

# Sitting Tall

In spite of transverse myelitis, Hollywood Writer Allen Rucker has the best seat in the house.

BY ALISON DALE

**O**n an ordinary Tuesday afternoon 15 years ago, Allen Rucker had a scratchy throat and felt like he was coming down with the flu. He was a 51-year-old Hollywood writer with a wife, two kids, and a mortgage. About 90 minutes later, he was paralyzed from the waist down with no control over his legs, bladder, or bowel. What he didn't know then was that the paralysis was permanent. He would never walk again and would need a wheelchair for the rest of his life.

The diagnosis was transverse myelitis (TM), a rare neurologic disorder caused by inflammation across both sides of one segment of the spinal cord. Researchers are uncertain of the exact causes of TM. The inflammation may result from viral infections or abnormal immune reactions. Some scientists suggest that TM is an autoimmune disease. In autoimmune diseases, the immune system—which normally protects the body from foreign organisms—mistakenly attacks the body's own tissues, causing inflammation and, in some cases, damage to myelin (the protective covering of nerve fibers) within the spinal cord. (See box, "Transverse Myelitis: The Basics.")

Researchers at Johns Hopkins are studying the relationship between TM and multiple sclerosis (MS), another inflammatory disorder of the central nervous system that has no known cause or cure. One drug that was originally developed for the treatment of MS—dalfampridine (Ampyra)—has also proven effective in the treatment of TM, according to Michael Levy, M.D., Ph.D., assistant professor of neurology and medical director of general neurology at Johns Hopkins University.

However, TM usually occurs just once and involves only the spinal cord, while MS always occurs



**HE GETS AROUND**  
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You no longer mourn the past or fear the future.  
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multiple times and involves the brain, optic nerves, and spinal cord. All disability in TM can be attributed to one lesion in the spinal cord, whereas in MS, disability relates to the number and location of many lesions.

### TREATMENT AND RECOVERY

For most, TM often involves paralysis as well as bladder and bowel dysfunction. Treatments are designed to reduce spinal cord inflammation and manage and alleviate symptoms. Physicians often prescribe anti-inflammatory corticosteroid therapy soon after the diagnosis is made in order to decrease inflammation and improve the chances and speed of neurologic recovery.

Patients with permanent physical disabilities might also consult with a range of rehabilitation specialists such as physiatrists (physicians specializing in rehabilitation), physical therapists, occupational therapists, vocational therapists, and mental health care professionals.

According to experts, one third of TM patients recover very well from the initial onset attack: They regain the ability to walk normally and experience minimal urinary or bowel effects. An-

other one-third show only fair recovery and are left with significant deficits such as spastic gait, sensory alterations, and urinary urgency or incontinence. The final third show no recovery at all and remain wheelchair-bound or bedridden and are dependent on others for the basic functions of daily living.

Rucker was in the last group. “In the final third of patients, nothing happens—there is no reversal, no return of function, no wiggling of the big toe, nothing,” he says. In 15 years, he has never shown any signs of recovery.

However, while the common one-third/one-third/one-third model is based on observing hundreds of TM patients, “We’re in the process of trying to develop hard evidence to say what percent of TM patients recover and what percent don’t,” Dr. Levy says.

### RESEARCH

Advances have been made in the treatment of TM since Rucker contracted it 15 years ago, says Sandy Siegel, president of The Transverse Myelitis Association ([myelitis.org](http://myelitis.org)). “There are definitely more options now than they had in the past,” says Siegel optimistically.

## Transverse Myelitis: The Basics

**SYMPTOMS:** The symptoms of transverse myelitis (TM) include a loss of spinal cord function over several hours to several weeks. What usually begins as a sudden onset of lower back pain, muscle weakness, or abnormal sensations in the toes and feet can rapidly progress to more severe symptoms, including paralysis, urinary retention, and loss of bladder control. Although some patients recover from TM with minor or no residual problems, others suffer permanent impairments.

**WHO GETS IT:** Transverse myelitis can occur in adults and children, in both genders, and in all races. It is estimated that about 1,400 new cases of TM are diagnosed each year in the United States, and approximately 33,000 people have some type of disability resulting from the disorder.

**CAUSES:** Researchers are uncertain of the exact causes of TM. The inflammation may result from viral infections or abnormal immune reactions. Another theory is that TM occurs as a complication of syphilis, measles, Lyme disease, and some vaccinations, including those for chicken pox and rabies.

Some scientists suggest that TM is an autoimmune disease. In autoimmune diseases, the immune system, which normally protects the body from foreign organisms, mistakenly attacks the body’s own tissues, causing inflammation and, in some cases, damage to myelin (the protective covering of nerve fibers) within the spinal cord.

**TREATMENT:** As with many disorders of the spinal cord, no effective cure currently exists for people with TM. Treatments are designed to reduce spinal cord inflammation and manage and alleviate symptoms. Physicians often prescribe anti-inflammatory corticosteroid therapy soon after the diagnosis is made in order to decrease inflammation and hopefully improve the chances and speed of recovery. Several new treatments are on the horizon.

Recovery from TM usually begins within 2 to 12 weeks of the onset of symptoms and may continue for up to 2 years. However, if there is no improvement within the first 3 to 6 months, significant recovery is unlikely.

Source: National Institute of Neurological Disorders and Stroke ([ninds.org](http://ninds.org))

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Dr. Levy says that if diagnosed today, Rucker might have recovered more fully. He would have been treated much more aggressively than in the past and had more choices for treatment, including steroids, plasma exchange, and some forms of chemotherapy, he says. The American Academy of Neurology (AAN) recently published a guideline on plasma exchange that concluded further study on its effectiveness in TM is needed. To read the guideline, go to [aan.com/globals/axon/assets/8132.pdf](http://aan.com/globals/axon/assets/8132.pdf).

“The majority of our patients are seeing significant recoveries,” says Benjamin Greenberg, M.D., M.H.Sc., director of the Transverse Myelitis and Neuromyelitis Optica Program at the UT Southwestern Medical Center at Dallas.

A number of experimental treatments are being investigated as well. For example, scientists are searching for “neuroprotective” drugs, which protect neurons from the inflammation caused by TM. “The idea is that even though the immune system is going in and causing problems, there would be a little force field around the neurons,” Dr. Greenberg explains. “But there has yet to be a drug proven to have neuroprotective capabilities. We’re still searching.”

Dr. Greenberg is also excited by the stem cell research of Steven Goldman, M.D., Ph.D., the Edward and Alma Vollertsen Rykenboer Professor and Chairman of the Department of Neurology at the University of Rochester. Dr. Goldman is investigating the ability of stem cells to repair myelin. Dr. Greenberg, who says Dr. Goldman’s work is cutting edge, explains the two aspects of this process. One is the delivery of the cell to the injured area; the other is the safety of the cells once they get to an injured area.

“When you put stem cells into the human brain or spinal cord to grow new myelin, you really only want new myelin, you don’t want the stem cells to grow a tooth, or a heart, or bone,” says Dr. Greenberg. His opinion is that Dr. Goldman’s experiments in mice have been very successful. Human trials are not happening yet but are on the horizon.

## WRITING IT OUT

Rucker began taking notes on his experience just days after he was paralyzed. Writing—one of the few activities he could still manage physically—provided a some respite from his grief. Of his time in the hospital, he jokes, “Staying in the hospital

puts you in the present. You no longer mourn the past or fear the future. You only fear lunch.”

Rucker had already been a successful, award-winning TV writer of network specials, awards shows, and documentaries, including “Christopher Reeve: A Celebration of Hope” for ABC, the “Family Values: The Mob and The Movies” for TNT, and “Big Guns Talk,” a TNT documentary about the history of the Western, for which he won a CableAce award. He had also written several books of nonfiction and humor, such as *The History of White People in America* (with Martin Mull) and *Hollywood Causes Cancer: The Tom Green Story* (with Tom Green).

Rucker continued to find salvation in writing—as well as success—even after his paralysis. As a Hollywood veteran, he had developed an arsenal of professional survival skills that he applied to his new challenges. “My solution with regard to my own career has been a simple, time-tested technique: Dance. Stay fluid. Reinvent yourself. Go where you’re wanted, not second-guessed or resented.”

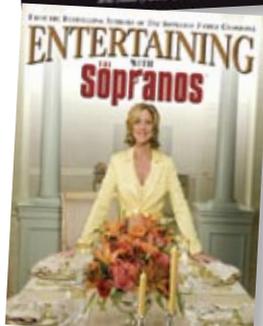
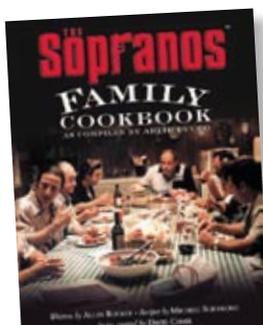
One person who never second-guessed Rucker was his buddy from film school: David Chase, creator of *The Sopranos*. Chase hired Rucker to write *The Sopranos Family Cookbook*. The book became a huge hit and led to two others based on the HBO series, *Entertaining with the Sopranos* and *The Sopranos: A Family History*.

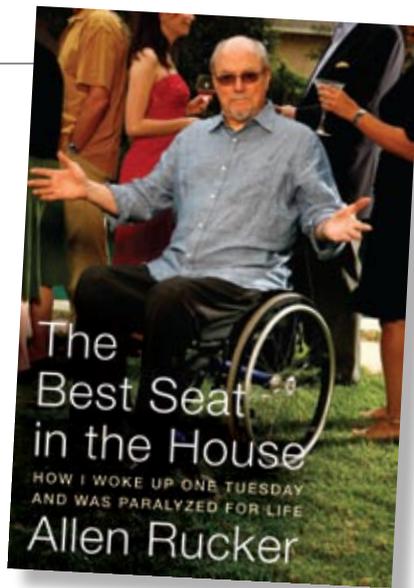
Not everyone was such a stand-up guy. “The truth is I have never been hired in television since I’ve been paralyzed by anyone I didn’t already know before I was paralyzed. And I have not been hired by a lot of people I *did* know before I was paralyzed,” Rucker says.

Rucker’s latest book, *The Best Seat in the House*, (HarperCollins Publishers, 2007, available on [amazon.com](http://amazon.com)) is the story of his journey into the world of permanent paralysis. He’s completely frank about his struggles and shares what he’s learned, even about practical matters such as the dangers of skin breakage, and often with humor. “Paralytics need to shift body position every two hours to avoid the dreaded bed sore,” he says. “It took me years to get used to setting an alarm and turning like a rotisserie chicken three or four times a night.”

But Rucker says he wrote the book as much for people who aren’t disabled as those who are. “I was trying to tell about the journey knowing there are a lot of people out there who are afraid

**“FAMILY” FRIENDS**  
Rucker has made a second career out of books based on friend David Chase’s *Sopranos* TV series.





### ALSO FOR THE ABLED

“A lot of people out there are afraid of becoming disabled,” says Rucker. “I’m saying it’s no walk in the park, but you can survive it.”

of becoming disabled or are afraid of becoming sick, and I’m saying it’s no walk in the park, but you can survive it,” Rucker says. He has received hundreds of letters, about half from family members of TM patients, who now have a new understanding of their loved one’s situation.

Even his neurologist gained a new appreciation of the patient perspective. “I never really knew what it was like to be in your position,” said Daniel Rovner, M.D., Rucker’s neurologist at Cedars-Sinai in Los Angeles, CA.

### CHANGING HIS TUNE, STRIKING A CHORD

Rucker’s illness caused marital difficulties. For a while after he became paralyzed, he and his wife lived on separate floors of their two-story house, each crying their eyes out in private.

“If we had been married three years instead of 30, or if we had crossed the line of mutual recrimination a few more times, one of us surely would have left the other,” Rucker recalls. However, they eventually learned how to cope with the upheaval that TM had caused. “What we did is focus on practicalities—paying the bills, taking care of grandma (who lived with us), and getting the kids going to school. It really helped us get through. But it’s a long process. It took a good year or two.”

Today his marriage is “very, very solid. She still drives me crazy, and I do as good a job as possible to drive her crazy,” Rucker jokes. But the couple recently celebrated their 44th wedding anniversary.

It also took years for Rucker to achieve a greater sense of compassion and wisdom for himself and other people with disabilities. “When I first became disabled, the last people I wanted to hang around with were other disabled people,” Rucker says. “I didn’t want to think of myself as disabled. But the older I get, I don’t see them as my ‘minority’—I just see them as whoever they are. Now I don’t think of ‘the disabled’ as a category, I just think of them as individuals.”

Acceptance has meant letting go of other labels that can be tempting to someone who experiences a life-altering illness. “When you are no longer a hero and no longer a victim, what are you?” Rucker asks. “You’re damn close to normal, and it doesn’t get scarier than that.”

*The Best Seat in the House* received a glowing review in *The New York Times Sunday Book Review*. But the author says his biggest reward has been the outpouring of response from readers, especially those

who have disabilities. “The letters have been the best part of writing this book,” Rucker says. “I’m paralyzed for life. It bums you out every once in a while. But if I get down, I turn on my Web site and read one of the letters from readers, which snaps me right out

of it. Just to think that there’s someone out there who read this book and got a laugh out of it, that the book made them feel good, it gets you out of your head.”

### STILL THE BEST SEAT

Rucker was shocked to discover that some people who have TM don’t know others who have it or about the Transverse Myelitis Association. Luckily, his book and his Web site are helping put an end to that.

Currently working on *The Cripple Chronicles*, the sequel to *The Best Seat in the House*, Rucker’s energy and output are at full throttle. He writes a blog for the Christopher Reeve Web site and is a contributing editor for *New Mobility* magazine. He drives a car outfitted with hand controls, travels around the country for speaking engagements, is the chair of the Writers with Disabilities Committee at the Writers Guild of America West, and loves to fish in Wisconsin. For a man who can’t walk, he sure gets around. NN

## Transverse Myelitis Resources

- ▶ CNN Health: Transverse Myelitis  
[cnn.com/HEALTH/library/transverse-myelitis/DSoo854.html](http://cnn.com/HEALTH/library/transverse-myelitis/DSoo854.html)
- ▶ Transverse Myelitis Association  
[myelitis.org](http://myelitis.org) 614-766-1806
- ▶ Transverse Myelitis Center at Johns Hopkins  
[hopkinsmedicine.org/neurology\\_neurosurgery/specialty\\_areas/transverse\\_myelitis](http://hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/transverse_myelitis) 410-502-7099
- ▶ Transverse Myelitis and Neuromyelitis Optica Center  
UT Southwestern Medical Center at Dallas  
[utsouthwestern.edu/utsw/cda/dept14802/files/634444.html](http://utsouthwestern.edu/utsw/cda/dept14802/files/634444.html)  
214-645-8800
- ▶ The Transverse Myelitis Network: Online Community  
[transversemyelitis.ning.com](http://transversemyelitis.ning.com)
- ▶ TransverseMyelitis.net: A site created by individuals who have been diagnosed with transverse myelitis  
[transversemyelitis.net](http://transversemyelitis.net)