptoms of urinary frequency, will it be convenient to step out? If you’re in individual therapy, how easy or difficult is it going to be to get to an office appointment?

There are many things to consider, but there are also plenty of effective options. The main thing is to not suffer in silence. “Let your healthcare provider know!” Dr. Giesser urges. “Mood disorders are almost always amenable to treatment—to medications, counseling, or better, to both.” And getting the treatment you need can make all the difference.

Alice G. Walton, PhD, is a New York-based health and science writer.

Have you experienced mood changes since your diagnosis? Share your experiences with others at [MSconnection.org](https://www.msconnection.org).

Learn more about [mood changes in MS](#).

Have you experienced emotional challenges since being diagnosed with MS? Take our [short survey](#).