# MS Patients Share Their Experiences With Pain And How They Cope

by AMANDA BEST

## Managing MS Pain

No two people experience multiple sclerosis (MS) the same way — a fact that becomes particularly evident when you start to discuss the types of pain the condition can cause.

We asked NewLifeOutlook writers and community members about their experiences with the many different kinds of pain that can plague people living with MS, and how they find relief.

**‘MS Hug’**

Sharp pain and feelings of pressure and tightness in the torso, often called the ‘MS hug,’ cause serious discomfort for many MSers.

“My worst pain has come from the inappropriately named MS hug,” says NewLifeOutlook writer Libby Selinsky, who suggests the symptom be renamed the ‘MS corset.’

“Seriously, we can’t let this symptom give hugs a bad name anymore!”

The so-called hug is actually the result of spasms in the muscles between your ribs. These spasms can cause feelings of pressure or squeezing, pins and needles-like numbness and tingling, and/or serious pain around the stomach and chest.

Some people experience the hug for short periods of time, but for others the sensation can last for days or even weeks at a time. And for some, the dreaded hug is almost ever-present.

Since MS hug symptoms are caused by nerve damage, standard over-the-counter pain medications do not usually help to relieve the pain. Muscle relaxants may help, so talk to your doctor about your prescription medication options.

NewLifeOutlook community member Leasha Lindley says she experiences the MS hug infrequently, and never knows what triggers it.

“However, I've found that I can breathe through them. In through the nose, out through the mouth! Big, deep breaths!”

She recommends sitting while doing this and trying to remain as calm as possible.

Pennie Gay Kramer suggests Fibromyalgia Relief pills, which can be found at Walgreens and claim to be a 100 percent natural way to manage symptoms of muscle, nerve and tissue pain.

“Miracle pills,” she calls them. “Oh my, it helped so quick. I think it’s the magnesium in them.”

Other options for managing the pain of the MS hug include taking a warm bath, massage and wearing compression garments, which help your nervous system interpret pain or burning sensations as pressure instead.

If you experience any new chest pain or breathing problems, be sure to see your doctor or go to the emergency room.

**Back Pain**

For other MSers, back pain is the worst — though sometimes it’s difficult to tell whether or not MS is the cause.

A number of things can cause back pain in MS patients, including spasticity (which we’ll cover on its own later) and lack of mobility.

Many NewLifeOutlook community members report severe lower back pain. Kathy Johnston says it doesn’t seem to matter if she’s laying down, sitting or walking — “Too much of anything and I am so stiff I can barely move the next day.”

NewLifeOutlook writer LeeAnne says she’s had serious back pain since before her MS diagnosis over 20 years ago.

“I went to sleep every night laying on an ice pack hoping to alleviate my pain so that I could drift off to sleep,” she says.

Now, LeeAnne finds some relief in massage; her husband massages her every night to ease the pain enough for her to sleep.

Kathy says she has found a chiropractor who does acupuncture and ultrasound, which has helped with her back pain. “Amazing results and has lasted longer than anything I have tried!” she says.

Other options that may provide some relief include propping a pillow behind your back while sitting, massage therapy, taking a warm bath and using a heating pad. It’s also worth making sure you’re using any mobility aids you have correctly.

**Migraine**

There certainly seems to be a connection between migraines and MS — over 40 percent of MS patients experience migraine pain, compared to 12 percent of the total population.

Though not all neurologists agree MS can cause migraines, the fact remains that many MSers get them.

A migraine is not just a bad headache. In addition to extreme throbbing pain on one or both sides of the head, migraine symptoms can include light and sound sensitivity, nausea, vomiting and vision problems.

*Next page: more on migraine, plus a look at trigeminal neuralgia and spasticity.*

**Migraine**

NewLifeOutlook community member Sandra Schwartz Aiken says she’s had migraines for years, but they were always blamed on sinus problems.

“After being diagnosed with MS they got worse, and are now finally under control with meds thanks to my neurologist,” she says.

Unfortunately many other community members report their neurologists are less helpful, often dismissing the idea that their MS and migraines could be related.

Migraines can be difficult to manage, but learning and avoiding your triggers, reducing and managing your stress-levels and getting regular exercise can all help. And don't give up on pain medications if the first couple you try don't help — keep experimenting until you find something that does.

**Trigeminal Neuralgia**

"I suffer with extreme trigeminal neuralgia (TN) pain — unbelievably intense short stabbing pain around my right eye," says NewLifeOutlook writer Gerard.

In MS patients, TN occurs when the myelin sheath around the trigeminal nerve, which is controls sensation in the face, is damaged. The pain it causes can be sharp and sudden — excruciating but lasting for short periods of time — or it can be a longer-lasting aching or burning sensation

A combination of two different medications largely controls Gerard's TN pain, which without medication is "blindingly brutal."

Gerard isn't alone. Several NewLifeOutlook community members describe TN as "the worst pain ever."

"The first time it literally brought me to my knees," says Gail Ferguson. "I was in a hotel at the time and rolled on the floor in agony."

Another community member says she passed out from the pain when her neurologist, in the process of telling her she didn't have TN, touched her jaw.

Contact with the face can trigger intense spasms of TN pain, as can things like sneezing, eating and drinking, talking and brushing your teeth.

Like Gerard, most MSers report finding relief from TN pain with medication — but getting that medication is not always easy.

Erin Blackburn, who describes the pain of TN as "almost as bad as labor," says when she went to her local ER the staff were unfamiliar with the condition and thought she was "a pill-popper."

"[The doctor] had to call the neurologist on call and look it up online to verify what I was saying."

**Spasticity**

'Spasticity' is used to describe muscle stiffness and spasms common in MSers. Spasticity occurs most often in the legs but can happen anywhere, and while for some it is uncomfortable but tolerable, for others it causes excruciating pain.

Writer Libby describes her spasticity as "sneaky."

"It turns on random muscles at weird times. Try relaxing when the tip of your tongue keeps twitching."

On the other end of the spectrum, community member Melinda Robinson says she gets "spasms and cramps that make [her] almost fall and scream out in pain."

Melinda recommends keeping a bottle of tonic water (which contains quinine) handy to drink when a spasm happens.

Another member says she can't move her spasticity causes her so much pain — but she finds relief using

cannabis.

However, if medical marijuana is not legal in your area or simply not an option you want to explore, many community members recommend the muscle relaxant baclofen.

There are several other medications that can help with spasticity as well, so talk to your doctor about what's right for you.

Certain exercises and stretches can also help; your doctor may refer you to an occupational or physical therapist, who can help you figure out what works for you.

**Resources**

Migraine Research Foundation (Migraine Fact Sheet)

National Institute of Neurological Disorders and Stroke (Trigeminal Neuralgia Fact Sheet)

National Multiple Sclerosis Society (Spasticity)

National Multiple Sclerosis Society (Pain)

Healthline.com (The MS Hug: What Is It? How Is It Treated?)

MS Trust (MS Hug)