

# Life With

# Multi-

There is no cure, but a holistic approach helps MS patients cope with an array of physical and cognitive symptoms.

By **Kyla Dunn**

Photographs By Ethan Hill

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PATIENT: **RONALD THOMPSON** ▲

Ronald was diagnosed with MS in 2002. Determined to enjoy life and always a night person, he still enjoys an active social life.

# Andrea and Ronald

**Thompson—a mother and son—share an apartment, half their genetic code, and a diagnosis of multiple sclerosis. Their experience of the disease, however, could not be more different.**

“Like day and night,” Andrea, 55, says. “It’s mind-boggling,” agrees Ron, 30. Diagnosed almost a decade ago, Andrea still finds her symptoms manageable: some cramping in her legs, some numbness and pins-and-needles sensations in her hands, and a little vertigo. She walks everywhere from their home in Manhattan, including across the Brooklyn Bridge to work and a hundred blocks north to Harlem to visit her parents. Ron, on the other hand, was confined to a wheelchair within three years of his diagnosis at age 24. Andrea’s type of MS is known as “relapsing-remitting,” characterized by flare-ups of symptoms that subside within a few months. Ron’s MS is “relapsing-progressive,” with each exacerbation moving him another notch toward disability.

This bewildering variation is typical of MS, a chronic autoimmune disease that gives each patient an unpredictable cluster of symptoms. As many as 400,000 Americans have the disease, according to the National MS Society, and an estimated 10,000 new cases are diagnosed each year. At the MS Comprehensive Care Center, part of the NYU Hospital for Joint Diseases, a team directed by Joseph Herbert, M.D., helps patients cope with the wide range of deficits that can result. The center takes a holistic approach, bringing together neurologists, nurses, psychologists, social workers, occupational and physical therapists all in one place. In addition to classes in Fall Prevention and Strength and Balance, it offers an innovative Cognitive Rehabilitation program, even Clutter Management for those who have lost the ability to organize and plan effectively. At its Open Clinic seminars, patients learn about the latest MS research, as well as potential treatments, and the center is involved in clinical trials of new drugs.

Each MS symptom stems from an inflammatory lesion in the brain or spinal cord—areas where the patient’s own immune cells mistakenly attack nerve cells responsible for sensation, move-

ment, or thought. The attack strips away portions of myelin, the protective sheath that normally surrounds each nerve fiber and thereby allows it to conduct electrical signals smoothly. “The way the doctors explain it to me is this,” says Andrea. “You have a wire—” She picks up an electrical cord from her living room floor and taps its plastic coating. “This is your myelin sheath. Underneath you have the copper. That’s your nerve cell. What’s happening with MS is that the outside of the cord gets frayed.” MS is typically disabling rather than fatal, although in severe cases life-threatening complications such as breathing difficulties or aspiration pneumonia can occur. At the moment, there is no cure—only drugs that may slow the appearance of new lesions.

Inflammation of Andrea’s optic nerves led to her diagnosis in 1999. At the time, she was the head teller at a bank and kept track of its cash. “This particular morning I looked at the ledger, and I couldn’t see the numbers. All the numbers were doubled,” she says. She had lost her depth perception, and was seeing spots. “I started crying,” she recalls. “I said, I’ve got to go to the doctor because something’s wrong.” Treatment with IV steroids reduced the inflammation and restored some of her vision within weeks, yet continuing problems with her eyesight kept Andrea from returning to work for a year.

Then in August of 2002, Ron was diagnosed. “I used to be a skateboarder, snowboarder, rollerblader, mountain biker,” he says. He had begun to trip unexpectedly, over nothing, and Andrea had noticed a change in his gait. “If you didn’t know my son and you saw him walking in the street, you would have thought he was drunk,” she says. When Ron’s legs were too weak and uncoordinated to let him rollerblade, and his feet could no longer sense the cracks in the sidewalk, they started going to doctors. A year later, Ron was still “furniture walking” at home—leaning heavily on a couch or table

to get from place to place. “Then he kept having exacerbations,” Andrea says, “and it just progressed to the point where he couldn’t walk.” African Americans, like the Thompsons, are more likely to have a genetic variant that puts them at risk for severe MS. “They tend to be diagnosed a few years earlier, and the disease is more aggressive,” Dr. Herbert explains. In response, the center is currently developing more-aggressive treatment approaches.

Ron is determined to make the best of it. “A lot of people, when something like this happens to them, they automatically shut down—like, oh, just because I can’t walk I can’t go anywhere. People are going to look at me,” he says. “So what? Let them look at you!” Always a night person, he still goes out to bars and clubs. “I tease him, and his friends tease him,” Andrea says. “They tell me Ron is like a babe magnet with this wheelchair. Girls are always jumping on his lap.” Ron laughs. “Yeah, that’s true. They feel bad for me, but at the same time they want to dance. And if I’m at the club, I’m going to get down and dance!”

There’s no denying the logistical inconveniences, however. Ron’s wheelchair won’t fit through their apartment’s bathroom door. “We got an estimate for how much it would cost to widen the doors and to do everything that has to be done,” Andrea says. “It was a little under \$25,000.” It is difficult to juggle her part-time work as a secretary, multiple doctors’ appointments, and caring for Ron. After a 14-hour double shift, she says, “I’m tired.” Yet she still needs to help Ron transfer from one place to the other—to go to the bathroom, to get dressed, to get into bed. “I have to tell myself: Don’t get angry; we don’t have a home health aide at midnight.”

Frequent injections are another unpleasant reality of MS. Before settling on his current MS drug, Tysabri, Ron tried almost every one of the ABCR drugs (Avonex, Betaseron, Copaxone, and Rebif) in use since the 1990s. Each modulates the immune system, in the hope of making



◀ **JOSEPH HERBERT, M.D.** Dr. Herbert directs the MS Comprehensive Care Center at the NYU Hospital for Joint Diseases.

MS flare-ups less frequent and less severe, and is injected somewhere between once a week and every day. The weekly Avonex injection needs to be given into a muscle, through a needle that is one and a quarter inches long. “I had to sit there and psyche myself up, ice my leg for 20 minutes or half an hour,” Ron says. “Both me and my mother hate needles.” Andrea hates them enough, in fact, to stretch her injections out to once every two or even three weeks, against doctor’s orders. Avonex also produces a day of debilitating flu-like symptoms: fever, chills, sweating, muscle aches, and fatigue.

Despite the downside, says Lisa Laing, B.S.N., a certified MS nurse, certified rehab nurse, and the center’s clinical coordinator, the injectable drugs were a major advance. Prior to the 1990s, there were no drugs available to slow progression of the disease. “Twenty, thirty years ago, if a patient was diagnosed with MS, there was this saying that a lot of doctors used: ‘diagnose and adios,’” she says. “Those medications slowed down the disease progression by approximately 30 to 35 percent.” Introduction of once-a-month Tysabri in 2004 was another major milestone. “It’s really almost twice as effective

as any of those injectable medications,” she says. “It reduces the number of flare-ups by 67 percent compared to placebo.” The medications do not work for every patient. But with Tysabri, Ron seems to have found a better treatment.

“There are a lot of other things that can go wrong, but so far we’re holding our own,” Andrea says, pausing to knock on wood. “It’s been two years since Ron’s had an exacerbation.”

**Not all symptoms of MS** involve movement and sensation. Approximately half of patients experience cognitive symptoms. “My memory is horrible,” says Evelyn Lebrón, 35, who was diagnosed in 1996. “You tell me something now, then ask me in two minutes—” She swipes a hand in front of her forehead as if cleaning a slate. “No recollection whatsoever.”

Late in 2007, things reached crisis proportions at her job with a process server. “I would be billing the wrong attorneys and sending the wrong papers to the wrong courts,” she recalls. One day, she had to ask her boss to explain something to her four separate times—even though she took notes (which she could not decipher later) and listened attentively. Evelyn went on disability for almost two months at the beginning of this year, during which she entered the MS Care Center’s six-week cognitive training program, which is designed by staff psychologist Joshua Bacon, Ph.D., adjunct associate professor of neurology, and Tamar Fromm, who is the center’s director of rehab services/senior clinical research coordinator, and a licensed occupational therapist and

certified clinical research coordinator. The program is intended to strengthen memory, problem solving, and concentration. "I did see an improvement," Evelyn says. "My memory still acts up, but I've learned to jot everything down. I have Post-it notes all over. I've cut down a lot on my mistakes."

People with MS are generally comfortable asking for this type of help, yet other symptoms of MS are so sensitive that patients hesitate to talk about them. "Sexual dysfunction is a common early symptom," explains Dr. Herbert, associate professor of neurology. This can involve decreased libido, erectile dysfunction in men, and genital numbness or lack of sensitivity in women. The list of uncomfortable topics doesn't end there.

"My biggest problem," Evelyn begins, then pauses for a long time, "is not having control of when I need to go to the ladies room." She finds bladder control fairly manageable; she simply goes every 45 minutes as a precaution. "But with the bowel," she says, "sometimes I have no control."

The embarrassment caused by these accidents can be profound. "I remember that happened when I first started dating my husband five years ago," she recalls. "All of a sudden I kind of shut down, and he was wondering what happened." She later mustered the courage to explain by phone: "I figured, if he wants to get the hell out, hey, it's better now than down the road." A lot of men had shied away once they learned about her illness. James was different. He told her there was nothing to be embarrassed about, and even invented a code word so she could let him know, discreetly, when an accident occurred. "Everyone has their guardian angel," she says. "He's definitely mine."

Social isolation can become a real problem for people with MS, says Fromm, who directs the occupational therapy program at the MS Care Center. "Some people retreat in their homes as their symptoms worsen," she explains. Depression is also common and may be a direct biological consequence of the disease. "We try to break the psychological paralysis and get them back out, enjoying what the city has to offer." Part of the center's holistic approach, these opportunities include trips to the Metropolitan Museum, Broadway shows, and "wellness" days of massage, yoga, and makeovers. Evelyn knows how valuable it can be to meet other people with MS. She met one dear friend through a telephone support group. "It's cool because I'm not embarrassed to talk to her about anything," she says. "Like, 'Are you having problems with your sex drive?'"

For Evelyn, the MS Care Center has been a "godsend." She says, "They have a very nurturing hand, Dr. Herbert has seen me when I've been at my wits' end, crying

hysterically and in pain. You have to find a doctor who is willing to listen to you and do something to comfort you." She adds, "I now tell everyone: MS Care Center. You have to go there. Don't worry, they'll take care of you."

**While treatment may** be holistic, life for people with MS is often partitioned into two domains: one containing people who know about the diagnosis, and one containing people who don't. Outside of work, Alan Buckwalter, 44, is vocal about his MS and serves as a peer counselor. Yet he chooses to keep it quiet at the office. As a self-described Type A, working in the highly-competitive world of financial services, he says, "I don't want people to think I'm making excuses." He wears a red MS Society bracelet on one wrist under his business suit but says his colleagues don't have to know why.

**The fact that many of Alan's** symptoms are invisible does afford a certain amount of privacy. "I'm sort of the poster child, if you will," he says. "You'd never know if you saw me walking down the street that I had this horrible, horrible disease." During one exacerbation he lost feeling in the entire left side of his body, from the neck down, and still has no sensation in his left arm from fingertips to elbow. "You know when you sleep on your arm—and wake up with no feeling? Mine is like that 24 hours a day." He once ran his thumb over his moving table saw, and had to get ten stitches. "The nurses in the ER were wondering why I wasn't screaming," he says. There's also the profound fatigue that often comes with MS. "I don't want it to slow me down, but it does," Alan, a father of two, admits. "My sons hate it. They always want to play more."

Some exacerbations can be disconcertingly visible. For a couple of months, Alan had facial myokymia—a rapid pulsing of the muscles in his cheek. "Too much caffeine this morning" he would joke to people who stared. Part of MS is learning to live with uncertainty, since such exacerbations can occur at any time. Reacting promptly is key, Alan explains. "You have to get the inflammation down" in order to reduce long-term nerve damage.

Most effective is to prevent exacerba-

**"We try to break the psychological paralysis and get patients back out, enjoying what the city has to offer,"**  
says occupational therapist  
**Tamar Fromm.**

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PATIENT:  
► EVELYN LEBRÓN

Evelyn was diagnosed with MS in 1996. A program at the MS Comprehensive Care Center has helped her improve her memory and concentration.

tions from happening at all, and Alan has had enormous success with drug therapy. Diagnosed with relapsing-remitting MS in 1995, at age 31, he first began treatment with Avonex. But when a promising new drug, now called Tysabri, entered Phase III clinical trials in 2002, Alan signed up through the MS Care Center. "Somebody did the Avonex trial for me," he reasoned, "so I'm going to do this one." During the subsequent three years, while he was on Tysabri—a monoclonal antibody that blocks immune cells from entering the brain—not a single new lesion appeared on his MRIs. "I was in remission the entire time. No exacerbations," he says. And Tysabri is typically administered by IV just once a month.

Alan realized how well the drug had worked for him in 2005 when the FDA abruptly pulled it from the market after two patients in a clinical trial died of a rare brain infection. After four months without Tysabri, Alan suffered two exacerbations back-to-back, each involving severe vertigo. "I had a hard time standing. I went to my older son's birthday party looking like I was drunk," he recalls. The FDA has put Tysabri back on the market—with a black box warning and restricted distribution—in response to the outcry from MS patients and their doctors. Alan has had no exacerbations and no new lesions since resuming treatment. Recurring pneumonia, though, has been a dangerous side effect, leaving Alan with permanent damage to his right lung. "Knowing the signs and symptoms," he says, "we can now catch it early." In July 2008 the drug's manufacturers reported two new cases of brain infection. For Alan, these are risks worth taking to keep his MS under control. "Knock wood. I say it every day: I'm such a lucky person," he says. For all MS patients, Dr. Herbert sees ample reason for hope: "There are some real blockbuster drugs coming down the pike," he says. Several oral drugs are currently being tested in clinical trials, as well as an IV infusion that is given just once a year.

Perhaps even Alan's drug hiatus was valuable in its own way: That summer, his seven-year-old son played bedside nurse, hooking up his father's IV steroids each day and going with him to appointments at the MS Care Center. "I don't want him to be afraid," Alan says. "I want him to understand Daddy's dealing with it." ●

