

The hidden symptom



Depression strikes 1 in 2 people with MS, and it can be difficult to recognize. But there are ways to cope.

by Aviva Patz



Dave Rosen (right) finds that spending time with family helps with his depression. Photo

Courtesy of Dave Rosen

Within six months of being diagnosed with multiple sclerosis in 2016, Dave Rosen lost his job, financial security, his health insurance, his company car—and, most devastating, an outlet for his passion, which was managing a chain of motorcycle stores and building custom bikes for celebrities. When his symptoms—including memory loss, difficulty speaking, balance and vision issues, headaches and overall body pain—became too limiting, Rosen's wife, Staci, had to go back to work full time. "At that point, I understood what true depression really is," says Rosen, who relocated from Connecticut to Florida for personal and financial reasons. "Because of MS, I felt like I was no longer the same person. Life is already difficult enough, but adding these continuing limitations wasn't what I was prepared for."

Rosen's story is all too common in MS. While depression strikes 20 percent of the general population, it affects about 50 percent of people living with MS, according to Rosalind Kalb, PhD, a clinical psychologist and consultant for the National Multiple Sclerosis Society. "And if you consider the people who feel down and depressed but don't meet the criteria for clinical depression, that number is a lot higher," she says.

There are numerous causes of depression beyond the life challenges that are inevitable with MS. In fact, brain changes brought on by the disease play a huge role. "The key message is that depression is one of the most common symptoms of MS, and it's very treatable," Kalb says. Here's what you need to know.

What depression looks like

The cardinal criteria for depression is feeling sad, tearful, hopeless and irritable most of the day every day for at least two weeks, or experiencing loss of interest in favorite activities, Kalb explains. And certainly, some people with MS fit that classic picture.



Jane Welzant is open about her symptoms, such as loss of interest and anxiety. Photo

Courtesy of Jane Welzant

Jane Welzant, who was diagnosed with MS in 1995 at age 38, says she has “difficulty starting the day, loss of interest, loss of appetite, anxiety and fear of going anywhere.”

But according to Kalb, irritability may be more pronounced in people with MS. “People may seem very touchy or quick on the trigger,” she says. Feeling hyper-reactive is a main symptom for Sabrina A. Davis, of Houston, Texas, who has lived with MS for 22 years. “Without my antidepressant medication, I’m angry and emotional all the time,” she says.

How depression is diagnosed

It’s tricky to spot depression in MS because the symptoms of depression may overlap with symptoms of the disease itself. “If you look at the diagnostic criteria for depression, they start with fatigue—and that’s the most common symptom of MS,” says Boston-based psychiatrist and MS expert Sarah Minden, MD. “People think, ‘my thinking is slowed down, and I have trouble concentrating, but it’s from my MS.’ Same with trouble sleeping or sleeping too much—people often discount or deny the possibility of depression. It’s easy to say, ‘It’s the MS.’”

One way mental health professionals tell the difference is by considering timing and severity. Take fatigue, for example. “While everyone is different, for many people [MS-related] fatigue is worse in the afternoon when your battery wears down,” Dr. Minden says. “But the fatigue that comes with depression tends to be worse upon waking, so it is hard to get out of bed.”

She adds that fatigue with MS will often improve if you rest, take a nap, or “recharge your batteries,” but that the weariness of depression is more persistent.

Causes of depression

Depression in MS can be a reaction to challenges, as Rosen’s experience shows. “The adversity and disability itself can make people feel depressed,” says Anthony Feinstein, MBB, PhD, a professor of psychiatry at the University of Toronto and Sunnybrook Health Sciences Centre who studies causes of depression in MS. “There’s also the uncertainty—you can’t predict what your symptoms will be tomorrow, let alone in 20 years. The unknown can itself be a cause of depression,” Dr. Feinstein adds.

Imaging (such as MRI) studies show that depression can also come from biological brain changes that occur in MS. According to Dr. Feinstein, lesions in frontal and temporal parts of the brain are associated with clinically significant depression, as is brain atrophy (shrinkage) in these regions. “There’s good data to show that if there are these specific brain changes, the chances of developing depression increase significantly,” he says.



Feeling hyper-reactive is a main symptom for Sabrina A. Davis, of Houston, Texas, who has lived with MS for 22 years. Photo Courtesy of Sabrina A. Davis

A second biological trigger for depression may be inflammation, which comes with MS. Similarly high rates of depression occur with other neuroinflammatory diseases, such as rheumatoid arthritis and inflammatory bowel disease. “There’s something about the

inflammatory nature of the illness that may contribute to higher risk of depression,” Kalb says. There’s not much research on inflammation and depression in MS specifically, but according to Dr. Feinstein, it likely plays a role in depression.

A third possible cause of depression in MS is related to the stress hormone cortisol. A research team funded by the Society found, in a 2010 study reported in *Biological Psychiatry*, that depression is linked to loss of brain volume—specifically in the hippocampus, an area of the brain important for memory, and that this pattern of shrinkage is related to abnormal levels of cortisol. “Levels of cortisol obey a circadian rhythm—they’re higher in the morning when you wake you up and dip as the day progresses,” Dr. Feinstein explains. “One of the theories behind major depression is that the cortisol levels can remain persistently high or that the fall-off over the course of 24 hours somehow is less.”

According to the Society, depression can be a side effect of some medications, including corticosteroids such as methylprednisolone, prescribed to treat relapses, and interferon medications, disease-modifying therapies used to slow disease progression. Several DMTs, such as Avonex, Betaseron, Extavia and Pelgridy, come with a warning that people with a history of depression should be closely monitored while taking the medication.

When screening is most important

There are three situations most likely to trigger depression in MS: around the time of diagnosis—when people may be grieving and fear the worst about the future; after an exacerbation, when there’s renewed pain, discomfort and disability; and during a crisis point, when grief and losses are magnified. It’s also true that people with a personal or family history of major depression are more at risk, especially at these moments of heightened vulnerability. For those reasons, friends and family should watch for signs of depression.

Stigma against mental illness

Few people want to admit to having depression, and people with MS are no exception. Three main factors get in the way of a diagnosis. The first is the persistent stigma against mental illness, as if it’s a personal weakness or moral failure. When friends advised Ann Borsellino, diagnosed with MS at age 38, to seek help for depression, she responded, “Who me? A psychiatrist? I am NOT crazy.”

The second is the mistaken belief, Kalb says, that, “I have MS—why wouldn’t I be depressed?” But depression should never be accepted as “normal.” Many people with MS are not depressed, she adds, and dealing with MS is challenging enough without the added pain of depression.

Third, she says, people say “my body is betraying me, so I don’t want to think there’s also something going on with my mind. I’ve got enough problems with the physical stuff.” But depression is a known symptom of MS, and it must be addressed. “This isn’t about pulling yourself up by your bootstraps or being a tough cookie,” Kalb says. “It’s about getting treatment for a condition that won’t get better on its own.” Welzant is open about her

struggles with depression because she feels it's just like any other illness that needs to be treated.

"There is help out there," she says. "Professionals are not judging you. Actually who cares if they are? You can feel better, so why hide?"



Grant Gordon, shown with his sister Devin Tomiak, lived with depression and MS. Photo

Courtesy of Devin Tomiak

Risk of suicidal thoughts

Grant Gordon, 28, was a sociable guy with a "gazillion friends" and a "supportive, connected family," according to his sister, Devin Tomiak. He was a successful chef (a James Beard nominee), who had decided to open his own restaurant and had already secured investors. On the morning he took his life, four months after his diagnosis with MS, he'd opened a bank account for the business and had been on the phone with architects.

"I don't know why Grant committed suicide," Tomiak says. When he got his diagnosis, he told his family, but he didn't tell any of his friends. "That's a lot to hold inside."

With greater depression comes greater risk of suicide. "The rates of completed suicide appear to be double what they are in the general population," Dr. Feinstein confirms. Most at risk, he adds, are young males within the first five years of diagnosis—which highlights the fact that the primary risk factor for suicide may not be disability, as might be expected. Gordon, for example, just had a little numbness in his feet. "The major risk for suicide," Kalb

says, “is untreated depression.”

Signs of depression in MS

Depression varies by individual, but generally, it includes some combination of sadness, loss of enjoyment of life, changes in sleep and appetite, low self-esteem, fatigue, poor concentration, suicidal thoughts and feelings of hopelessness, according to Dr. Feinstein, plus a tendency to be irritable. Depression can also exacerbate MS symptoms, so you might also notice “every single MS issue feels worse—pain, sleep, or problems with thinking, concentration and memory,” Kalb says.

If you’re experiencing depression

Ask your healthcare provider for a referral to a mental health professional for a full evaluation or call an MS Navigator (1-800-344-4867) for help identifying mental health resources in your community. You can also do a free, private self-screening on the website of Mental Health America (mentalhealthamerica.net), a partner of the Society. Kalb recommends printing out your results and bringing them to your healthcare provider, saying “this is how I tested, what do you think we should do?”

Strategies for coping

Don’t keep it to yourself, Kalb urges. “This is not something you should try to manage on your own because it doesn’t work that way.”

Treatment may involve adjusting your DMTs, if necessary, and some combination of cognitive behavioral therapy (a type of talk therapy that examines and reprograms negative thought patterns) and antidepressant medication, because they may also help with MS symptoms such as sleep issues, pain and bladder control. If your depression stems mainly from the challenges of living with MS, consider joining a local MS support group—you can search by ZIP code on nationalMSSociety.org.

By talking about her brother, Tomiak hopes she might be able to help people living with MS who experience depression. Tomiak says that people with MS expect to have side effects and that “depression could be one of them. And that’s OK. It can just be part of the disease. There’s nothing shameful about it. The important thing is to get it treated. Don’t be afraid to take measures to ensure your safety.”

Although Ann Borsellino’s friends had to bribe her with beer to get her to see a psychologist, it eventually turned her life around. “If only someone had told me early on that depression was a symptom of MS, just like all the other ‘strange’ things that were happening, I would have sought treatment for it like I did for the numbness and tingling 19 years ago,” Borsellino wrote in a blog on MSconnection.org. “The ‘happy pill’ has helped me cope, not feel sad, and be part of what’s going on at work, with my family and special events.”

As for Dave Rosen, he’s appreciating that time at home taking care of his kids. He also practices yoga, meditates and prays. He consciously focuses not on limitations but on

possibilities. “My drive to help with depression is to find what moves me and follow that,” he says. “I find whatever thing helps get me through that minute and that day—a work project, an accomplishment for the day and, most important, staying engaged and connected with supportive people who help me stay positive and inspired.”

Aviva Patz is a writer in Montclair, New Jersey.

Find more information about [depression in MS](#).

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