2019

# Selective Dorsal Rhizotomy (SDR)

## Information for families and carers who are considering SDR surgery

**Association of Paediatric Chartered Physiotherapists**

## What is Selective Dorsal Rhizotomy?

Selective dorsal rhizotomy (SDR) is a specialist neurosurgical operation used to reduce spasticity (muscle stiffness) in some children with cerebral palsy. The aim of surgery is to make movements easier and to improve comfort; **it will not cure cerebral palsy**.

After SDR surgery children need physiotherapy rehabilitation for up to two years to maximise the expected benefits.

SDR surgery is now available as an NHS procedure for children who fulfil the selection criteria.

## Cerebral Palsy and Spasticity

Cerebral palsy occurs when a baby sustains a brain injury very early on in life. This can be before they are born, around the time of birth or up to two years after birth. The brain injury results in problems with movement and posture control, but can also lead to learning, behaviour and sensory difficulties (vision and hearing). Children with cerebral palsy can appear very different. This is due to both the size and the location of the brain damage which can affect the severity and type of problems a child will have.

In cerebral palsy we describe movement problems related to:

- The **area** of the body affected:
  - Bilateral – both sides of the body
  - Unilateral – just one side.

  You may also hear these called diplegia and hemiplegia.

- The **type** of movement problems:
  - Stiffness (spasticity)
  - Weakness (hypotonia)
  - Uncontrolled movement patterns and postures (dyskinesia, dystonia)

- The **severity**:
  - The Gross Motor Functional Classification System (GMFCS) is a scale of I to V, where Level I describes children who are least affected, and level V where children have very little movement and are fully reliant on equipment and their carers. (See appendix).

Muscle spasticity can interfere with a child's ability to learn to move around. Spasticity and associated muscle spasms can be painful and upsetting. They can disrupt sleep and make it difficult to participate in daily life.

In cerebral palsy the brain injury itself will not get worse over time, however, as children grow their movement problems can lead to muscle imbalances, where some muscles pull more than others. Over time this can cause shortening of muscles and tendons (contractures) and make movements more difficult. Therefore treatments to reduce muscle stiffness are an important part of the management of children with cerebral palsy.

However it is important to know that just removing spasticity alone will not lead to improvements in function for a child; any treatment must be related to a child's specific developmental goals and supported with appropriate therapy and assistive equipment when required.

**Movement problems in cerebral palsy can be due to**

- Muscle stiffness (spasticity)
- Uncontrolled movement patterns (dystonia)
- Problems starting and stopping movements quickly and smoothly.
- Difficulty maintaining a muscle action at the right time with the right force
- Problems using muscles together to create a controlled movement,
- Muscle weakness due to the brain injury (cortical weakness) and also due to lack of use (muscle atrophy).
- Muscles which are too short (contractures)

## What does the SDR surgery involve?

SDR surgery is performed under general anaesthesia and takes around 4-5 hours. The surgeon makes a cut in the lower back at about waist level. A small part of one back bone is removed, to allow the surgeon to see the nerves coming out of the spinal cord - these are the nerves that take messages to and from the legs.

The surgeon divides the nerves into groups

- Sensory nerves – those that bring information about feeling in the legs
- Motor nerves – those that control the movement in the legs

The motor nerves are protected and will not be cut. The sensory nerves are tested electrically and between 50% and 75% of these nerve fibres are cut. This will reduce the spasticity in the legs. The surgeon will ensure that the nerves that supply the bladder and bowel are protected and this will prevent any problems with incontinence. The bone will be replaced at the end of the procedure.

## Which children are eligible for SDR?

SDR has been found to be most effective in reducing spasticity and improving movement in children who have **bilateral spastic cerebral palsy**, mainly affecting the legs, and are classified as **GMFCS II and III**. NHS England and Scotland have clear guidelines on who is eligible for SDR funding and how to be referred to a specialist centre for assessment.

**SDR referral criteria:**

- Aged 3 years to 9 years inclusive with a diagnosis of cerebral palsy with spasticity mainly affecting the legs;
- Dynamic spasticity in the legs which affects function and mobility, and no dystonia;
- The MRI brain scan shows typical cerebral palsy changes of white-matter damage of prematurity or periventricular leukomalacia (PVL), and no damage to key areas of brain controlling posture and coordination*;
- Functions at GMFCS level II or III;
- There is no evidence of genetic or neurological progressive illness;
- Only mild to moderate leg weakness with ability to maintain age appropriate antigravity postures - crawling, standing and walking
- No significant scoliosis or hip dislocation (Reimer's index should be <40%)

* Lesions in basal ganglia or cerebellum are contra- indications to SDR, since they are associated with other cerebral palsy types (dystonia / ataxia).

The APCP acknowledges that SDR can be suitable for some children with more severe cerebral palsy (GMFCS IV) where spasticity causes pain and makes it hard for children to be positioned and cared for. However currently SDR is not commissioned by UK NHS services for GMFCS IV, as other treatment options may be considered more suitable. This means it can only be done as a self-funded procedure.

### How can I find out whether SDR is the best option for my child?

Children with cerebral palsy, who have spasticity, should be under the care of their local movement disorder team. This team may include a Paediatrician or a Neurologist, Physiotherapist and Orthopaedic Surgeon. There are slightly different arrangements for England, Wales, Scotland and Northern Ireland so if you are not sure then the best person to speak to is your local Paediatrician and physiotherapist. You can make an appointment with them to discuss the different treatment options available and the risks and benefits. They will need to consider if your child fits the referral criteria for SDR, so they may have to arrange some more tests before they can make the referral. Your child may need a brain scan (MRI) if they have not had one already, to check where their brain is damaged. They may also need hip and spine x-rays.

If your child fits the referral criteria for SDR the next step is to make a referral to one of the specialist centres for an SDR opinion. You may find it helpful to discuss SDR with your physiotherapist before the appointment so you know what questions to ask. Most centres will invite your physiotherapist to send information before the appointment, but you can also ask them to come with you if you would find this helpful; please just let the specialist centre know that they will be coming.

At the specialist centre appointment you will be asked questions about your child's early development; they will want to know how your child is affected by cerebral palsy, how they move, what they find difficult and how they have responded to previous therapy and treatments. Your child will have a detailed physical assessment. At the end of the assessment the specialist team are usually able to confirm whether SDR is suitable for your child and what benefits they would expect. As post-operative physiotherapy is essential to obtain the best results after SDR, suitable children and their families need to be motivated and show that they are able to cooperate with therapy in an intensive way for at least two years after surgery. As this is a permanent procedure they may suggest other spasticity treatments before SDR. This will allow them to give you the best possible information about how your child will respond when some of the spasticity is taken away.

### Are there alternatives to SDR?

SDR is just one option in the management of spasticity in children with cerebral palsy and it is important to realise it is not suitable for all children. Alternatives to SDR include medication, long-term exercise and activity as supported and advised by a physiotherapist, use of botulinum toxin injections into the spastic muscles, splinting and orthopaedic procedures. There are NICE guidelines related to spasticity management in children and young people, available on-line, which also explain treatment options and their benefits and risks.

Not every child with cerebral palsy requires intervention and many children are able to lead full and happy lives with exercise and activity alone.

## What are the risks?

There is good evidence that when SDR is done under strict controls in specialist centres, it carries low risk. In the recent NHSE study (2018) the most common risk was localised wound infection, these all resolved with no long term problems. Some children experience changes in sensation during first few weeks after surgery. This is described as itching, tingling, burning and sometimes pain and there may be areas of numbness. Children are offered medication to reduce these sensations and they usually improve by 6 months, it is unusual for problems to go on for longer.

## Is SDR available under the NHS?

SDR is now available as an NHS funded procedure where children fulfil the referral criteria. NHS funding includes the surgery and immediate post-surgery rehabilitation. There is also money available for community rehabilitation; your local physiotherapy team can apply for this via the specialist centre. It is essential that the local physiotherapy is discussed and agreed before surgery goes ahead.

Some families wish to provide additional rehabilitation at their own cost, to supplement the NHS therapy. This is not essential to achieve the best outcome. Where parents do chose independent rehabilitation it is usually because it they want more flexibility to fit in with family life. We recommend that families discuss this with their NHS team so therapists can work together for the best outcomes for the child.

## What can I expect SDR to achieve?

There is now enough evidence to demonstrate that SDR can be associated with long term benefits when children are carefully selected. These benefits are not only related to reduction in spasticity, but also to improved functional activity and quality of life.

Children's spasticity is reduced immediately after surgery and their legs will appear more relaxed. However because SDR reduces the sensory information from the legs, children will find it difficult to co-ordinate their movements immediately after the surgery. They can appear weaker as this reduced control unmasks existing leg weakness found in cerebral palsy. This is why rehabilitation is essential. An intensive physiotherapy programme will help children learn to use their body in new ways. Strength and abilities will gradually improve, although it may take up to two years for the full benefits to be seen.

How quickly children recover after SDR is directly related to their strength and abilities before surgery. Children who are GMFCS II will improve more quickly than children who are GMFCS III. However all children will need help to stand and walk immediately after surgery. In addition, some children who walked independently without any walking aids before surgery, may need aids after the operation, at least until they build up their co-ordination and confidence. Children who already use aids may need something different but this will be assessed by the rehabilitation team. All children should have access to a wheelchair for longer distances and to allow rests and it is important to discuss this with children so they understand what to expect. Children will also need to use splints such as ankle foot orthoses after surgery.

In the longer term you can expect your child to remain flexible, as spasticity is reduced permanently. Evidence shows that children maintain the functional improvements they have gained as they grow. However studies that have looked at whether children need orthopaedic surgery show that 70-80% of children are still likely to need surgical procedures. Therefore it is very important that children are reviewed regularly as they grow so they can receive timely treatment.

Children with cerebral palsy are more likely as a group to have issues with bladder and bowel function. There is moderate evidence for improvements in bladder and bowel control after SDR.

It is important to remember that SDR is not a cure for cerebral palsy, and although function improves over the first 2 years most children remain within their GMFCS level even after SDR. This is usually because of other movement problems such as poor balance and co-ordination. As children can be very different it is important to discuss with the specialist team the specific goals for your child before surgery so that you can balance rehabilitation with your child's everyday life. Your child will have regular reviews at 6, 12 and 24 months after surgery and these are good opportunities to check your child's progress and get advice for the next stage of their rehabilitation.

## Resources and further information

NHS England Commissioning Policy: Selective Dorsal Rhizotomy (SDR) for the treatment of spasticity in Cerebral Palsy (children aged 3-9 years). Reference: 170063PNHSE

National Institute for Health and Care Excellence. (2012 (updated 2016)). Spasticity in under 19s: management (CG145) Clinical guideline, https://www.nice.org.uk/guidance/cg145

National Institute for Health and Clinical Excellence. Selective dorsal rhizotomy for spasticity in cerebral palsy. Interventional procedure guidance 373, December 2010

## Hospitals that provide SDR assessment and surgery

There are currently five centres in England and two in Scotland that provide National Health funded SDR assessment and surgery (June 2019)

The English centres are:

- Alder Hey Children's Hospital, Liverpool
- Bristol Royal Hospital for Children
- Great Ormond Street Hospital for Children, London
- Leeds General Infirmary
- Nottingham University Hospital

The Scottish centres are:

- Royal Hospital for Sick Children, Edinburgh
- Royal Hospital for Children, Glasgow

**More information can be found on the relevant hospital websites.**

Appendix 1

## The Gross Motor Function Classification Score (GMFCS)

The Gross Motor Function Classification Score is a standardised classification system that describes the gross motor function of children and young people with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, the actual quality of movement.

The GMFCS is categorised into the following 5 levels:

**Level I** - Walks without restrictions: Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

**Level II** - Walks without assistive devices: Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

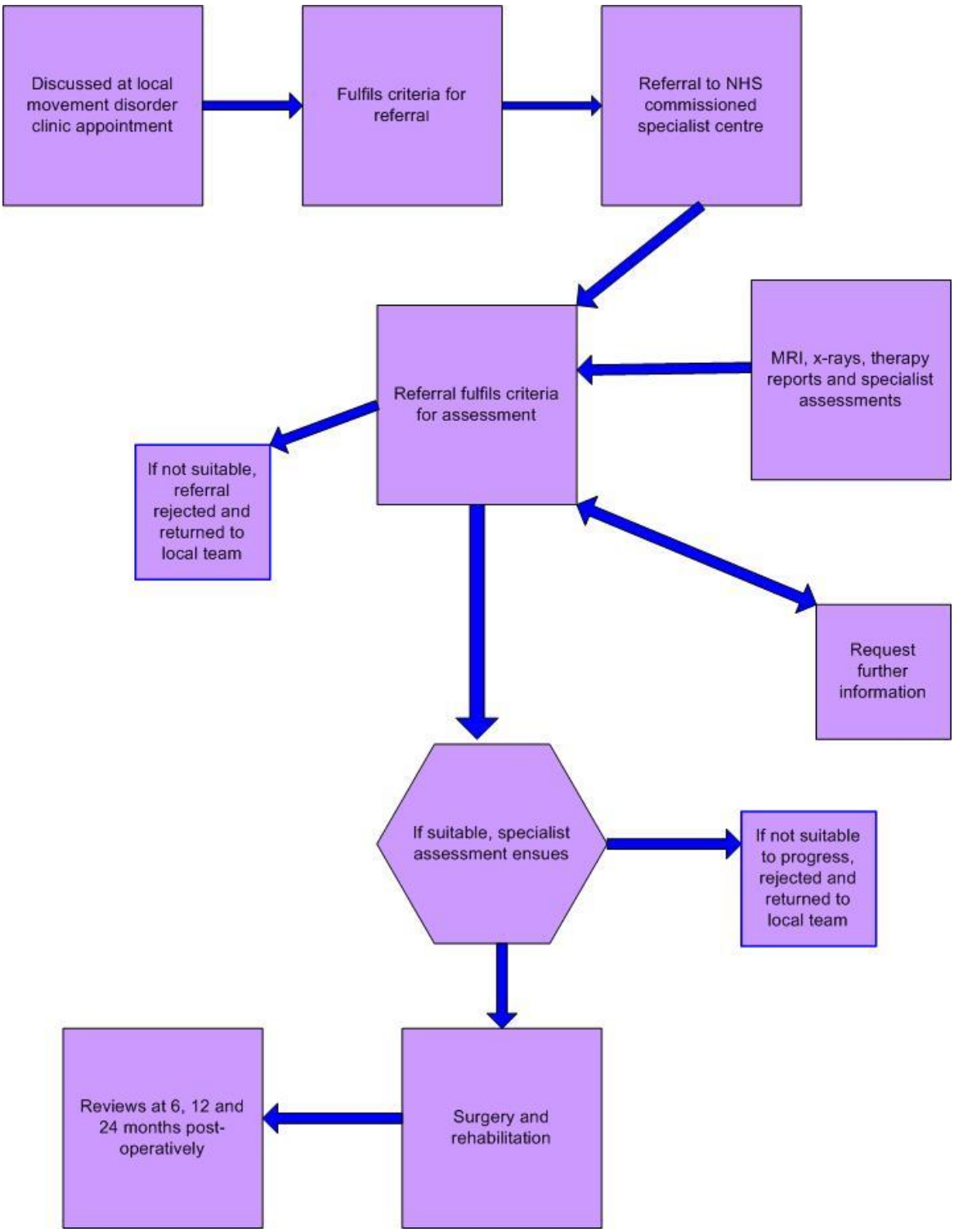
**Level III** - Walks with assistive devices: Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

**Level IV** – Has limited self-mobility / may use powered mobility: Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

**Level V** – Has severely limited self-mobility even with assistive devices: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Appendix 2

## SDR Referral Pathway



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