



Selective dorsal rhizotomy guide for families

Holland Bloorview
Kids Rehabilitation Hospital

SickKids[®]

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We have created this guide to help you better understand selective dorsal rhizotomy (SDR) surgery and the rehabilitation that follows.

This guide includes information about what you need to know:

- before surgery
- during your child’s rehabilitation stay
- the transition back home

Please feel free to contact us whenever you have any questions.

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Understanding Selective Dorsal Rhizotomy (SDR)

SDR is a permanent surgical procedure that reduces spasticity.

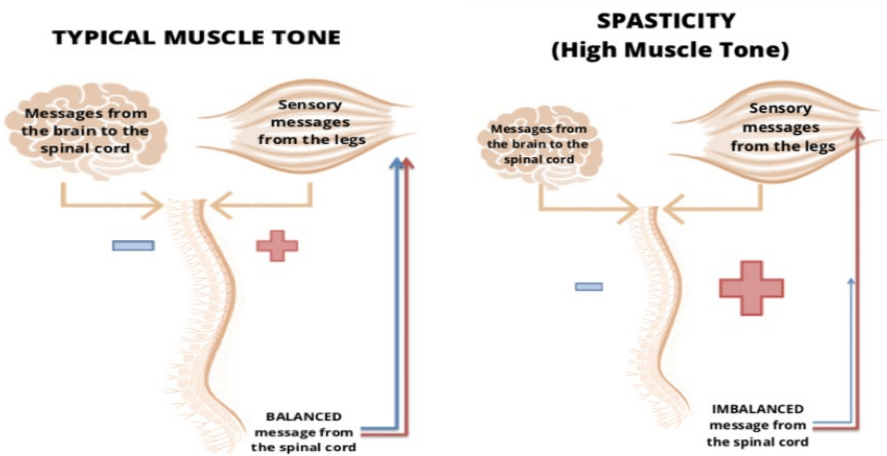
Many children with cerebral palsy (CP) have stiffness (increased muscle tone called spasticity) in the muscles of their arms and legs which affects their ability to move. Children with spasticity may find the stiffness interferes with how much they can move and how fast they can move. Spasticity can make activities like sitting, standing and walking hard to do.

What causes spasticity?

Spasticity is caused by atypical or irregular communication between the brain, spinal cord, nerves and muscles.

All of us have a certain amount of stiffness in our muscles - this is called muscle tone. Muscle tone helps us maintain our posture and move at speeds through ranges of motion that are needed during various activities, such as walking, sitting and standing

Usually the messages (nerve impulses) traveling from the brain to the spinal cord, and coming from the muscles to the spinal cord, are balanced. This allows muscles to contract and relax when appropriate and in a coordinated manner. In children with CP, there has been an injury to the brain causing there to be fewer “relaxing” messages from the brain which causes the muscle to be more spastic (feeling of stiffness). The muscle is tight and tense even though it is not doing anything.



Comparison of nerve impulses in typical and spastic muscles

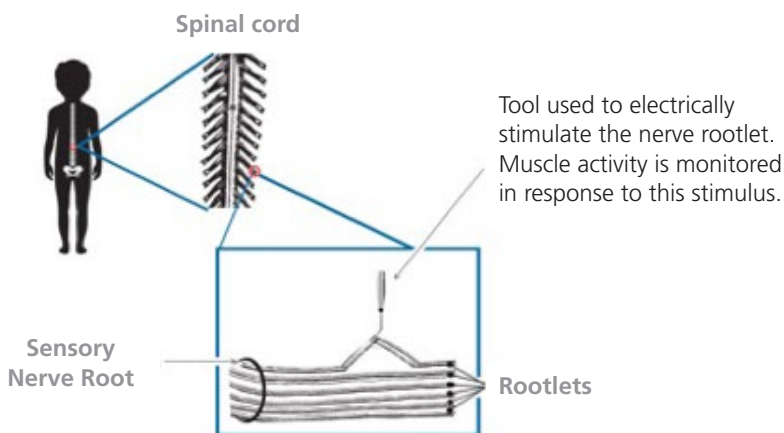
How does the surgery work?

Although we cannot repair the injured part of the brain contributing to spasticity, it is possible to operate on the sensory nerves of the spinal cord to reduce the incoming messages that tell the muscle to contract or stiffen.

Sensory nerves carry information from the muscles to the spinal cord. At the end of the nerves, it separates into smaller strands (like strands of a rope) and these strands are called sensory nerve rootlets. Cutting some **sensory nerve rootlets** reduces the number of messages from the muscles to the spinal cord telling the muscles to contract.

What happens in the surgery?

The surgery requires making a 4 inch long opening along the centre of the lower back. The **vertebrae** (the name for bones in the spine) are cut to expose the spinal cord. The sensory rootlets are carefully identified and separated. During the surgery, the surgeon will use information from the pre-operative clinic assessment (see pg 8 “Holland Bloorview- Baseline functional assessment”) and an **electromyograph** (a machine that measures the strength of nerve signals) to figure out which sensory rootlets to cut.



Goals of surgery

The goal of surgery is not just to reduce spasticity, but to allow movement to be easier, leading to functional improvements in your child’s life. The aim is that by cutting some sensory nerve rootlets, the messages that tell the muscle to contract or stiffen (contributing to spasticity) are reduced.

SDR surgery aims to reduce spasticity to:

- Improve walking patterns, or sitting balance
- Decrease the energy demands for walking or moving
- Make it easier to perform activities of daily living such as getting dressed or bathing

The goals of your child’s surgery will be identified by you and the team at your first clinic visit.

The Importance of therapy

Movement is complex and spasticity is only one factor impacting your child's ability to move. SDR is only one tool to help children with CP improve their function. Although reducing spasticity in the legs may make movements easier, there will still be other potential challenges affecting movement such as decreased strength, balance, or motor control (coordination).

Therapy after surgery will help your child strengthen their muscles and improve their motor control. These changes take time and require intensive therapy.

After the surgery you will notice that your child's muscles feel "looser" and their underlying weakness will make it more difficult for them to move. You will notice that your child will tire more quickly trying to do their regular activities or movement than before the surgery. For this reason, they will require lots of rest.

Where will my child have therapy?

After surgery, your child may stay at Holland Bloorview for up to three months to participate in the inpatient rehabilitation program. Family/caregiver involvement during the inpatient stay is extremely important to help support your child with the many post-operative recommendations made. During this time, your child will practice new motor skills and movements during therapy.

After your child is discharged from Holland Bloorview, they will participate in therapy in your community for up to a year to continue to build their functional abilities. After one year, your community team will help determine how often the therapy should be scheduled.



Preparing for surgery

If you have decided that you would like to proceed with a SDR for your child, this section will help you understand how to prepare and when to start preparing.

When your child's SDR has been scheduled, start thinking about:

1. Pre-surgery appointments

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Neurosurgery Consultation at SickKids:

You will have an outpatient appointment with the neurosurgeon to discuss the surgical procedure in more detail, as well as the physiotherapist to complete the Gross Motor Function Measure (GMFM) which assesses your child's gross motor abilities in sitting, crawling/kneeling, standing and walking.

Referrals:

In the month before surgery, the neurosurgeon will refer your child for a Pre-Anesthesia Clinic (PAC) appointment as well as to complete bloodwork.

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Baseline Functional Assessment:

Within a few months before your child's surgery, a baseline functional assessment will be done. The baseline assessment is to establish your child's abilities before the surgery and use it to compare and measure progress after the surgery. Expect to spend half of a day (around 4 hours) at Holland Bloorview to complete a baseline functional assessment and pre-admission orientation.

The baseline assessment will include:

- **6 minute walk test** (6MWT) which measures how far your child can walk in 6 minutes. Please bring your child's walker and AFOs if they use these to walk.

- **Questionnaires** about: pain, your child's abilities and independence with mobility and self-care activities, and specific goals for the surgery.
- **A gait lab assessment** using motion analysis equipment.

Pre-admission Orientation at Holland Bloorview:

A pre-admission orientation of Holland Bloorview will be arranged to help you prepare for your stay. The orientation will be with one of the inpatient social workers. Your child does not have to attend the orientation.

2. Planning ahead for admission to Holland Bloorview

Here are some tips to think about when planning ahead for admission:

- Make arrangements for accommodation. One parent/caregiver can stay overnight by your child's bedside.
 - For families coming from far distances, there are limited overnight accommodations at Holland Bloorview. These are not covered under OHIP. You can visit the Holland Bloorview Family Accommodations website: <https://www.hollandbloorview.ca/services/programs-services/family-accommodations> to find out more about our accommodations.
- Budget for out-of-town expenses such as meals, transportation, and accommodations etc.
- Make arrangements to be off work.
- Organize childcare if you have other children.

Before your Holland Bloorview admission, please contact team members from your outpatient community service provider for funding and resource support. Below is a link with potential funding resources: www.hollandbloorview.ca/fundingprogramsguide



Surgery and your stay at Sick Kids

Day of surgery

1. Arrive at the hospital 2 hours before the surgery. Register at “admitting” on the main floor.
2. After registering you will be directed to the 2nd floor Pre-operation area. No more than two adults may go with your child. In the Pre-operation area your child will be asked to put on a hospital gown and the nurse will start to get your child ready for surgery.
3. After your child is taken to the operating room, you will go to the surgical waiting room for the duration of the procedure. Once the procedure is finished the neurosurgeon will come and give you an update.
4. Your child will go to the recovery room and a hospital volunteer will take you (one parent/caregiver at a time) to see your child.
5. After your child is settled they will leave the recovery room and go up to the Neurosurgery ward where you will remain for the rest of the admission (5-7 days).

First few days after surgery

Children usually spend the first three days lying flat in a hospital bed. During this time, because your child will be unable to leave the bed safely, they may use a catheter and bedpan for toileting. There might also be some constipation because of the pain medication and lack of physical activity. Additionally, sometimes after surgery, bladder control can be temporarily affected due to normal swelling and healing of the nerves that go to the bladder.

Around the third day after surgery, your child will be assisted to sit up for short periods of time. Bed exercises may also be started at this time.

The physiotherapist will teach you how to move your child safely. The physiotherapist will review positioning recommendations and any post-surgery restrictions with you.

Managing Pain and Discomfort

It is expected that your child might have some pain or discomfort after the SDR. Members of your child's health care team will help address any pain and discomfort.

The pain your child experiences can range from mild to severe. Each child experiences pain differently. Children may also express it differently than adults. Sometimes using scales or pictures is helpful for your child to describe their pain level. The amount of medication given depends on the child's age and weight.

During the first few days after surgery, pain medicine is usually delivered through an IV tube. After that, your child can start taking pain medicines by mouth. Pain medicine works best when taken before pain gets severe. It should be taken regularly and it is often recommended your child take pain medication 30 minutes before therapy to help manage pain during the session.

In addition to medication, other strategies to help to manage pain include:

- Physical comfort measures such as repositioning using cushions or wedges
- Relaxation/deep breathing
- Music
- Distraction through toys and games - it may be helpful to bring a favourite blanket or toy from home.

At both Sick Kids and Holland Bloorview, there are Child Life Specialists and a Therapeutic Clown program. The staff working in those roles are experienced with helping children manage their pain and can provide suggestions and support both to caregivers and children.

Other types of discomfort

At first, your child may have lower back pain. However, there are other types of discomfort your child might experience after the surgery.

Itching

The incision on your child's back might itch as it heals. It is important that your child does not scratch at their incision even when itchy. This will improve over time and your doctor in the inpatient program can discuss with you ways to make your child feel more comfortable.

Dysesthesias (Dis-es-thee-sia)

Your child might be more sensitive to touch in the first few weeks. They may experience feelings of tingling, prickling or numbness in the legs or feet. These sensations are called dysesthesias and are caused by the handling of sensory nerve rootlets during SDR surgery. Dysesthesias are temporary, but they can cause discomfort when they occur.

Muscle spasms

Muscle spasms can occur after the surgery. Knee splints may be recommended to help manage hamstring spasms. There are also medications that can be used to manage spasms if needed.



Precautions after surgery

Avoid rough housing and bouncing activities such as horse-back riding, tobogganing etc., for **at least 2-3 months**. If you are not sure, confirm all those activities with your child's surgeon before participation.

After the surgery, your child's physiotherapist will review movement precautions with you. After surgery, your child is allowed to complete any **active movement** they feel comfortable doing. However there are restrictions with **passive movement**. (*passive movement is a movement performed by another person without voluntary motion on the part of the child*)

For the first 6 weeks after surgery no PASSIVE:

- **Trunk rotation (twisting)**
- **Side bending**
- **Bending forwards beyond normal range**
- **Arching back (or hyperextension) beyond normal range**
- **No vigorous hamstring stretching for 6 weeks after surgery.**
 - Stretching should be limited by back pain and symptoms of dysesthesias in feet (neuropathic pain).
- **Do not lift your child from under the arm pits. Children should be lifted with support under their bum and back**



Your stay at Holland Bloorview

Usually, your child will be transferred to Holland Bloorview from Sick Kids 5-7 days following their surgery.

Inpatient Rehabilitation Program

At first, your child will work on more basic skills such as sitting, weight-shifting, kneeling, crawling and transfers. Then they will work on higher-level skills, such as walking and climbing stairs. During this period at the hospital, your child will build muscle strength, learn new movement patterns, and improve mobility skills used for daily activities.

Your child's rehabilitation team will meet with you around 10 to 15 days after your child's admission (and around every 4 weeks thereafter). This process is called the Family Team Meeting (FTM).

In the FTM, rehabilitation priorities and rehabilitation progress will be discussed and the team will also provide a more accurate estimate of the length of stay.

The inpatient rehabilitation program may last up to three months. If you live in/near Toronto, your child may be able to transfer to the day patient program after the first 6 weeks. Here is the link to the Day Program for more information. <https://www.hollandbloorview.ca/services/about-your-visit/virtual-tour/day-program>

Depending on how close you live to Holland Bloorview your child may be able to go home on weekends after the first few weeks.

Social Work

Social workers are trained to support the social, emotional and service needs of children, and their families.

At the beginning of your admission, you and your child will be introduced to a social worker. Your social worker is available to meet with you on a regular basis and will provide social work support depending on your need.

A social worker can assist you and your child in ways such as:

- providing preadmission orientation
- assisting with funding & resource needs once your child has been admitted
- coping/emotional support, family counselling, or community connections
- chairing family team meetings

Physiotherapy

Your child will receive physiotherapy 5 days a week for 45-60 minutes to work on range of motion, strengthening and practice new movement patterns that may now be possible because of reduced spasticity. Physiotherapy will be based on specific goals discussed with you and the team during the rehabilitation plan.

A physiotherapist (PT) will:

- assess your child's gross motor skills and mobility after the surgery
- review precautions
- make recommendations for positioning and transfers
- make recommendations for orthotics, splints, walkers, standers, and adapted tricycles

A physiotherapy assistant (PTA) may also be involved to carry out the program prescribed by the PT.

Occupational Therapy

Your child will receive occupational therapy two to three times a week for 45 to 60 minute sessions.

An occupational therapist (OT) will:

- assess your child's daily activities such as dressing, bathing and play
- work on functional transfers (for bathing and toileting), trunk control and sitting balance, as well as work on reaching and weight bearing activities to target strength and fine motor skill development
- look at equipment to increase safety, accessibility and independence (e.g. toilet seat, bath seat)
- An occupational therapy assistant (OTA) may also be involved in the care of your child carrying out the program prescribed by the OT.

School

Holland Bloorview has a small, specialized school. See here for more information on the Bloorview School Authority. (https://bloorviewschool.ca/vendor/ckuploads/files/Secondary_Programs_March_2020_Final.pdf).

During the school year your child will attend school when not in therapy. The classroom teachers and teaching assistants will help support the recommendations made by your child's therapists. These recommendations will be related to your child's therapy goals such as using a standing frame or specific seating during school hours.

Therapeutic Recreation

The Therapeutic Recreation (TR) team works with clients and families to cope with hospitalization and to improve health and quality of life for children and youth through participation in recreation and leisure activities.

TR Specialists will:

- assess your child's leisure interests, abilities and resources to provide recreation programs and services that respond to your child's needs
- assist with programs that promote the development of your child's leisure, functional and social skills to assist them in actively participating in recreation and leisure at home, at school, and in the community

TR programs are offered by TR specialists and assistants 365 days of the year to inpatients.

Some example of TR programs include:

- kitchen programs
- gym programs
- music
- arts and crafts
- board and card games
- therapeutic pet visiting
- Snoezelen room
- Social group games
- Therapeutic Playroom (clients aged 0-6 only)
- Swimming
- Special events and outings

The TR team can also provide additional education and resources for recreation and leisure programs suitable for each client within their home community upon discharge.

Child life services

Child Life Specialists will be available by referral from a member of your inpatient care team to help promote your child's ability to cope, help with motivation, and encourage their understanding related to surgery and rehabilitation goals.

Equipment used during rehabilitation

Your child's therapists will teach you and your child how to safely use equipment for positioning and mobility. The therapist will also provide you with information about how often and how long each piece of equipment should be used.

We want your child to move the equipment as independently as possible because it is important for their rehabilitation in helping to build strength, coordination and endurance.

If your child already owns a wheelchair or walker we ask that you bring your child's personal equipment to the hospital.

Wheelchair

All children use a wheelchair after SDR. Sitting tolerance is gradually increased based on reported pain and/or symptoms. The wheelchair is adjusted to fit your child's needs. Your child will need to sit up straight while in the wheelchair to encourage their best sitting posture.

Standing frame

This piece of equipment is used to help your child stretch and build strength in the legs and trunk. It also helps your child begin to bear weight on their legs. While using the stander, your child should wear their ankle foot orthoses (AFOs).

Walker

Most children begin walking with a rear facing walker (a walker that gives support from behind). If your child has a walker, please bring it with you to Holland Bloorview.

Adapted tricycle and tricycles

During some therapy sessions your child will also use an adapted tricycle. Your child's therapist might also recommend using it at other times of the day to help build strength, coordination and endurance.

Your child must always wear a helmet when riding. Please bring your child's helmet from home if you have one.

Ankle Foot Orthotics (AFOs)

Your child may be able to use their existing AFOs following the surgery. If your child uses hinged AFOs (the ankle is able to bend), straps will mostly likely be added to limit this motion while your child is regaining their strength.

AFOs should be worn throughout the day but may be removed at night.

Knee splints (also known as zimmers/gaitors)

Knee extension splints may be used for positioning/stretching after surgery. If your child has a pair please bring them with them to Holland Bloorview.



Going home

Planning ahead for the return home

Having things set up at home before your child is discharged from the hospital will help ease the transition home. Our staff will do our best to make your child's transition from hospital to home as smooth as possible. Your community school and therapists will be invited to join the discharge planning meeting by teleconference.

Outpatient therapies

After being discharged from the hospital, your child will begin outpatient physiotherapy and occupational therapy at your local children's treatment centre.

The recommended frequency of therapy is as follows:

- 3-6 months post-surgery: two sessions of PT per week, and one session of OT per week and then return to usual OT program
- 6-12 months post-surgery: one to two sessions of PT per week and then return to usual PT program

Home program

In addition to outpatient therapy sessions your child will be expected to do an in-home exercise program. At the time of discharge the inpatient therapist will provide you with a home program that is adapted to your family's needs and living circumstances. This home program will be updated and progressed by your community therapist.

Follow-up appointments

The first follow-up appointment will take place a month after the SDR. The appointment will be with the neurosurgeon at Sick Kids in the Neurosurgery Clinic.

To measure your child's progress, your child will have follow-up appointments with the multidisciplinary SDR team at Holland Bloorview. These appointments will be scheduled at around 6, 12 and 24 months after surgery. After this time, frequency of follow-up appointments will be determined individually for each child.

At each appointment, the team will examine your child and will provide therapy recommendations as needed. The chart below shows which specialists your child will see during the three follow-up visits.

SDR follow-up appointments at Holland Bloorview

Specialists to see	Appointment Date (length of time after surgery)		
	6 months	12 months	24 months
Developmental Pediatrics	✓	✓	✓
Physiotherapy	✓		✓
Orthopedics	✓	✓	✓
Neurosurgery	✓	✓	✓
Motion analysis		✓	

You will be contacted by letter to notify you of your next appointment.



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