

Strange sensation



The MS hug can cause painful constrictions, but there are ways to ease the symptoms.

by Aviva Patz



Erika Richardson's experience with the MS hug twice put her in the emergency room. Her mother told the hospital staff about the possibility that the

intense chest pressure was from an MS hug.

Photo courtesy of Erika
Richardson

Erika Richardson, 47, of Green Cove Springs, Florida, twice experienced pain and pressure in her chest so extreme that emergency room doctors suspected she was having a heart attack. "They started administering baby aspirin, ordering nitroglycerin and running an electrocardiogram," says Richardson, who has had progressive multiple sclerosis since childhood. Her mother, who was acting as her care advocate, explained the possibility that the intense chest pressure and stabbing sensations between Richardson's ribs were actually from an "MS hug"-and proceeded to educate the bewildered hospital staff on what that is.

The MS hug, a type of pain associated with MS that goes by the medical term dysesthesia, feels different for each person. "Some people describe a boa constrictor-type squeezing that is almost constant. Other people describe a band of burning pain that comes and goes," explains Mary Alissa Willis, MD, associate program director of the Mellen Center for MS at the Cleveland Clinic. "The pressure can be so intense at times that taking a deep breath is difficult." And yet no actual tightening is taking place. Rather, the sensation is caused by lesions-or scarring from MS disease activity-affecting the sensory pathways in the spinal cord. The brain may respond to the signals with a mix of sensations that include tightening, tingling, burning, stabbing pain or an electric-shock-like feeling. It ranges from "annoying" to "very painful," and can last a few seconds or persist. Some people feel the sensations in their hands, their legs and feet, or around their head.

MS hug

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Not everyone with MS experiences the MS hug, but some 15 to 20 percent of people with MS report painful spasms, and 25 percent or more report dysesthesias, abnormal or unpleasant sensations, according to Dr. Willis. MS hugs may develop as a symptom of an MS relapse or flare-up and may be worsened by fatigue, heat, infection, stress or overexertion. There's no specific treatment, and people who experience it deal with it in a variety of ways.

How medication can help

No medications address the MS hug specifically, but because it's linked to hypersensitivity of damaged nerves, doctors may prescribe drugs that stabilize the irritated nerve membranes. Those include anti-convulsants like Neurontin, Trileptal and Lyrica.

A muscle relaxer, such as baclofen, also may be helpful, Dr. Willis says. An antidepressant such as Elavil, can help as well, as it modifies how the central nervous system reacts to pain. Some patients find relief with topical lidocaine. Traditional pain-relieving medications such as Ibuprofen, Tylenol and topical diclofenac, another non-steroidal anti-inflammatory drug (NSAID), don't work because they don't affect the nerves, Dr. Willis says.

Richardson, who has experienced MS hugs for 28 years, takes an anticonvulsant, muscle relaxer and Percocet, a prescription painkiller.



Caroline Kyriakou found relief through steroid treatment for an MS hug that lasted two weeks. Photo courtesy of Caroline Kyriakou

Caroline Kyriakou, 37, of Boston, received IV steroids to treat an MS hug that lasted two weeks—during the flare-up that led to her diagnosis in 2006, as well as during a relapse. “The steroids luckily helped decrease my symptoms,” she says.

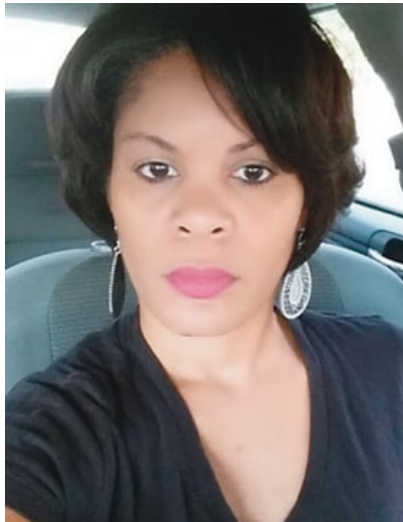
Different ways to cope

Medications work best when paired with other coping mechanisms, according to Heidi Maloni, PhD, national nursing clinical director of the Veterans Affairs, MS Centers of Excellence, at the VA Medical Center in Washington, D.C. “You might not be able to eradicate MS hugs altogether—you might need to live with a little bit of tightness,” she says. “Non-pharmacological treatments help with management and empower patients.”

Non-drug coping mechanisms:

- **Avoid triggers.** Ashley Ringstaff, 29, of Austin, Texas, tries to minimize stress and heat, and she avoids wearing anything constricting, which can trigger her MS hugs. “It

feels like I'm being squeezed in a bear hug from the inside out," she says. But she can't control weather change, which also sets off her MS hugs.



Keisha Kuma manages her MS hugs by staying calm and cool, lying in a quiet place and waiting for the sensations to pass. Photo courtesy of Keisha Kuma

Keisha Kuma, 45, who lives in Atlanta, isn't sure of her exact triggers but has noticed some patterns. "If I'm tired and keep pushing myself, especially in the heat, all my symptoms are more prevalent." Her MS hugs last 5 to 20 minutes. "It feels as if the Incredible Hulk is getting a mammoth from prehistoric times and placing it on my chest," she says.

- **Relaxation techniques.** Kuma, who experiences MS hugs about every other month, lies down in a cool, quiet place to wait for the feeling to pass. "It calms the body and focuses the mind away from the pain," Maloni explains. Richardson uses deep breathing techniques to relax. Kyriakou also tries to relax and not panic. "The MS hug is a very uncomfortable feeling, but stressing out will only make it worse," she says.
- **Managing clothing.** While tight clothing can be a trigger for some people, others find it actually helps ease MS hugs. One of Maloni's patients wears an abdominal brace. "It's the gate theory of pain," Maloni explains. "You close the gate on one type of pain and open the gate on a lesser sensation," in this case, pressure.



Minimize your exposure to stress and heat, advises Ashley Ringstaff (left), who also avoids wearing constricting clothes, which can trigger her MS hugs.

Photo courtesy of Ashely Ringstaff

- **Warm compresses.** Temperature sensations travel along the same nerve pathways as pain, so heat can tamp down pain. “When you have pain, there are chemicals that are released in the muscles-histamine (a compound involved in the body’s immune response) and prostaglandins (compounds that act like hormones),” Maloni explains. “Heat decreases the expression of both.” Richardson finds it helpful to wrap a heating pad around the affected area. Topical capsaicin, made from hot peppers, can also bring heat to the skin.
- **Exercise.** Walking, stretching, yoga, gentle swimming and other movement can help manage MS hugs. “When we have pain, signals coming into the body from the central nervous system, the pain is sensed, and our body modulates it with the neurotransmitters serotonin, adrenaline and endorphins,” Maloni says. “Exercise is pain modulation” in that it stimulates those same neurotransmitters. It’s also a distraction, she adds.
- **Nutrition.** Certain minerals are known to reduce muscle spasms and may help with MS hugs. In a blog on Multiple Sclerosis News Today, Judy Lynn writes that after testing her mineral levels, a naturopath suggested potassium, calcium and magnesium supplements to ease her MS hugs.
- **Meditation.** You can train your brain to interpret something bad as something good, or at least neutral, so you might try to see the sensation of pressure as warmth, for example. “You control your perception of the sensation by bringing your consciousness

to it," Maloni says. "You're able to manage the pain instead of just trying to ignore it or distract yourself from it."

- **Acupuncture.** The Chinese medicine practice has been shown in clinical trials to reduce pain in general, and may be a way to help manage MS hugs. "Hypnosis. Studies at the University of Washington show that it helps ease neuropathic pain. "Hypnosis is self-management at its best because you own it, and you can use it anytime you feel out of control," Maloni says.
- **Cognitive behavioral therapy.** Seek out a therapist who specializes in pain psychology. "If you're thinking, 'I'll never get rid of this or none of these medicines work...' then they won't," Maloni says. "Changing your thinking can help change your reaction to the pain."

Aviva Patz is a freelance writer in Montclair, New Jersey.

To learn more, see the National MS Society's page on [Pain](#) or the Momentum story, [Pain, pain go away](#).