



## Spasticity

*Thirty and forty years ago, no one “in the know” believed that aging with a spinal cord injury would be something we’d care about. Back then, no one believed any of the “survivors” would survive long enough for it to matter. Now that assumption has been disproved and the tune has changed. We’re identifying and learning more about the issues and concerns facing survivors – problems like fatigue, upper extremity pain, urinary system problems, and caregiver issues. But spasticity doesn’t seem to have a place on that list. There hasn’t been much research into spasticity and aging, and what SCI survivors tell us varies. Some say their spasticity has gotten worse over time, some say it has lessened, and most don’t say much of anything.*

### What DO we know?

It seems that as people age with spinal cord injury, they *focus* less on their spasticity. When none of the treatments that are acceptable to them work, many begin to think that spasticity is like the weather: You can complain all you want, but there isn’t a whole lot you can do about it. So, while spasticity doesn’t necessarily stop being a problem, it’s not mentioned when survivors visit their physicians or it’s not documented if it is mentioned. As a result, researchers don’t have any real information to sink their teeth into. Instead we rely on clinicians’ observations and some good sound logic and intuition based on what we know about spinal cord physiology.

At least in theory, there’s reason to suspect that just getting older may lead to an overall *decrease* in spasticity. Nerve conduction slows down over time, nerve cells in the spinal cord may degenerate, muscle mass and fiber size may decrease, and blood circulation within the cord itself can diminish. All of these should lessen spasticity.

Even more important, many people, over time, learn to deal more effectively, or become more “comfortable,” with their spasticity. As they get stronger, they learn to overpower their spasms, or they learn what triggers their spasms and they avoid those things.

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Some people even "use their spasticity" – to empty their bladders, to transfer, to dress, even to stand and walk. Others say it keeps their muscles toned and improves circulation. Some suspect it helps keep bones stronger and better mineralized. True or not, spasticity may not be entirely bad.

## Warning Signs

Changing spasticity – regardless of your age – is often a symptom as much as a problem. Sensations that you may not even be able to perceive, but which your nervous system senses when something is wrong, make spasticity increase.

Within the nervous system itself, perhaps the most serious complication is a cyst or cavity in the spinal cord (sometimes called post-traumatic syringomyelia). Increased spasticity is a common symptom of this complication. However, *decreasing* or disappearing spasticity can also sometimes be a sign of a cyst. Other diseases that may develop in the spinal cord – tumors, Guillain-Barre syndrome, transverse myelitis, a spinal cord stroke – also may cause spasticity to change. Other problems *outside* your nervous system also can make spasticity increase. Urinary tract infections, an over-full bladder, or a skin sore are just a few examples.

Finally, YOU may change in ways that make spasticity become *more of a problem*, even though the spasticity itself doesn't get any worse. Things like shoulder joint pain, fatigue, or general weakness may make it harder to deal with what once was a reasonable amount of spasticity. The result is the same as if the spasticity actually had increased. The bottom line: don't ignore a significant change in your spasticity.

## Two Perceptions

So how much spasticity is *too much*? Unless you're one of those people who "walks on his spasticity," uncontrollable spasms can make life pretty miserable. Ask John, who has an incomplete C6 spinal cord injury. He thought long and hard about function and quality of life issues and finally got to the point where no spasticity treatment would have been too drastic. After too many years of incredible spasms and mega-doses of anti-spasmodics, he was ready to take a look at dramatic, nerve-destroying surgical procedures, even if it meant potentially sacrificing sensation and sexual function that he had below his injury site.

"Life was nearly impossible," he says. "I feared staying in bed; my legs would launch me out of it." His hip was dislocating because of the spasticity and he was taking so many anti-spasmodics that his memory was failing. He tried rhizotomies with only short-term success. Now, he's waiting to have a pump implanted.

Phil has pretty bad spasticity too; he blames it, at least in part, on his worsening scoliosis. Though he's independent in his wheelchair, he describes his spasticity as "very interfering." Still, unlike John, he thinks most any intervention is too drastic. In the more than 20 years since he broke his neck, he has tried various oral medications; some worked a while, some didn't, and overall he didn't like the side effects. He won't consider a rhizotomy because of its permanence. Besides, he's one of those guys who say his spasticity helps him with his transfers. He has given a bit of thought to the baclofen pump, but he's still very hesitant, taking a "wait and see" approach.

## Spasticity

Two different survivors; two different approaches to dealing with their spasticity. Both seem to have ended up at least thinking about the baclofen pump, but that's probably coincidental. The pump is generally effective, but countless people have had excellent results with rhizotomies too.

Regardless, the purpose here is NOT to promote one type of spasticity management over another or to tell you WHAT you should do about spasticity. Instead, we'd like to help you learn to recognize WHEN it's time to do something.

## Is it a problem?

These are some of the questions that you might want to ask yourself:

- Is spasticity limiting your function?
- Are there things that the spasticity keeps you from doing?
- Is the job of your attendants or helpers made harder because of spasticity?
- Are you using more personal assistance – to keep you positioned in your chair, to pick you up when a spasm throws you on the floor?
- Are there other safety risks – losing control while driving your power wheel chair, car or van?
- Is the treatment you're currently using as bad as the problem itself?
- Are anti-spasmodic drugs affecting your memory, concentration, and energy level?
- Are your sleeping and waking cycles out of kilter?
- Has the amount of money you spend – on medications, on attendant care, on treating related skin problems – gotten out of control?
- Are your spasms becoming harder and harder for you to cope with?
- Does shoulder pain make it harder for you to fight them?
- Are they frustrating your new personal assistant also?
- Are they becoming more than your aging caregiver can handle?
- Can you no longer stay alone because of your spasms?
- Does someone always have to be around to reposition you in your chair?
- Have the oral medications stopped working or do other medications make them ineffective?

## Parting Thoughts

Think about it. Having a satisfying life is what it's all supposed to be about. Only you know what it takes to give you the quality of life you want. If you decide it's time for a change, educate yourself about the pros and cons of each option. Then, find a health care provider who understands both spinal cord injury and spasticity and who will look with you at the big picture. You may be getting older and your spasticity may be keeping you company all the way. But if you're knowledgeable about your alternatives and their implications, that long term companion of yours need not be such *bad* company.

This is a publication of the RRTC on Aging with Spinal Cord Injury, which is funded by the National Institute on Disability and Rehabilitation Research of the US Department of Education under Grant #H133B30040. The opinions contained in this publication are those of the grantee and do not necessarily reflect those of the US Department of Education.