

Steroids to Self-Help: **Active** **Responses** to an MS Attack



BY MARY ELIZABETH McNARY, MA, CRC

Illustrations by David Clark

How many MS attacks have people had since diagnosis? “Too many to count,” says one. “Lots!” cries another. “Very few in the first twenty years and then they started happening frequently.” “Haven’t had one in a while, but I’m always waiting.” “Just one, but that was **enough**.”

An MS “attack,” “exacerbation,” or “relapse” is formally described as “a sudden worsening of pre-existing symptoms, or the development of new neurological

symptoms, which lasts at least 24 hours,” in the Society’s “Sourcebook.” Most attacks last longer than 24 hours, and all can vary in severity. But they almost always begin suddenly. And they all cause anxiety and disruption.

Society literature explains that “recovery may be full or partial. There may be disease progression, or residual symptoms after an attack.” Which is another way to say that some symptoms go away completely, but others are permanent and still

others may linger and then disappear or become far less pronounced. It may be hard to tell what will happen in the first weeks or months after an attack. Recovery is a unique process for each individual. But it is not a passive process!

Science and art

What do people do to cope and speed their recovery? From steroids to self-help, to life planning, people find that getting better requires both art and science.

Michelle Manor-Newsome relies on science. "When something's going on, I call my doctor," she said. "Once she makes sure it's a real attack, I go into the hospital for Solu-medrol (an IV steroid medication, frequently prescribed for MS attacks). It works for me in 2–3 days."

Joni Bell, who was diagnosed twenty-nine years ago, reports two decades of successful steroid treatment. "I knew what to do. I'd do it, and be back to normal in six weeks," she said. "I retired in 2000 when the steroids stopped working. I didn't have an attack for five years after retirement, which probably speaks well of retirement," she laughed. "When I had my last attack, IV immunoglobulin eradicated all my symptoms fast."

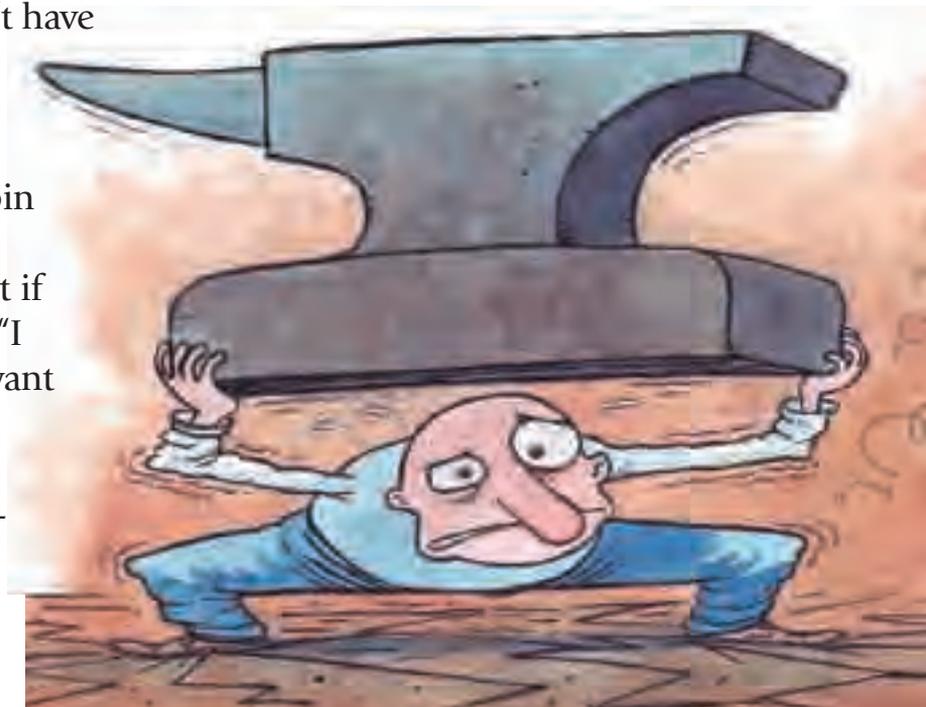
Over the years, Bell learned the art of getting back on track after flare-ups: "I refuse to awful-ize or be a victim. I want to be in good shape for the cure. I'm a car dealer's daughter who never walked anywhere until after my diagnosis. Now walking is one of the best things I do for myself. I stopped driving after five fender-benders, but I planned ahead and bought a

house close to public transportation and the supermarket. I intend to renovate so I can reside on the first floor if need be," she summed up, showing that she takes her own best advice: "Remain active and keep your sense of humor!"

Time to adapt

Nancy Kannell shares Joni Bell's penchant for planning. "We left our colonial home for a rambler," she said. "I'd been making my preschoolers brush their teeth before breakfast so I wouldn't have to climb back upstairs. The day we moved into the new house, I was giddy about being able to walk from my bedroom to the kitchen ten times if I wanted to!"

But some of her attacks have left their mark. "When I realized that the only way for me to go to Disney with my kids was if I used a scooter, I decided it would be selfish to miss out just because I was vain," she said. "Kids don't care how you participate, just that you do."



Lanka Karunaratne, who retired on disability from a fast-paced corporate job, described a similar mental victory. "When I realized that I couldn't get around without holding onto my boyfriend, I knew that I couldn't be too proud," she recalls. "I use a cane now when I need to. Sometimes I still want to push myself, but I know that I shouldn't. It's a constant struggle between my mind and my body."

Time to grieve

"Whenever people with MS experience attacks that leave them unable to do what they want to do, the way they want to do it, it's a significant loss," said Dr. Rosalind Kalb, who is director of the Society's Professional Resource Center, and a practicing psychologist who sees people with MS two days a week. She believes that taking the time to grieve over a loss is an essential first step toward figuring out how to tackle it.

"People have to let go of the way things used to be before they are able to problem-solve effectively for the future," Dr. Kalb said. "Healthy grieving is what allows people to regain their confidence. Then they can set new goals, and identify the resources and tools they need to help them reach those goals."

Time to rebuild

Michelle Manor-Newsome pointed out, "You don't have to decide a loss is permanent. Just manage it, whatever it is!"

That attitude is music to the ears of Marion Levine, MEd, CRC, Vocational Rehabilitation Coordinator at the National Rehabilitation Hospital (NRH) in Washington, DC, where Manor-Newsome

received professional rehabilitation.

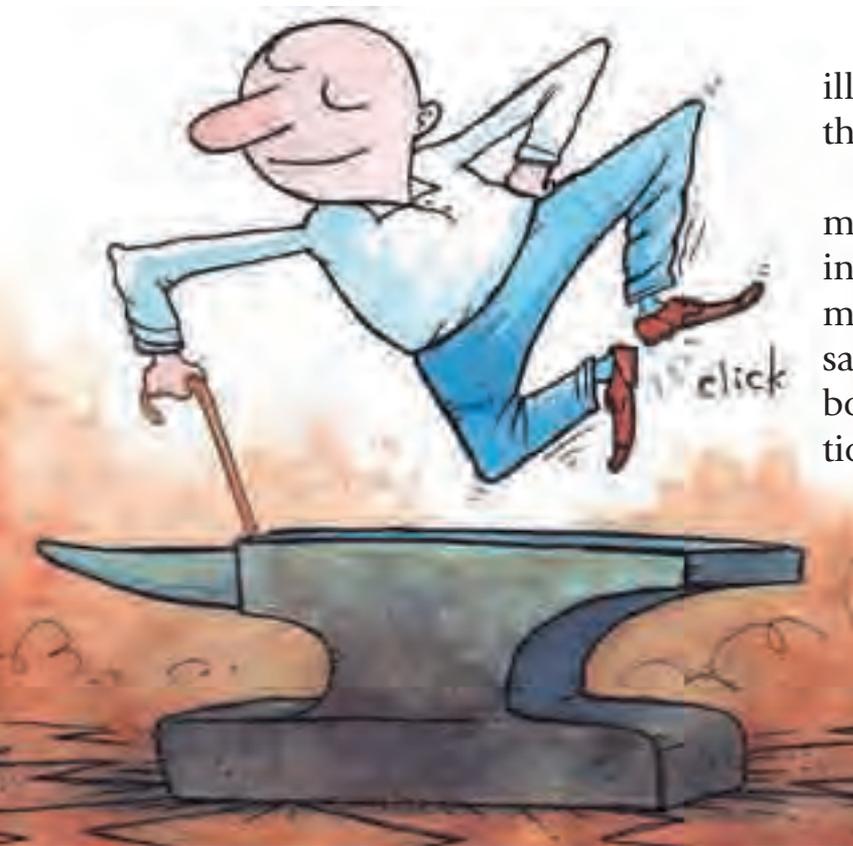
"NRH provides a multi-disciplinary, team approach to maximize independence and facilitate return to home, community, and work," Levine explained. "We try to help each person achieve the highest possible level of function and independence."

Team Rehab

Rebuilding involves a carefully planned program of exercise, training, activities, and sometimes the use of adaptations or devices to address specific needs. The needs can be physical, cognitive, job-related, or in any combination. Rebuilding happens by active planning and practice, with the help of a range of professional therapists and self-help activities, in any combination. People may create a rehab plan more or less on their own—using their doctor's referrals, their Society chapter, and community resources—or they may go to a comprehensive rehab center for assessment and care.

"I try things one way now, and if I can't do it, I try another way," Manor-Newsome said, describing the outcome of her NRH rehab program. "I learned lots of cheating devices that help me feel empowered." She's now on her way back to work, part time. "If that works out, it's more than just a paycheck; it's getting out, staying engaged, involved, and active," she concluded.

"When you don't regain all you had before, it's essential to find the new 'normal,'" said Nancy Kanell. "Winning the battle with MS is really a head game. MS is probably going to beat us in a physical battle. But our spirit is within our control. I feel I win every day that I don't let MS



illness. I feel lucky to be able to look at this as a blessing.”

Retired attorney Ronnie Hugh has a more pragmatic attitude. “When I’m having physical difficulties due to MS, I say to myself that I’ll accept what happens,” he said. “This isn’t easy for me but once my body relaxes, I have a recovery of functions in time—at least to some extent.

I’m lucky that this happens. I think a real element in this is giving up for awhile to allow physical healing.

“My volunteer work keeps me connected and it causes very little stress. There are no significant negative consequences if I can’t do something,” he concluded.

Clearly, the MS community has many ways to define recovery and a wealth of ideas about how to rebound after attacks. I listed some of the arts people use. Please help us add to the list. E-mail editor@nmss.org with your suggestions.

The self-help arts

- keeping a journal
- making or listening to music
- relaxation exercises
- meditation
- prayer
- gardening
- exercise program
- crafts (woodworking, knitting, pottery, decorating)
- cooking or baking
- creative writing
- painting or sculpture
- sewing
- reading
- yoga
- qui gung
- tai chi
- thanking your helpers
- helping someone else ■

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keep me from enjoying the people and activities that I love.”

Lanka Karunaratne is now working as a volunteer for her Society chapter: “Being naturally ambitious and driven, it’s been difficult at times. I realize, however, that I have a greater purpose. I realize that I was put on this earth to help others with this

Science resources

- Contact your chapter for referrals to area rehab professionals.
- Your physician (or insurance company) may want to review “Rehabilitation: Recommendations for Persons with Multiple Sclerosis”—an expert opinion paper issued by our Medical Advisory Board in 2004. See nationalmssociety.org/ExpertOpinionPapers or ask your chapter for a copy.