

Muscle Spasms

By PALS Diane Huberty, CNRN

There are three main “muscle things” that occur with ALS: Spasticity, cramping and fasciculations. All three are uncomfortable and spasticity and cramping can be very painful. It is helpful to determine just which is causing the pain in order to get the right medication. Medications that work for spasticity don't necessarily work for muscle cramps and vice-versa.

Spasticity is an upper motor neuron problem and is present to some degree in ALS. For some patients it is minimal, for others extreme. Spasticity can actually be helpful in maintaining function as the rigidity helps replace normal muscle strength, but it causes jerky, hard to control movements. Spasticity causes a tightening of muscles that results in a stiffening of that part of the body in an exaggerated reflex. It is actually triggering both the muscles to flex and the muscles to extend that part of the body at the same time. It can occur in any muscles - the arms, legs, back, abdomen, or neck. A simple touch can trigger it and it may last only a moment or persist indefinitely. Spasticity isn't always painful but it can be, especially if it triggers muscle cramps that add to the pain.

Muscle cramps are very common in ALS, probably due to muscle fatigue or irritability from screwed up nerve impulses. They can be terribly painful and can occur in any muscle - feet, legs, arms, abdomen, chest, back, and (my all time favorite for sheer pain!) the neck and jaw. They can be in small muscles or affect big ones -- good old-fashioned charlie horses. As the muscles are affected by ALS, cramping is noted in that area. The cramping becomes less severe with time because the weakening muscles simply can't work up a good cramp anymore. They tend to be repetitive - once something starts cramping up, it does so over and over for a miserable hour or so. They tend to occur more if you have overdone exercise, if the muscle is cold, or if circulation is decreased. Holding a book up to read in bed on a cool night will just about guarantee some whopping good hand cramps and result in interesting finger gestures!

Fasciculations (muscle twichings) are probably due to nerve irritability. They occur in smaller muscle bundles inside large muscle bundles and can be observed as well as felt. Fasciculations are not so much painful as irritating. It can feel as if someone is popping corn inside your legs! They can be incredibly persistent and keep you from sleeping.

Is it Spasticity or Cramping?

Spasticity tends to affect larger areas of the body - arm, leg, trunk, neck. All the muscles in the area tighten up and the entire area may be so tight it hurts. Muscle cramps are generally limited to a single muscle and the pain, although intense even in small muscles, is limited in area.

Spasticity often begins with an odd sensation, sometimes described as a quiver, rushing and spreading through the area and becoming painful as they tighten the muscles and more so as the muscles tire. Muscle cramps start out painful and just get worse as they tighten up.

Spasticity in the legs generally causes them to stiffen out. In the trunk, back or neck it causes your body to arch a bit. In the arms it may flex or extend the arm.

Spasticity is often most striking when you first wake up or start to move after sitting still for a while and can often be connected to a sensory trigger. Of course that trigger can be as mild as a gentle touch so the connection may not be made.

Muscle cramps often affect the hands and feet making fingers and toes curl incredibly tightly. Spasticity is more widespread, less likely to affect just those muscles, and more likely to stiffen them out than to curl them.

Medications

Spasticity can usually be helped by medication but sometimes is a very stubborn problem. One consideration in treating spasticity is to find a balance between relieving excessive and painful spasticity and maintaining a certain level of spasticity, which can be helpful by replacing muscle strength. The meds for spasticity are primarily *Baclofen*, *Dantrium* and *Zanaflex*.

Although Baclofen is often listed under meds for cramping and prescribed for it, the indications say "Clinically, baclofen is used to treat spasticity." In my experience, Baclofen did not reduce cramping at all. However, if spasticity is triggering the cramping, Baclofen may reduce cramping by reducing the spasticity. Some patients experience weakness or tiredness while taking it but these problems can often be reduced if the dosage is decreased. In 1996 the FDA approved the use of Baclofen, delivered by an implanted pump, for the treatment of spasticity due to spinal cord injury and this is now being tested on ALS patients.

Zanaflex is the most recent medication approved by the FDA for treatment of spasticity. Zanaflex is less likely to cause weakness but may cause sleepiness. This can often be minimized by starting with a low dose and gradually increasing it until spasticity is relieved.

Dantrium has been used for spasticity, but because of its potential for causing liver problems, is less frequently used since other meds are now available. It does seem to still be used for bladder control problems caused by spasticity however.

Quinine is a drug long used for muscle cramping but in 1995 the FDA said studies showed it lacked effect for "nocturnal leg cramps" and it is no longer sold for this purpose. Well, I don't know about "nocturnal leg cramps" - I had cramps all over at all hours of the day and quinine worked very well for me! I took it twice a day, morning and late afternoon or evening. (I have few muscle cramps these days - not much left to cramp up - so I no longer use it.) I would certainly recommend asking your doctor about trying quinine. I do not recall what dose I took, but do know that too large a dose will cause weakness. I am told the smallest tablet made is 260mg. I would recommend beginning with half a tablet and increasing to a whole one if it is ineffective. It is also available in 200 mg capsules. It is much less expensive than the other drugs prescribed and, in my experience, the most effective. Like any drug, it does have some potential side effects (and cannot be taken by pregnant women) but it does not cause physical and psychological dependence as Valium does in long-term use. Aside from the weakness when I took the larger dose, I noticed no other immediate side effects. After more than 5 years of daily use, I did notice sweet foods started to lose any sweet taste, especially chocolate. Quinine is very bitter so I assumed it was the culprit since I wasn't on any other meds at the time. It was a minor problem and when I did stop taking quinine, I found the ability to fully enjoy an Oreo was gradually restored!

Valium and other muscle relaxants may be tried for spasticity but are probably better used for muscle cramps. However, their side effects and cost make them a second choice to quinine in my opinion.

I have not heard of anyone having any real success in reducing the fasciculations (muscle twitching) with any medication.

About the Author

Diane Huberty is a retired RN. She worked general Med-Surg units, then 5 years in Critical Care where she began specializing in Neuro and earned Neuro Certification (CNRN). Diane was diagnosed with ALS in 1985 at the age of 37. When her hospital opened a Neuro Unit, she was selected for the position of Neuroscience Educator. She was able to continue working in that position until 1995, when arm weakness and fatigue made it too difficult to continue and she retired. Through the Internet, Diane communicates daily with other ALS patients and keeps up on research, treatments and care issues. In addition to maintaining and posting a set of ALS Frequently Asked Questions on the ALS newsgroup (sci.med.diseases.als), she has her own ALS website (<http://home.att.net/~liveletdie5/ALS/home.html>) which focuses on nursing care rather than research. Diane can be contacted by email at “liveletdie@att.net”.