

# Selective Dorsal Rhizotomy (SDR) in SCOTLAND

INFORMATION FOR FAMILIES  
and CARERS of Children who are  
suitable for SDR Surgery

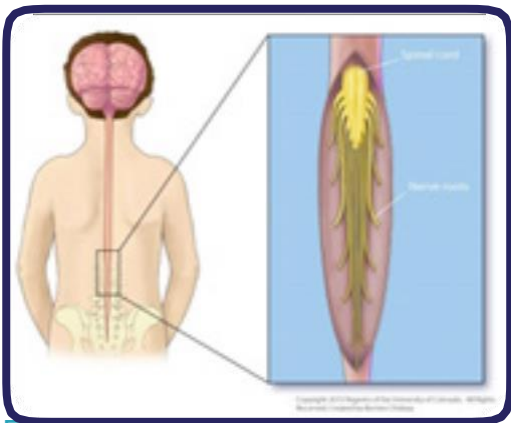
## Where will the operation take place?

There are four paediatric neurosurgical centres in Scotland. This operation will take place either in Glasgow or Edinburgh where there are specialist teams trained to look after children who are having the operation called Selective Dorsal Rhizotomy (or SDR for short).

## What happens during the SDR operation?

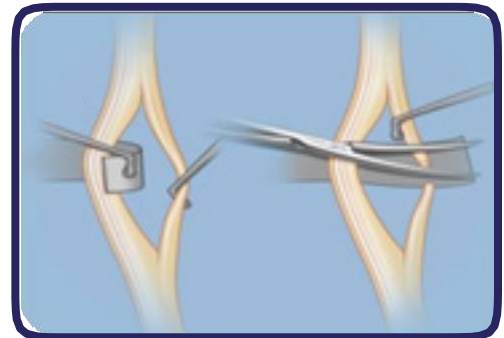
SDR is carried out while your child is under general anaesthesia and takes around 4 hours.

A skin incision (or cut) is made in the upper lumbar spine. The spinal canal is opened at only one level. Under the operating microscope, the membrane covering the spinal cord is opened and the lower end of the cord, with the sensory roots entering it, is identified.



Each of the sensory nerve roots is then subdivided into four or five rootlets. Each rootlet is stimulated to identify the ones that contribute most to the spasticity and these rootlets are then divided. The process is repeated for all the other nerve roots on both sides, aiming to divide the appropriate percentage of sensory rootlets.

At the end of the procedure, the membrane covering the spinal cord is closed again, the back muscles are returned to their original position and the skin is closed with dissolvable stitches.



## What are the risks with SDR?

SDR is an irreversible surgical operation and carries some risks. Your Neurosurgeon will explain the risks to you.

Complications after SDR are uncommon but you need to be aware of them.

Complications include:

- Infection
- Leak of cerebrospinal fluid from the wound or development of a fluid collection below the skin
- There may also be severe leg weakness or incontinence; however as all the nerve roots are carefully checked by stimulating them during the operation and monitoring their response, severe weakness and incontinence are very rare complications
- There are also risks associated with general anaesthesia
- Scoliosis (a curvature of the spine) in the long term following SDR has been reported in medical literature. This is generally associated with the traditional technique which exposes about 3 inches of the lower spine. This technique is not used in our centres.

## What should we expect after the procedure?

SDR is not a cure for cerebral palsy. Reduction in spasticity is immediately apparent after the procedure but the pre-existing weakness in muscles and difficulties with co-ordinating movements remain.

You should expect your child to be in hospital and to engage in post-operative rehabilitation care with the inpatient team for about 3 weeks prior to transfer back to your local community team.

It takes time for the strength in the legs to return. With an intensive exercise and activity programme, supported by physiotherapy advice, your child will learn to use their body in a new way. Leg movement will become easier and the level of control, dexterity, range and speed will increase over time.

It may take up to two years for the full benefit of the procedure to become clear.

Many children develop hypersensitivity in the soles of their feet after surgery—this is temporary and will improve. Socks/shoes and standing help to reduce this and medication can help if it is causing problems with your child's rehabilitation. There may also be sphincter disturbance, which could mean a decrease or improvement in bladder or bowel control which could be permanent. This may be frustrating for both you and your child. Your child may also experience muscle cramps after an active day which require medication.

There is evidence to demonstrate that SDR is associated with long-term benefits. These relate to a permanent reduction in spasticity and to improved movement and walking as well as improved quality of life for both the children and their families.

Whilst the aims of SDR include a reduction in later orthopaedic surgery, there is an ongoing need for monitoring your child's progress and there may be a need for further operations.

# What happens on admission to hospital?

In the next section, we will talk about what happens when your child is admitted to hospital for SDR.

## Pre-operative assessment

A full pre-operative physiotherapy and orthotics assessment will have been carried out a few weeks before SDR when you visited the hospital to confirm that your child would benefit from SDR. We will conduct another assessment when your child is admitted to hospital for surgery and this assessment serves as a baseline for subsequent follow up reviews after surgery. A plan will be formed by yourself and the team regarding the care required for your child after surgery. This will include specific planning for the ongoing care of those living at significant distances from the two provider centres in Edinburgh and Glasgow.

## Orthoses (sometimes known as splints)

For most children undergoing SDR treatment it is necessary to use orthoses after surgery to help with rehabilitation. Normally this will be Ankle Foot Orthoses (AFOs). Many children undergoing SDR surgery will already be AFO users and their own AFOs or other orthoses may be completely appropriate for use immediately after surgery and for rehabilitation.

As part of the pre-operative assessment an orthotist from the hospital will be part of your child's multi-disciplinary team (MDT) for SDR.

If your child usually wears orthoses, and these fit and work well then these will be used immediately following surgery. This will be decided when your child has their assessment.

If new orthoses are required then the orthotist from the operating centre will try to cast for your orthotic treatment before your child's surgery if possible. If the team feel it is appropriate the orthotist may choose to cast your child in the initial days after surgery. This will be assessed on a case by case basis.

The physiotherapist in the hospital will be in touch with your child's local community physiotherapist to get an up-to-date report.

# What happens before the operation?

You will be asked to come to the hospital on the day before the surgery.

When coming to the hospital please bring:

- Your child's wheelchair (if your child already uses one)
- AFOs and suitable footwear
- Long warm socks
- Shorts & T-Shirt
- Pyjamas or nightgown, dressing gown and slippers

Other items you may wish to consider bringing with you are:

- A favourite toy, doll, or stuffed animal
- A favourite blanket and/or pillow
- Story books or colouring books
- Reading books or magazines
- Favourite movies on DVD
- Tablet and/or mobile phone (patient Wi-Fi is available on the Ward)

Your child's neurosurgeon will visit you to explain about the operation in more detail, discuss any worries you might have and ask you to give your permission for the operation by signing a consent form.

The nurses and doctors will complete the required paperwork and checks and one of the physiotherapists will also see you to do some final assessments.

It is important that your child does not eat or drink anything for a few hours before the anaesthetic. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure.

On the day of surgery you will be able to accompany your child to the anaesthetic room in the operating theatre.

# What happens after the operation?

After the surgery is completed, your child will be brought to you from recovery once they have woken up. Once your child is fully awake he/she will return to the ward. Close monitoring throughout the first 24 hours ensures good pain control, usually using patient controlled analgesia (PCA) given into a vein (intravenously/IV).

Your child will be helped to change their position in bed every few hours by the nursing staff. While your child remains in bed, they will have a urinary catheter in place draining off urine into a collecting bag. Some children complain of mild headache at this stage. Some children may also experience uncomfortable legs in the first few days after surgery but this can be managed with appropriate medicine.

On the second day following surgery, the medicine for pain is reduced slowly. Gentle physiotherapy in the bed is started and the urinary catheter is removed on day 2 or 3.

It is usual for children to have some numbness in their legs in the first week. Your child's legs will be less stiff than before surgery, but may also be significantly weaker at this stage.



Your child will be encouraged to start sitting out of bed on day three. Physiotherapy is then gradually increased, paying particular attention to maintaining good trunk balance and range of movement in the lower legs. Muscle strengthening exercises are also started. On day five or six, we would expect that your child's discomfort will be easily controlled by simple pain relief given by mouth. A programme of physiotherapy will begin, with two daily sessions.

The aim of this exercise programme is to continue to develop strength

in the legs, trunk and pelvis, increase range of movement in the legs, develop better leg movement, and to develop and improve walking. All this takes time and will be continued after hospital discharge with support from your local physiotherapy service.

If your child's current orthoses are not suitable or the orthotist has not already taken casts for your child's orthoses pre-operatively, they will visit your child on the ward within a few days following surgery in order to review and possibly cast for new orthoses. If casts were taken before the operation the orthotist will visit your child on the ward for fitting and delivery soon after surgery. If casts are taken after surgery, the new orthoses will then be fitted to your child by arrangement and agreement with your child, yourself and the team.

If your child is accustomed to wearing Ankle Foot Orthoses (AFOs), you are likely to need the same type of footwear post-operatively.

If your child was not an AFO wearer previously they will need long calf length socks without any thick patterning to them and suitable footwear (e.g. trainers) in order to stand with the AFOs. Typically the orthoses fit neatly into standard trainers one size larger than they would usually wear or bring the largest pair of trainers that your child currently wears. Your orthotist can help with any further advice you need about what to expect from orthotic use.

The hospital orthotist will arrange a review of the AFOs to coincide with the most appropriate physiotherapy session in your child's in patient/acute rehabilitation stage. Any adaptations that may be required will be carried out at this time and any further reviews or adjustments prior to discharge back to your local service will be arranged.

Children following SDR will require an enhanced programme of exercise and activity after discharge. Parents will have the opportunity to learn how to participate in the rehabilitation process prior to discharge, and will be given ideas for starting their home exercise programme, which can then be adjusted by their local physiotherapist.

Prior to discharge you will make a discharge plan with the hospital team and your local team for follow up. Follow up will usually be with your regional team but the hospital team will see you at specific intervals.

The hospital physiotherapists will be in contact with your child's local physiotherapist in the community and there will be opportunities to discuss any concerns following discharge home as they arise.

## What happens when we get home?

Once home, your child may tire more easily after the operation and may not manage a full school day or week. A phased return may be helpful but should be discussed with your local therapy team and your child's school.

The neurosurgical team will usually review all patients around 3 months after surgery for a wound check. Assessments similar to the ones before your child's surgery will be carried out at 6 months, 1 year and 2 years by the hospital based physiotherapists so that your child's progress can be closely monitored. Gait analysis (formal walking assessment) will be repeated after 2 years.

Your child will also continue to have regular follow up appointments within the regional clinic.

You will be seen by your local orthopaedic surgeon if there are any concerns with musculo-skeletal alignment noticed during follow up assessments.

Progress and any suggested recommendations following assessment will be discussed with you and your child's local physiotherapist and your child's Cerebral Palsy Integrated Pathway Scotland (CPIPS) assessments will continue every year with your local physiotherapy team. CPIPS is a national surveillance program in Scotland launched in 2013 which monitors muscle, bone and joint health by regular clinical examinations by a child's physiotherapist and x-rays to monitor the position of their hips.

All future orthotic care will be carried out by your child's local orthotic team. The orthotic team who treated your child while they were an inpatient will remain available for advice should you or your local service wish to contact them for any reason. Your acute centre orthotist will communicate with your local orthotic team regarding the orthotic treatment you have received while undergoing SDR surgery and post operative treatment.

Your local physiotherapist and orthotist will monitor change and provide the advice and support you and your child needs.

## Questions?

This is a lot of information to take in and you may prefer to ask questions whenever they arise.

There is a further leaflet 'Information for Children' that you may wish to read with your child.

Please feel free to contact the SDR co-ordinator; Jacqueline Clark if you have any enquiries about any of the above information and you will be directed to the most appropriate person to help with this.

[Jacqueline.clark5@ggc.scot.nhs.uk](mailto:Jacqueline.clark5@ggc.scot.nhs.uk)

## Further Reading

Selective Dorsal Rhizotomy has undergone extensive review by the National Institute for Health and Clinical Excellence (NICE) as part of a stand-alone evaluation, the latest version of which was published in December 2010:

<http://guidance.nice.org.uk/IPG373/Guidance/pdf/English>

A wider review of the treatment of spasticity in children was published in July 2012 and updated in November 2016:

<http://publications.nice.org.uk/spasticity-in-children-and-young-people-with-non-progressive-brain-disorders-cg145>

The NICE guidance strongly advises that SDR should be undertaken by a multidisciplinary team with specialist training and expertise in the care of spasticity in patients with cerebral palsy, and with access to the full range of treatment options. This is the service we offer in Scotland.

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Adapted from information provided by North Bristol NHS Trust, Great Ormond Street Hospital and Oswestry—Selective Dorsal Rhizotomy.

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