

Staff Director: John Youngbauer

Researchers: Julie Steward and Katherine Froehlich

Editor: Judith Galas

Graphic designers: Mike Irvin and Ken Golden

Consumer focus group: Jeri Johnson, Matt Sherman, Sandy Etherton, Lorainne Connistra, Corky Roste, Bob Mikesic, Kevin Robinson, Ranita Wilks, and Barb Lumley

Editorial consultants: Steve Brown, Ph.D.; Frederick Maynard, M.D.; June Isaacson Kailes, MPH; Barbara Hall-Key; and Cheryl Vines

Guest consultant: Daniel Lammertse, M.D.

Copyright. 1996.

The Rehabilitation Research and Training Center on Independent Living. (1996). *Spasticity*. Lawrence, KS: The University of Kansas, The Rehabilitation Research and Training Center on Independent Living.

Abstract: No single definition covers spasticity – uncontrolled muscle spasms caused when motor nerves cannot communicate with the brain. Most agree that these characteristics point to spasticity: Increased muscle tone or firmness, exaggerated stretch reflexes, uncontrolled movements, altered posture, and interference with walking (if person is walking). Muscle spasms that come from muscle cramping, torn muscles, or lower-back pain are not spasticity.

Health professionals think that a certain amount of spasticity in people with spinal cord injury is normal and healthy. Movement, for instance, even if uncontrolled, helps maintain muscle mass and tone. Spasms also put pressure on bones and help maintain bone density. The rapid circulation of blood that occurs during spasms increases blood flow and can decrease the change of blood clots. For some, spasms can be triggered to assist in chair-to-bed transfer and standing.

Spasticity challenges are pain, sleep disruption, difficulty with breathing (if affecting chest muscles), movement difficulty, fatigue, bladder and bowel problems, muscle/bone/joint distortion, scrapes that can turn into pressure sores, and intimacy problems. Stress and loss of self-esteem are also byproducts of spasticity.

Something as small as an ingrown toenail or piece of elastic pinching the waist can set off a spasm. Look for tight clothing, kinked or obstructed catheter tubing, improperly inflated wheelchair cushions, chilly air, and other obvious pain or discomfort triggers. The cause may signal serious internal problems, such as urinary tract infections or blood clots. Therefore, the services of a health-service professional may be necessary.

To reduce spasticity, follow good hygiene rules to reduce infections and check regularly for pressure sores or infection. Also, keep limber with stretches and range-of-motion exercise and move more slowly when feeling stiff. Take warm, not hot, baths or showers. Avoid alcohol because it can increase the intensity and duration of spasticity.

Medication can control spasticity. In the past, barbiturates were prescribed for spasticity, but now baclofen (also known as Lioresal) is used even though one-third of those who take do not find it effective. Others, of varying effectiveness, are diazepam (Valium), Dantrolene sodium (Dantrium), Clonidine (Catapres), and skeletal muscle relaxants. In some situations, surgery – a drastic, irreversible treatment – to cut nerves is advised.

Several therapies are available to manage spasticity. Medications alone usually are not enough and work best when people control their stress level and have a home program of stretching and exercise.

The Secondary Conditions Prevention & Treatment series of booklets was written and produced three times yearly by the Research & Training Center on Independent Living, 4089 Dole/University of Kansas, Lawrence, KS 66045-2930. Supported by a grant from the Education and Training Foundation under the aegis of the Paralyzed Veterans of America.

Spasticity: Finding and Keeping Control

Spasticity – uncontrolled muscle spasms – results from damage to the nervous system. Spasticity is a normal part of a spinal cord injury (SCI), and many people with SCI develop spasticity to some degree. It may surface within hours of the injury or after some months. More commonly it occurs within the first two to three weeks after the injury.¹

Spasticity may vary from occasional muscular contractions to those that are severe and long-lasting. Spasticity may be helpful when it occurs in a mild form or infrequently. The muscle movement brought on by the spasms increases muscle tone, improves circulation, or helps strengthen muscle and bone. Stiff, extended legs may help a person stand, walk with braces or make transfers. Some people trigger their spasms to assist them in their bowel and bladder programs.

Severe, frequent or painful spasms, however, clearly disrupt people's lives. These spasms may disturb sleep and can cause fatigue. They can interfere with people's ability to feed themselves, to bathe and dress, and to work. Severe spasticity may make it hard to drive or even to guide a wheelchair with predictable safety.

Spasticity often embarrasses people who have recently experienced a spinal cord injury. They worry that their uncontrollable movements may hinder personal interactions, including conversations and sexual closeness. But many of those who have lived with spasticity for awhile view their spasticity simply as a part of life.

The health-service profession offers a number of approaches to calm or stop spasticity. Depending on the severity of the spasms, range-of-motion exercises, stress management, electrical stimulation, prescribed drugs and even surgery have been used. Each offers some help, but some treatments — like medication and surgery — bring complications.

Many people with spasticity find that most solutions come with trade offs. They must decide if decreasing spasticity is worth some changes that may occur in daily routines, drug side effects, or loss of some mobility and feeling from surgery.

This booklet looks at spasticity — what causes it, what can be done to ease it and what are the side effects and trade offs of some treatments. This information may help those with SCI manage their spasticity more effectively.

What is spasticity?

Spasticity is hard to fully define because the workings of the body's nervous system remain largely a mystery.² Spasticity commonly goes along with injuries or conditions that involve the nerves and muscles. It occurs in people who have had a brain injury or a stroke, in those with cerebral palsy and multiple sclerosis, and in people who have had SCI.

Many people with SCI report experiencing any of three main types of spasms, as defined below:

- Extensor spasms are a common type of reflex muscle contraction seen after SCI. These spasms cause a rigid straightening of the knees and pointing of the toes.
- Flexor withdrawal spasms are a bending or drawing up of joints such as in the hip and knee.
- Clonus is a series of many rapid, short movements that occur when the muscle quickly alternates between contractions and partial relaxations.

No one single definition covers spasticity, but most people agree the condition has a few common characteristics:

- Increased muscle tone or firmness
- Exaggerated or intense stretch reflexes
- Uncontrolled movements
- Some altered posture
- Interference with walking, in people who can walk

Some people confuse any involuntary, quick movement or tremor, or any condition with rigid or extremely stiff muscles, as spasticity. Muscle spasms that come from muscle cramping, torn muscles, or lower-back pain are not spasticity.

The most common and distinguishing link connecting all the traits related to spasticity is stimulation. Spasticity is a reflex or uncontrolled response to something that excites the nerve endings and produces muscle contractions. It is an uncontrolled response to a physical stimulus. This stimulation isn't always associated with activity or movement. Sometimes the nerve endings can be aggravated by a lack of movement. Lying down or sitting in one position for long periods also puts pressure on the skin or brings on muscle stiffness. Pressure and stiffness can excite the nerve endings and cause a spasm. This is why some people have spasms during the night when they've been sleeping in one position.

Most often the spasms come when a muscle is stretched and especially when the muscle is stretched quickly. The stretches stimulate the "movement sensitive" nerve endings in the muscles. But any number of other things may stimulate the nerves: fatigue, stress, pain, tight clothing, a cold breeze blowing across the skin, a bump in the road, an infection, or a simple human touch. These or other stimuli excite the motor nerves and can cause the muscles to contract uncontrollably.

In the first weeks following their injury, some people with SCI hope their spasticity really is a sign that voluntary muscle movement may be returning. The spasms, however, may not be a signal that the body is regaining control of its movements. Rather the spasms show that the motor nerves are still alive and excitable, but that they are disconnected or unable to communicate with the brain.

What causes spasticity?

Just like a short in a lamp cord, spinal cord injury puts a road block in the brain-to-motor-nerve pathway. The nerve impulses from the brain that once affected the voluntary or involuntary movements of muscle located below the injury can't travel beyond the spine's lesion or injury. The motor nerves to the muscles below the spinal injury may be working, but the injury has broken their connection with the brain, the central nervous system that directs and guides most of the body's movements.

Researchers who study spasticity think this lack of natural nerve connections may also be the cause of spasms. In people without SCI, the spinal cord pathways do more than just get the



body's muscles moving. They also help the muscles move smoothly and with control. In people with SCI, the spinal cord pathways aren't able to control the movement of muscles. If the motor

nerves become stimulated in some way, they'll move without control. They can't get the message from the brain to move slowly and with control.

Levels of intensity

The frequency or intensity of these uncontrolled movements varies with each person and may vary from day to day and by activity. Spasticity is usually separated into three broad categories: mild, moderate and severe. For the most part, these categories are too broad to be really meaningful.

What feels moderate to one person, may feel severe or mild to another. A health-service provider may observe that a spasm seems mild, but the person with SCI may experience that spasm differently. This discrepancy can create problems in studying spasticity.

In one study of 72 people who experienced spasticity, researchers determined that 40 percent of the participants only experienced mild spasticity that did not interfere with daily functions. Another 40 percent had moderate spasticity that interfered somewhat with daily activities, and 20 percent had severe spasms that caused considerable discomfort and life disruption.⁴ Many research studies on SCI and spasticity suggest what this study found: More people have the milder-to-moderate forms of spasticity.

Some people who study SCI and spasticity have found that severe spasticity is more likely to occur in people who have had major health complications in the months right after their injuries. The severe spasms they experience contribute to even more health complications such as urinary tract infections, pressure sores, bowel impactions, and muscle and joint contractures. So, it's possible that the severity of the initial injury, the level of the spinal lesion, plus other organ and tissue damage and the health problems that follow may suggest a person's level of spasticity.⁵

They may also alert the person with SCI to the possibility that a cycle may be developing in which spasticity and health complications may feed on each other. For example, a person with pressure sores may have more spasticity in response to the wound. These spasms, however, damage even more skin as the body's quick movements rub or injure the skin further. A vicious cycle of pressure sores and ever-increasing spasms quickly develops. This possible relationship between early health complications and severe spasticity suggests a few important things:

- Physical therapy and a routine of daily exercises may be especially important early on for people with SCI who have other health problems.
- Early and careful attention to health complications and their solutions may help to reduce the severity of spasticity in the future.

Those who study spasticity also find that intensive physical therapy right after injury may be the best way to ease or even prevent spasticity in people with SCI. These therapies include range-of-motion exercises and proper positioning of limbs shortly after injury. Early physical therapy may help a person regain more voluntary movements and experience less spasticity.⁶ The availability of therapies may be limited, however, by lack of insurance coverage. Check with your health-service provider to see what services are available and at what costs.

Responses to spasticity

Just as people experience different levels of spasticity, people also have varying responses to their spasticity. Some are angry or embarrassed when their muscles move uncontrollably. Those with severe spasticity may be upset or irritable because they are in pain.

On the other hand, some people pay little attention to their spasms and regard them as casually as any other routine occurrence.

If you have recently acquired a spinal cord injury and are a person who's experiencing spasticity for the first time, you might be surprised to know that many people who have had spasticity for awhile basically think it's no big deal. With time, most people acquire a perspective that helps them take their spasticity in stride. "Spasticity doesn't keep me from doing the things I want to do," said one person whose spasticity ranges from moderate to severe. That sentiment is shared by many who have spasticity.

Some people may feel self-conscious at first. They may worry about what others will think of them if their legs or arms begin to move uncontrollably. One young man even strapped his legs to his wheelchair so that no one would notice if a spasm occurred while he was in public. Those who have gotten comfortable with spasticity, however, may even find humor in it. "It can be an icebreaker," said one man, chuckling.

How spasticity affects the overall quality of your life and how you respond to it in the months and years ahead will determine what, if anything, you want to do about it. In this booklet you'll find information about lifestyle changes that can help control or stop spasticity. You'll also learn about the medications that people have used to control spasticity and about surgical procedures.

It's important to remember that prescribed drugs and medical treatments may not be necessary. Before you begin to think that you must do something about your spasms, remember this: Spasticity is a normal part of SCI and many people do nothing at all to control or stop it. In fact, spasticity has some obvious benefits.

Benefits of spasticity

Most health professionals agree that a certain amount of spasticity in people with SCI is not only normal, but also healthy. Much of the information on spasticity and SCI stresses this and indicates that not all spasticity should be treated with prescribed drugs or surgery. Spasticity can even play a helpful role in the overall health and daily living of people with SCI.

- Movement, even if uncontrolled, helps maintain muscle mass and tone.
- The rapid circulation of blood that occurs during spasms also increases blood flow and decreases the chances of blood clots.
- For some, spasms can be triggered to assist in chair-to-bed transfers and standing.
- Spastic rigidity or flexion in the legs and arms can sometimes help with getting dressed in the morning.
- Leg rigidity can provide support for those who walk with crutches.
- Intentionally triggered spasms can help with bladder and bowel programs.
- Spasms put pressure on the bone and help maintain bone density.

One of the most important benefits spasticity offers is the role it can play as a warning system. Spasticity that increases in one area of the body may be a sign of trouble. For example, you might have an undetected urinary tract infection or pressure sore that you can't feel, but that is stimulating the motor nerve and causing the spasms. Notify your health service professional if you notice any significant increases or decreases in spasticity.

People learn to adapt to their own levels of spasticity, and many find ways to take advantage of spasticity's positive sides. But no matter how helpful spasticity can be or how much people try

and stress the positive, muscle spasms still affect life. Depending on their severity, they can sharply affect a person's ability to get things done during the day.

Drawbacks to spasticity

As most people with SCI already know, spasticity has several drawbacks. Family members, professional health care workers, and personal assistants sometimes need to be reminded that spasticity brings an array of challenges. The following list portrays many of the drawbacks to spasticity.

Pain: Muscle spasms can cause pain that ranges from mild to severe and that can last only a few seconds, or several minutes, or longer. When spasticity intensifies, the accompanying pain may increase.

Sleep disruption: Spasticity often increases at night when the body has been lying in one position for a long time. Spasms often wake people up, and this sleep loss leads to daytime fatigue.

Difficulty with breathing: If spasticity affects the chest muscles, people with SCI may lose their breath during the spasms.

Difficulty with fine motor skills: Spasticity can hinder people's abilities to care for themselves. Eating, dressing, bladder and bowel programs, and driving a car or a powered wheelchair require fine motor skills – steady hands and fingers. Spasticity may disrupt or stop these activities.

Difficulty with large muscle movements: Transferring between the bed and wheelchair, walking with braces, or pushing a manual wheelchair may become unsafe, difficult or impossible.

Overall fatigue: Spasticity tires the body. So in addition to losing sleep at night, a person with spasticity may become tired during the day as well.

Bladder and bowel problems: Spasms can bring on a slow trickle of urine or, less frequently, a sudden emptying of the bladder or bowel. This can be embarrassing, uncomfortable, and disruptive.

Joint contractures: With time, recurring and severe spasticity can change the positions and shape of some muscles and bones. Ankles may turn in, heel cords may shorten, hip and knee joints may tighten and become contracted. These changes can alter posture, ease of dressing and making transfers. The person's self-image may also be affected.

Skin breakdown: Skin, especially on the heels, back, elbows and buttocks may be rubbed raw during a spasm. These scrapes can develop into pressure sores which, in turn, may trigger more spasms and set up a cycle of spasticity followed by pressure sores.

Intimacy problems: People want to be close to those they love. Muscle spasms, however, may interfere with intimacy. A new partner or a partner who is just becoming familiar with spasticity may fear that his or her touch will trigger spasms. Some people who have experienced spasticity for awhile, however, regard the spasms more as an inconvenience that can be worked with or ignored. It may become a little easier to deal with in time.

Some people experience painful spasms that distract from sexual intimacy. They admit that if they've been dealing with pain and spasticity during the day, they can really be "too pooped to pucker" later in the day.

Those who have shared their personal experiences stress that relaxation is important. Proper positioning of the head and limbs may be important so that spasms aren't triggered. Romantic massages can set off spasms, but applications of heat or ice have been known to stave them off. What's important is that partners not get discouraged. They need to share their uncertainties, concerns, struggles, and successes with each other and develop satisfying ways to show each other concern and love.

Self-image: Some people with spasticity, especially those who have recently acquired a spinal cord injury, are embarrassed by their spasticity. They may be afraid that people will stare at them. Others indicate that they are not afraid to be in public because of their spasticity. They encourage those who are not yet comfortable with spasticity and the attention it may gain that the embarrassment will go away.

Stress: Any or all of the items mentioned in this list can be stressful. As well, people with spasticity lead full and engaging lives. They may feel anxious, angry, annoyed, frustrated, helpless, or depressed. These feelings create even more stress, and stress can also trigger spasticity.

Ways to control spasticity: Check the obvious first

Because spasticity can be triggered by pain or discomfort, it's best to first check the body for any signs of trouble. Something as small as an ingrown toenail or a piece of elastic that pinches the waist can set off a spasm. A useful way to reduce spasticity is to check the obvious first:

- Tight clothing
- Tight leg-band bags or external catheters
- Kinked or obstructed catheter tubing
- Under- or overinflated wheelchair cushions that may be caused by simple conditions such as an altitude change that alters the inflation pressure of the cushion
- Chairs edges that press against the back of the knees or into the back
- Chilly air and drafts

If none of the obvious signs listed above provide clues to the spasticity you are experiencing, you may want to visit with a health-service professional to determine if any of the following problems are occurring. Sometimes, very serious internal problems may stimulate the nerves such as:

- Urinary tract infections
- Bladder stones
- Pressure sores
- Constipation
- Muscle and joint injury from stretches or strains
- Blood clots

Remember, even though you may not feel the discomfort from a bladder stone or blood clot, these irritations stimulate the nerves and can increase or decrease spasticity. Here are some suggestions that may help you reduce spasticity:

- Follow good hygiene rules to reduce the chance of infections.
- Perform range-of-motion exercises twice a day to avoid contractures and joint problems.
- Check every inch of your body regularly for pressure sores or infections. If you can't check your entire body by yourself, ask for assistance from a personal assistant or a family member.
- Move more slowly when you are likely to be stiff in the mornings after being in bed all night or after you've been sitting for a long time.

- Take the time to completely empty your bladder and bowel regularly and take precautions to reduce infections during this routine.
- Pay close attention to your body's comfort. Is the room too cold? Are your pillows, chair cushions, blankets and clothing smooth and soft to the touch?
- Take warm, not hot, baths or showers.
- Take good care of your skin and nails. Keep your toenails trimmed and watch for ingrown nails.
- Be sure your clothing is not too tight. A suggested rule of thumb is that you should be able to slide your hand in a waistband and under a belt or the elastic and straps of undergarments. Shoes should also have plenty of toe room.
- Give yourself plenty of time to perform your daily tasks and personal care. Hurried movements while dressing, bathing, eating or performing bladder and bowel programs are more likely to trigger a spasm.
- Use of specially designed adaptive equipment, such as a standing stall, may help to stretch muscles and this can reduce spasticity for some. If you're not familiar with a standing stall, talk with a physical therapist.
- Pad or cushion sharp and hard edges on your bed and wheelchair. If you do strike these edges, the padding will reduce the stimulation and also the possibility of injury.
- Find ways to reduce stressful feelings. Deep breathing exercises, meditation, reading, writing in a journal, listening to music, prayer, or just taking a moment to be quiet may be helpful.
- Avoid alcohol or limit your consumption because alcohol can increase the intensity and duration of spasticity, even though the initial effect may be to relax the muscles.
- Keep reading and learning about better ways to care for yourself.

Treatment options

Even though most health professionals think a certain amount of spasticity in people with SCI is normal, you may be experiencing more spasticity than you'd like. At some times in your life, you'll probably find that the tips mentioned above just aren't always enough to control or stop your spasticity.

You might want to look into additional ways to control or to stop your spasticity and to talk to your doctor if you're experiencing any of the following disruptions:

- Severe or prolonged pain
- A reduction in your ability to do the day to day things you want to do
- An inability to continue with physical therapy
- Spasticity-related problems that cause difficulties in your personal relationships
- A decline in your ability to take care of yourself

Many people turn to medications or surgery to gain this control. Doctors who are familiar with SCI, however, may encourage people with spasticity to first see if a twice-daily routine of range-of-motion exercises doesn't ease the spasticity. Too often, this simple method is overlooked even though it can be very effective. When medications or other treatment methods are used, range-of-motion exercises are still a benefit.

In addition to the tips already mentioned, the health profession offers several methods for reducing or stopping spasticity:

• A wide variety of medications

- Surgery
- Electrical stimulation and other devices

Each of these methods has its pluses and minuses. Some work better for some people than for others. What you select will depend on you and your specific needs and situation. Learn about the advantages and drawbacks of each method so that you may decide if the positives outweigh the negatives. Be sure to first try the least invasive approaches with the fewest side effects. You can always select more or different treatments or medications if your first choices don't work well for you.

Should you take antispasmodic drugs?

Some people see prescribed drugs as a second- not a first-step approach to controlling spasticity. They caution that prescribed drugs have long-term side effects, and many are highly addictive. Most cause some withdrawal symptoms such as seizures, increased spasticity and depression. Sometimes withdrawal can begin if only a few doses are missed. Sudden withdrawal from these medications can be serious. People on any of these medications should make sure that all their health-service providers, including hospital staff, know they are taking antispasmodics so that dosages aren't missed.

In general, people taking antispasmodic drugs may experience fatigue, confusion, and dizziness. This may make it difficult to regulate dosages. Over time, they may have damage to their liver, kidney, and other internal organs.

Knowing more about the side effects of antispasmodic drugs and their long-term impact on the body may help you decide if you want to turn to medications as a way to deal with your spasticity.

Many people decide to take antispasmodic medications when lifestyle changes and physical therapy hasn't decreased their spasticity. Prescribed drugs can help with muscle pain and spasms, but they won't improve muscle weakness, physical dexterity or mobility. Antispasmodic drugs only treat spasms and relieve pain.

History of medications

Barbiturates – drugs used to induce sedation and sleep and to control convulsions – were once used to treat spasticity. But they aren't prescribed today by doctors who are familiar with spasticity and its treatments. In fact, no one should be taking barbiturates for spasticity. If you want to be sure you aren't, you can find barbiturates and their related prescription drugs under some of these trade names: Amytal, Tuinal, Alurate, Butisol, Nembutal and Seconal.

Several other prescribed drugs have proven safer and more effective than barbiturates. Several skeletal muscle relaxants (SMRs) are often prescribed for spasticity. One type of tranquilizers, medically known as benzodiazepines, are effective. The most commonly used benzodiazepine is diazepam, better known as Valium. Dantrolene sodium, which works directly on the skeletal muscles, and baclofen, which works directly on the nerves, also are in widespread use.

Until the late 1980s, most physicians and researchers familiar with spasticity were in agreement that no one antispasmodic drug was clearly better than any other. All had their drawbacks, and no one drug was effective for most people. All shared the common side effects and had to be carefully monitored.

Baclofen

For at least 20 years, baclofen – known by the trade name Lioresal – has been the drug of choice to control spasticity.⁷ It has proved helpful with all types of spasticity, but with mixed results.

Oral baclofen doesn't help about one-quarter to one-third of the people who take it.⁸ To be really effective, it must be given in high dosages. These high levels often cause unpleasant, even harmful side effects — sedation, dizziness, weakness, confusion, nausea, and low blood pressure. "My mind just wasn't clear," says a former baclofen user, who says he stopped interacting with people because it became too much effort to think and to talk.

About one-third to three-quarters of those on oral baclofen report some side effects, most minor, with drowsiness being the most common.⁹ Unlike some other antispasmodic drugs, baclofen is not associated with liver damage.

In the early 1990s, however, this well-known and frequently used drug emerged as a possible front-runner in a new drug therapy for severe spasticity. With those who experience severe spasticity, baclofen has been used with great success as a fluid injected directly into the spinal canal. This method is known as intrathecal baclofen and involves a surgical procedure. The term *intrathecal* means to be within a sheath, because the drug is going under the membranes that cover the spinal cord.

Intrathecal baclofen directly bathes the spinal cord and decreases the excitability of the spinal cord reflex units that cause spasticity. One study shows that intrathecal baclofen can be effective at 1/100th of the strength that would be required if it were taken by mouth.¹⁰ This



means that less of the drug travels through the bloodstream and on to the brain so fewer sideeffects result.

This therapy seems to be more frequently used in some parts of the country than in others, and most often is unheard of except in the larger SCI treatment centers. To find out more about it and whether it would be an appropriate treatment, you most likely will have to be referred to a neurosurgeon or to a physiatrist, a doctor who specializes in physical medicine or rehabilitation.

Intrathecal baclofen is not enthusiastically supported by everyone, and is by no means universally viewed as a treatment of choice. Some, however, feel this treatment is on the cutting edge. It has proved a real benefit to some people whose severe spasticity has not responded to any oral medications. It is likely to be recommended only in certain situations when surgery is the alternative and when the individual has access to a hospital or treatment facility where maintenance of the pump can be conducted.

Intrathecal baclofen involves a surgical

procedure, so it is expensive. Many third-party insurance payers, however, do cover it. Because it includes surgery and some risk for infection, the person with spasticity must thoroughly

understand the procedure and know its risks. Before a person has surgery to implant the baclofen pump and catheters, he or she is first given a trial injection into the spinal canal to see if baclofen offers relief from spasticity. People having a good response to the injection would then undergo a short surgical procedure.

A catheter, or plastic tubing, is placed into the spinal canal through an incision made in the lower back. The tube is then tunneled around the abdominal wall to a pocket at the front of the abdomen. The pump, filled with baclofen, is placed in the pocket under the skin and is connected to the catheter.

The pump contains enough baclofen to last about three months. When it approaches the end of the baclofen supply, a doctor or nurse trained in the maintenance of the pump can refill it. Doses are programmed and can be adjusted to be higher at night to stop spasticity during sleep. The battery that runs the pump is surgically replaced about every three years with a simple procedure that is like the one used to replace pacemakers.

The surgery itself is considered low-risk, but any surgical procedure carries with it a risk of infection. In this procedure, the area at risk for infection is the spine. Spinal meningitis can occur when proper procedures are not followed. Therefore, a very strict protocol must be adhered to. Once the pump is inserted, however, it's own in-line filter acts as a barrier to bacterial contamination of the spinal fluid. Without these filters, the risk would be higher for infections like spinal meningitis. Remember: Infection should still be a concern for anyone implanting or using the pumps.

Only a few individuals with severe spasticity are on intrathecal baclofen. Those who are report improvement in their daily life, especially in self-care, transferring, sleeping, and stopping urinary incontinence. For several, the medication made it possible for them to begin or to continue working, driving, and taking care of themselves.

In a 1988 study done by Barbara Parke¹¹ and a 1989 study done by Richard Penn¹², intrathecal baclofen improved function in several people. One person with an indwelling catheter became continent. Skin integrity improved in several people. Feeding, dressing, and hygiene skills improved, and pain was reduced or eliminated. "In most cases, spasticity, performance of bowel and bladder programs, and performance of ADL (activities of daily living) improved after delivery of intrathecal baclofen... improvement came almost immediately and the decrease in spasticity and increase in function has been striking."¹³

In the Penn study of 20 people — half with SCI and half with multiple sclerosis — all had a reduction in muscle firmness. Spasticity decreased in 18 people. Spasms were reduced enough so they did not interfere with daily life, and no one reported drowsiness, confusion or infections.

Intrathecal baclofen still causes fatigue in some people. Overdoses can cause coma, slowed or stopped breathing, sedation, low blood pressure, and confusion. A sudden stoppage, however, can cause severe withdrawal symptoms such as seizures and hallucinations. A pump that runs dry, therefore, could be a serious problem. People who may not live within easy travel of a clinic may want to carefully consider whether they would be at risk of running out of intrathecal baclofen before a trained medical person could refill the pump.

The implantation itself also has caused some problems. Some studies report dislodged catheters that had to be surgically replaced. Pumps have failed, and some people had pain at the implantation site. People who used their leg rigidity to walk or transfer from bed to chair, had to carefully program doses so that muscle tone wasn't reduced too much.

Some studies suggest that people may build a tolerance for the drug, and that the dosage may have to be increased over time. But in the Penn study where participants used the drug for

almost five years, the researcher said the "immediate effects of intrathecal baclofen on spasticity can be maintained over the long term."¹⁴ Effectiveness is not indicated for everyone, however, as some studies show that about 3 to 4 percent of adults with severe spinal spasticity have no clinically significant response to intrathecal baclofen.¹⁵ For some with severe spasticity, intrathecal baclofen may be an answer. Many people with spasticity, however, have and will continue to use other medications.

Diazepam (Valium)

Diazepam is a frequently prescribed and widely used benzodiazepine in the treatment of muscle spasm and pain.¹⁶ But it offers only short-term help,¹⁷ and over time, its dosages must be steadily increased to maintain the same effect. Diazepam is better known as Valium to many and is associated with addictive medications and this gradual increase in dosage also increases the danger of addiction and withdrawal.

Like other benzodiazepines or tranquilizers, diazepam has serious side effects of sedation and may cause depression. In fact, doctors are cautioned about prescribing diazepam to people who suffer from depression because it may increase danger of suicide attempts.

Diazepam has several serious drawbacks. It affects a person's attention span and memory. It can slow thinking and cause confusion, dizziness, and behavior changes. Because it's broken down in the liver, long-term use might affect that organ. Diazepam is also dangerous when used with alcohol. The combination can cause a person to lapse into a coma and stop breathing. People who suddenly stop taking it can experience withdrawal symptoms such as anxiety, insomnia, vomiting, diarrhea, and seizures.

These side effects and possible addiction and withdrawal symptoms should make people cautious about taking diazepam. Because there's no strong evidence that it works any better than baclofen or dantrolene, some doctors hesitate to prescribe it.

Dantrolene sodium (Dantrium)

Dantrolene sodium is a muscle relaxant that works on the muscle fibers to soften spastic muscles. It works directly on the muscle's contracting mechanisms and not through the nervous system. It doesn't completely stop contractions. Studies show it seems to work best on clonus and on spasticity that is stimulated by stretch.

Dantrolene sodium must be watched carefully for any harmful effects on the liver and cardiovascular system. In fact, liver function tests must be given before a person is put on dantrolene. These tests must be initially repeated after three months and then every six months for as long as the medication is taken. Fatal liver damage can develop with little warning, even after several years of taking Dantrium. Liver problems have occurred most frequently in women over the age of 35.

Dantrolene sodium also has been linked to acne and can cause a loss of pep and energy, muscle weakness, drowsiness, dizziness, giddiness, vomiting and severe diarrhea. These effects, however, are directly related to the dosage given. It should not be used by people with known heart, lung or liver conditions.

Other skeletal muscle relaxants (SMRs)

Skeletal muscle relaxants, or SMRs, are the most often prescribed drugs for pain associated with muscle spasms.¹⁸ Most physicians familiar with SCI and treatments for spasticity

prescribed the SMRs baclofen, Valium or Dantrium, because they are known to help with spasticity.

Other SMRs may not be as useful for spasticity, but may be prescribed by doctors less familiar with treatments for spasticity. Some of these SMRs are sold under a variety of trade names: carisoprodol (Soma), chlorphenesin carbamate (Maloate), chlorzoxazone (Paraflex and Parafon Forte DSC), cyclobenzaprine hydrochloride (Flexeril), metaxalone (Skelaxin), methocarbornol (Robaxin and Robaxisal), and orphenadrine (Norflex, Norgesic, and Norgesic Forte).

If you're taking a muscle relaxant for pain and muscle spasms, you might want to check your medicine bottle to see if you are taking one of the SMRs that are less effective for spasticity.

Other treatments

Medication

Clonidine, a prescription drug sold under the trade name Catapres, also shows some promise in the treatment and control of spasticity. Clonidine in tablet form is known to many physicians as a medication to lower blood pressure. It also has been used to treat spasticity, but with only partial success. The drug sometimes caused low blood pressure. Its effectiveness also was affected by digestion. Results were uneven depending on what the person ate and whether the medication was absorbed quickly or slowly into the bloodstream.

Clonidine patches, however, look more promising. The patch goes on the arm, underneath clothing. The drug passes through the skin, providing an even dosage over many days. In early testing, most people were able to reduce or stop their use of other antispasmodic drugs. None of the trial users got low blood pressure. The patches cost more than the pills, but they offer a simple development in the treatment of spasticity.¹⁹

Surgery

For some people with SCI, spasticity remains severe despite the combination of physical therapy and antispasmodic drugs.²¹ For them, surgery may be a last resort. They hope that the severed or removed nerves can no longer cause spasticity. But surgery is not always a permanent solution. Some doctors and people with spasticity report that spasms and pain have returned even after surgery.

Surgery involving the nerves can be described in several ways, depending on the exact procedure. A neurectomy cuts out a part of the nerve. A tenotomy surgically divides a tendon, and a rhizotomy cuts the spinal nerve roots. In addition to reducing spasticity, people who have surgery lose whatever feeling or nerve function they may have had in the area.

Surgery's most negative drawback is that it's irreversible. Cutting the nerves may eliminate all hope of improved function, and this loss of hope can hay a strong psychological effect on people. Most people prefer to avoid a drastic treatment that cannot be reversed and that ends their hope for some return of function. Because the health professions now have an array of effective medical treatments, surgery is becoming less and less necessary.

Intrathecal phenol or alcohol

Phenol-glycerin or alcohol applied directly to the nerves that cause spasticity can offer a permanent spinal nerve block. When injected in or around a nerve that controls a spastic muscle, the chemicals stop the spasticity by interrupting the nerve pathway.

But alcohol and phenol injections can also cause pain at the injection site and can produce tissue scarring. To minimize any damage, the needle carrying the chemicals must be used with a monitor that exactly locates the troublesome nerve or with open surgery so the nerves can clearly be seen.

Intrathecal alcohol or phenol may stop the spasticity, but these chemicals can also damage the nerve roots. Depending on which nerve roots are treated, this damage can lead to loss of bladder reflex and penile erection. The injections, however, work almost instantly, are long acting, and inexpensive.

Electrical stimulation

Electrical stimulation has been used to control ongoing pain. It's now being used to stop or control spasticity. Spinal cord stimulation (SCS) uses an electrode, an extension wire and a pulse generator. The electrode is implanted along the spine near the level of the injury or at a place where the stimulation will offer the most benefit.

The electrode is then attached to a wire that is connected to a generator located under the skin in a pocket in the side. The generator is powered by a battery that is replaced every two years, depending on use. The electrical impulse produced by the generator travel along the wire and to the electrode. These impulses then reduce or disrupt the signals coming from the nerves that trigger the spasms.

SCS can reduce the frequency and severity of spasticity and the amount antispasmodic medication a person needs. It decreases the discomfort of severe spasticity and helps with breathing if spasticity affects the chest and abdominal muscles. SCS has been effective for treating spasticity in people who have not responded well to more conservative measures.²²

Closing thoughts on therapies

Any of these therapies might be used during a person's life. No one treatment has conclusively shown to be more effective than another. A combination of therapies seems to offer the best results for most people.

People with SCI and spasticity may want to work with a physical therapist to learn about hands-on stretching and range-of-motion exercises to calm spasticity.

Others may get control or a lessening in spasticity with the help of intrathecal pumps or with other medications. Once their spasticity is more controlled, they can then work to improve their fine motor skills with an occupational therapist. Some of these therapies may be covered under your health insurance plan and others may not.

Look at the whole picture and find those medications, methods, and routines that work best for you to control or stop spasticity and that have the fewest side effects. No one approach is the best for everyone.

Be sure to talk with your health care professional about which therapies are approved for U.S. Medicare reimbursement or for payment by other insurance companies. Some drug pumps and spinal cord stimulation systems, for example, are covered. Don't forget to talk with other people who have an SCI. They may already have information about insurance coverage and can share valuable information about what treatments have helped them control or work with their spasticity.

If spasticity is a problem for you and if you want to ease or reduce the amount of spasticity you're having, refer to this booklet to learn about all the different therapies. One or more can help you control or stop spasticity. Remember:

- Severe spasticity may not be something you just have to learn to live with.
- Several therapies are available.
- Medications alone usually are not enough.
- Stress management is important.
- A home program of physical therapy, stretching, or range-of-motion exercises alone, or in combination with prescribed drugs, may be a good option.
- These various medications and surgical treatments may have undesirable long-term effects, so learn everything you can about the treatment you're considering.
- Weigh the benefits against the physical, mental, and financial costs before selecting any treatment.

Terms You May Hear

Antispasmodic (an-tie-spaz'-mod-ick): A prescription drug used to control or stop spasticity. Barbiturate: (bar-bich'er-it): Any of a group of barbiturate acid drugs used as sedatives. Benzodiazepine: (benz-zo-di-as'-e-pen): A chemically related group of drugs that have depressant effects on nerve transmission and that are useful for reducing anxiety and muscle tension.

Contracture (kon-trak'-chur): A tightness of tissue around the joints and in muscle that limits movements and function.

Extensor spasms: A reflex movement that results in a rigid straightening or extension of the muscles and limbs.

Flexor spasms: A reflex movement that involves bending-such as a bending of the hip, knee or toe joints-and a shortening in muscle length that causes the joints to bend or pull.

Health-care worker: This broad term can refer to a number of professionals who work in the health-care field such as doctors, nurses, psychiatrists, and physical, occupational and relaxation therapists.

Hypertonia (hi-per-to'ne-a): Extreme muscle tension.

Implantable pumps (im-plant'-a-ble pumps): Small, computer-controlled devices that automatically release small amounts of drugs from a reservior into body fluids.

Intrathecal (in-tra-thee'-cal): To go under the membrane covering the brain or spinal cord. **Neurectomy** (noo-rek'-te-me): Surgical removal of a nerve or a part of nerve.

Quadriplegia (kwod-re-plee'-jee-a): Damage or loss of movement and feeling in all four limbs caused by disease or injury to the nerves within the eight cervical segments of the spine that are located in the neck.

Rhizotomy (ri-zot'-e-me): Surgical severing of spinal nerve roots or the bundle of nerves coming directly out of the spinal cord. The procedure is done to relieve pain or spasticity.

Spasm (spaz'-em): A sudden, uncontrolled tightening or contraction of a muscle or a group of muscles.

Spasticity (spa-stis'-e-tee): A condition of the nervous system characterized by exaggerated reflexes, increased muscle tone and involuntary jerking movements of muscles.

Tenotomy (te-not'-e-me): A surgical sectioning or cutting of a muscle tendon to lengthen the muscle-tendon unit and increase movement in the joint.

References

- ^{1, 3, 17} Kottke, F. J., & Lehmann, J. F. (1990). *Krusen's handbook of physical medicine and rehabilitation*. 4th edition. Philadelphia: Harcourt, Brace, & Javonovich, Inc., W.B. Saunders Co.
- ^{2,20} Young, R. R. (1994, November). Spasticity: A review. *Neurology* 44, Supplement 9.

^{4,5,19,21,22} Goodman, C.L., & Hill, K. (1992, February). Managing spasticity. *Paraplegia News*.

- ⁶ Little, J.W., Micklesen P, Umlauf R, & Britell C. (1989, February). Lower extremity manifestations of spasticity in chronic spinal cord injury. *American Journal of Physical Medicine & Rehabilitation*, 68(1), 32-36.
- ^{7,9} Jamous A., Kennedy, P., Psychol, C., & Grey, N. (1994). Psychological and emotional effects of the use of oral baclofen: A preliminary study. *Paraplegia 32*, 349 353.
- ^{8,10} Mayo Clinic. *Intractable spasticity: Treatment intrathecal with baclofen*. Rochester, MN: Author.
- ^{11,13} Parke B, Penn, R.D., Savoy, S.M., Corcos, D. (1989, January). Functional outcome after delivery of intrathecal baclofen. *Archives of Physical Medicine and Rehabilitation*, 70: 30-32.
- ^{12,14} Latash, M.L., Penn, R.D., & Corcos, D.M., Gottlieb, G.L. (1989, June 8). Intrathecal baclofen for severe spinal spasticity. *The New England Journal of Medicine*, 320:1517-1527.
- ¹⁵Albright, A. L., Cervi, A., & Singletary, J. (1991, March 20). Intrathecal baclofen for spasticity in cerebral palsy. *Journal of American Medical Association*, 265 (11), 1418-1422,
- ^{16,18} Waldman, H. J. (1994). Centrally acting skeletal muscle relaxants and associated drugs. Journal of Pain Symptom Management, 9: 434–441.
- ²³(1992, February). Spasticity: Definition Needed. *Paraplegia News*.