

Parent Guide to Spasticity Management Services

Your child's doctors have found spasticity in your child's legs. The spasticity is making it difficult for your child to walk, but there may be treatments that can help.

What is spasticity?

Spasticity is a condition in which certain muscles are stiff and tight. This condition can interfere with normal movement, speech and gait.

Spasticity is usually caused by altered communication between the brain and the spinal cord and muscles. When this complex communication works properly, muscles have appropriate muscle tone—enough to hold postures and move freely and efficiently. When this complex communication process is altered by changes to the brain, muscles can become spastic.

Spastic muscles are tight and resist motion that occurs quickly. Since typical movement occurs with velocity, spastic muscles will contract and resist motion rather than relax. This impairs an individual's ability to selectively control muscles for smooth movement.



How can spasticity be treated?

There are surgical and non-surgical treatments for spasticity. Non-surgical options include therapy, medications and adaptive equipment, including orthoses. Surgical options include a neurosurgical procedure called selective dorsal rhizotomy. Your child will be evaluated to determine if he or she might be a good candidate for the procedure.

What is a selective dorsal rhizotomy?

Selective dorsal rhizotomy, also known as SDR, is a neurosurgical procedure that aims to reduce spasticity in the legs of young children with bilateral spastic cerebral palsy. This procedure is typically appropriate for children 3 to 12 years old who have the ability or potential to walk. Surgery lasts three to four hours and is performed in an operating room. Your child would be asleep under general anesthesia during the surgery.

To perform the procedure, your child's neurosurgeon would make a small incision in your child's lower back. Using special equipment, he or she would find the abnormal nerve rootlets and cut some or all of them, leaving normally firing rootlets intact. Intensive physical therapy would follow the procedure for a minimum of six months and up to a year to increase strength, improve balance and alignment, and eventually increase your child's independence at home and at school.

Research has found that children with leg spasticity who undergo the procedure and follow it with physical therapy experience a significantly greater improvement in gross motor abilities than children with leg spasticity who undergo physical and other therapies alone.

SDR surgery takes place at The Johns Hopkins Hospital, which is adjacent to Kennedy Krieger Institute. Your child would stay as an inpatient at Johns Hopkins for about five days, and would then be seamlessly transferred to Kennedy Krieger's inpatient rehabilitation hospital for four to eight weeks of post-surgical rehabilitation and therapy.





Goals of SDR:

- Decrease spasticity in the legs
- Improve walking, both now and as your child grows and develops
- Make walking more balanced, smooth and efficient
- Assist with the orthopedic management of bone and joint growth and development
- Reduce the likelihood of pain developing in the future

Your child may be a candidate for SDR if:

- Spasticity is in both legs, and in the legs more so than the arms
- Spasticity is in both legs and interferes with walking
- Selective motor control of the legs is present
- Your child can walk, with or without the help of a walking aid, but walking requires effort
- Your child has good trunk strength
- You're concerned about pain in your child's future
- Spasticity compromises bone and joint (orthopedic) health in your child's legs
- Your child is motivated and able to work hard in therapy, and wants to improve his or her walking



SDR might not be appropriate for your child if:

- Your child has a movement disorder, such as ataxia, dystonia or athetosis
- Your child's arms and legs are both significantly impaired by spasticity (quadriplegia)
- Your child has weakness in the trunk or difficulty sitting
- Your child has subluxation of the hips or severe joint contractures
- Your child is unable to walk independently or with a walking aid
- Your child is unable to cooperate or participate fully in regular therapy



How is the decision about whether to perform SDR made?

Because SDR surgery is irreversible, great care is taken in determining who might benefit. Your child will be evaluated, in detail, by several medical professionals. Our SDR team includes experts in neurosurgery, physical medicine, orthopedics, nursing, physical therapy and child life. The team always includes a child's parents or caregivers in the process of deciding whether to proceed with SDR surgery.

Physical therapy evaluation:

In the first step of the evaluation process, a physical therapist will evaluate your child before his or her clinic visit—or, if you are traveling from far away, on the day of the clinic visit. During this evaluation, the physical therapist will:

- Determine where in the body your child is experiencing spasticity, and what movements are difficult for your child
- Ask your child to move his or her leg joints in certain ways, and will also move your child's leg joints in specific patterns
- Observe how your child walks, and assess the effort he or she makes to walk
- Note how he or she moves from one position to another, looking at balance, coordination and strength
- Have your child walk on a special electronic floor mat that will take a recording of his or her footprints
- Videotape your child as he or she walks
- Determine if your child is able to follow directions and is motivated to participate in therapy that will take a minimum of six months.

Interdisciplinary team evaluation:

During your child's clinic visit, the interdisciplinary team will:

- Talk with you and your child about your concerns and goals
- Review your child's brain MRI and the results of the detailed physical therapy evaluation
- Assess your child's leg movement—by both moving your child's legs, and asking your child to move his or her legs under observation—looking at muscle tone, selective motor control, and leg and body strength
- Assess how your child's leg joints move to see if there are muscle or bone restrictions that could be separate from spasticity
- Watch your child walk

After the evaluation, the team will confer privately to determine the best course of action for your child and make recommendations. The team will share its recommendations with you, and together, you and the team will determine what will happen next.

What if we opt for SDR surgery?

If SDR surgery is recommended, a nursing clinical care manager will collaborate with you, your medical payer source, a Kennedy Krieger insurance specialist and the Kennedy Krieger interdisciplinary rehabilitation team to discuss financial funding and clinical approval of the following: admission, team treatment plan and discharge planning needs. Your insurance benefits for inpatient rehabilitation will be reviewed with you before scheduling surgery.

A tour of Kennedy Krieger's inpatient hospital will be offered as part of the pre-operation planning process. We'll also discuss transportation and local lodging, if needed. The nursing clinical care manager will also coordinate with the discharge planner at The Johns Hopkins Hospital to plan for a smooth transition for your child from that hospital to ours, following surgery.



Notes

Contact Information

For more information, please contact the Kennedy Krieger Institute Spasticity Management Services team at:

- Phone: **443-923-9440**
- Fax: **443-923-9445**
- Email: **SDRInfo@KennedyKrieger.org**

To make an appointment, call **443-923-2600**. For urgent concerns outside of office hours, call **443-923-9200**.

Forms

All forms for school, nursing care, medical equipment, etc. may be sent to us at the fax number above, or to:

Rehabilitation Department
Attention: Fred Finkenbinder
707 North Broadway
Baltimore, MD 21205

Team Members

- Clinical coordinator: **443-923-9440**
- Pediatric nurse practitioner: **443-923-7995**
- Orthopedic surgeons: **443-923-2700** and **443-997-2663**
- Physiatrist: **443-923-9440**
- Neurosurgeon: **443-923-7995**
- Physical therapist: **443-923-9280**
- Inpatient case manager: **443-923-9416**
- Outpatient nurse coordinator: **443-923-9440**

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