

ABSTRACT/SUMMARY

This Handout will introduce you to selective dorsal rhizotomy (SDR) and discuss important points to think about when considering this surgery for your child.

What is it?

In SDR, surgeons select and cut specific nerve roots on the back (dorsal) part of the spinal cord that carry sensory signals from your muscles to the spinal cord. These sensory nerves are targeted because they play an important role in generating spasticity. Normally, signals from these sensory nerves are balanced by opposing signals from the brain, which maintains normal muscle tone. When brain or spinal cord damage upsets this balance, excess sensory signals can lead to spasticity. SDR improves spasticity by partially restoring the proper balance. Because spinal nerves are cut and cannot grow back, this is a one-time procedure that leads to permanent and irreversible changes.

Why do it?

When less invasive procedures are unable to adequately control spasticity in the legs that is interfering with mobility or positioning, this procedure allows for more normal tone and may help a child learn to walk more smoothly and efficiently. While not eliminating all abnormal tone in the legs, it can provide a real benefit for a child who has good strength and balance, little or no fixed contractures and strong motivation and support. While the procedure improves tone in the legs, researchers have also seen improvement in hand use, speech, and energy levels in children after they've undergone SDR.

Who does it?

This procedure is usually performed by a pediatric neurosurgeon.

Where is it done?

The SDR procedure is performed at various hospitals across the country. Some families choose to have it done locally, if that is an option. Others elect to – or must – travel to another facility. As with all medical procedures, choices of locale may relate to whether the family has private medical insurance, public health coverage, such as Medicaid, or a combination of both. It is always advisable for a family to communicate with their health coverage program representative at an early stage when contemplating having their child undergo SDR, thus enabling them to identify factors which might affect their choice of locale.

What if we decide to travel outside the state?

For those who must travel, there are a variety of frequent flier charity programs available that provide assistance with airfare (American Airlines Miles For Kids In Need Program, Delta SkyWish, LifeLine Pilots, Northwest Airlines Kid Cares, to name a few). There are also volunteer pilot organizations that assist families in overcoming the financial barrier airfare may present. The National Patient Air Transport Helpline, whose website is <http://www.npath.org> is a valuable resource in investigating this option.

How is it done?

While there are variations in technique among surgeons and between hospitals, SDR is always performed under general anesthesia. **The procedure usually lasts about 4 hours.** The skin and muscles over the lower spine are cut and the base of the spinal cord is exposed for 2-3 inches along its length. Using a special machine to stimulate the nerve rootlets (small parts of the nerve roots) nerve rootlets that lead to abnormal responses are identified and cut. Usually 25-50% of all tested rootlets are cut. Afterwards, the area is closed up and the skin sutured back together.

What are the side effects/possible complications?

In addition to the risks associated with general anesthesia, common possible complications from this surgery include infection, pain, altered sensation, and changes in bladder or bowel function. Other, more long-term complications can include low back pain, scoliosis or kyphosis (spine curves), and hip displacement.

What should you look for when choosing a surgeon/center?

Like any surgical procedure, it is usually best to find an experienced surgeon and operative team and to have it performed at a setting that offers a team approach and is used to working with children.

What's the rehab involved afterwards?

The post-SDR rehab protocol is determined by each individual physician, and is both intense and frequent. It is not uncommon for a child who has undergone SDR to require physical therapy 5 days a week for the first six months following surgery. This allows for muscle strength in the legs to be re-established and built up. There are also exercises incorporated into a home program, so it is important that parents are able and willing to follow-through with those as an integral part of the rehab regimen.

Will my child return to baseline?

It is important to recognize that your child will have some temporary weakness in the first few weeks following SDR, before he/she starts rebuilding strength. Children who walk independently prior to SDR typically resume independent walking within a few weeks after the procedure. The same should hold true for children who were walking with crutches or a walker prior to undergoing SDR.. Children who were dependent on a seated mobility aid, such as a wheelchair, will present with greater range of movement shortly after SDR, thus improving comfort, positioning, and ease of care.

How can I talk with other families who've had the procedure done?

Most medical centers and teams maintain a list of post-SDR families who are willing to communicate with other families considering SDR. Parents should request a family whose child's pre-SDR profile was/is similar to theirs. There is also a listserv offered through WebMD designed for families who have experience with SDR to communicate with and support each other. Parents can learn more by writing: SDR Parents, c/o Ann Harrell, 506 N. Washington Street, Bourbon, IN 46504; by calling (574) 342-0618; by emailing ann@hoosierlink.net; or by visiting the website <http://www.bourbon.org/dylanshaw>

What can parents do to prepare for the surgery and subsequent rehab?

Parents should not be afraid to ask questions before the surgery takes place, and to network with other parents and professionals who have experience with SDR. They should also explain what to expect to their child in terms that they think he or she will understand and not find threatening.

Using a coloring book, creating a story about a child 'just like Johnny', including a special doll/stuffed animal, are all good strategies. Parents should also talk with their child in terms he or she can understand about the rehab that will need to take place, and how pivotal a role he or she plays in it in terms of motivation and cooperation. Supports should be in place for after the surgery, as well, in terms of arranging sibling care, meals, and anything else the family will need while the parents invest time and energy caring for their child during their hospitalization and their post-surgery rehabilitation.

What will happen to my child in the future?

Every child is a unique, so predicting their future after SDR is inexact.. While there is not a great deal of long term follow-up data regarding children who have had the newer types of rhizotomy, what does exist is promising in terms of reduced spasticity and improved functioning and quality of movement..

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RESOURCES:

http://www.wemove.org/spa/spa_nss.html

<http://www.stlouischildrens.org/default.aspx?tabid=89&acn=view&aid=1470>

http://my.webmd.com/hw/back_pain/shc29sdr.asp#shc29sdr-1948-sdr-parents

<http://www.ihc.com/xp/ihc/documents/pcmc/dorsalrhizotomy.pdf>

<http://www.curesearch.org/resources/resource.aspx?ServiceId=3>

<http://www.npath.org/>



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