Selective Dorsal Rhizotomy for Parents & Carers Could this surgery help *my* child?

Caroline Hardaker
Highly Specialist Children's Physiotherapist
www.carolinehardakerkidsphysio.co.uk

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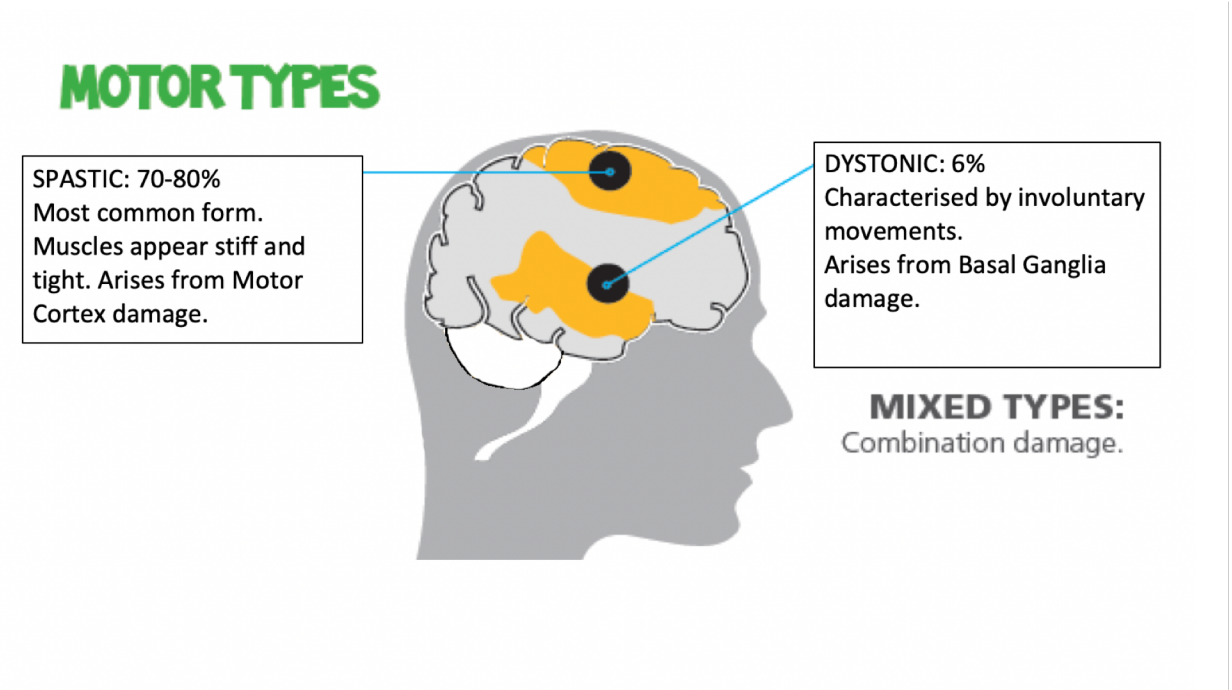
Contents

Moving for Children who have Cerebral Palsy

Why movement can be difficult for children with CP

- CP is a neurological disorder caused by a non-progressive brain injury/malformation that occurs while the child's brain is developing. CP primarily affects body movement and muscle coordination (www.cerebralpalsy.org)
- Can have problems with muscle tone, spasticity, weakness, control of movement.
- Typical development of movement has clever building blocks so that one skill allows development of another. This is disrupted for children with CP.
- Spasticity is only one piece of this puzzle but it is an important one.
- Permanently removing spasticity provides the opportunity, with therapy, to build strength and gain more typical patterns of posture and movement.
- Always a ceiling to someone's potential, no matter how hard I train there is a limit to how fast I could run a marathon. Baseline ability together with motivation and compliance with rehab is key.

Classification of movement disorders



Children with dystonia tend to have more significant motor impairment than those with spasticity so dystonia is associated with a higher GMFCS level.

A combination of different movement disorders may be present. High levels of spasticity can mask the presence of dystonia.

What is spasticity?

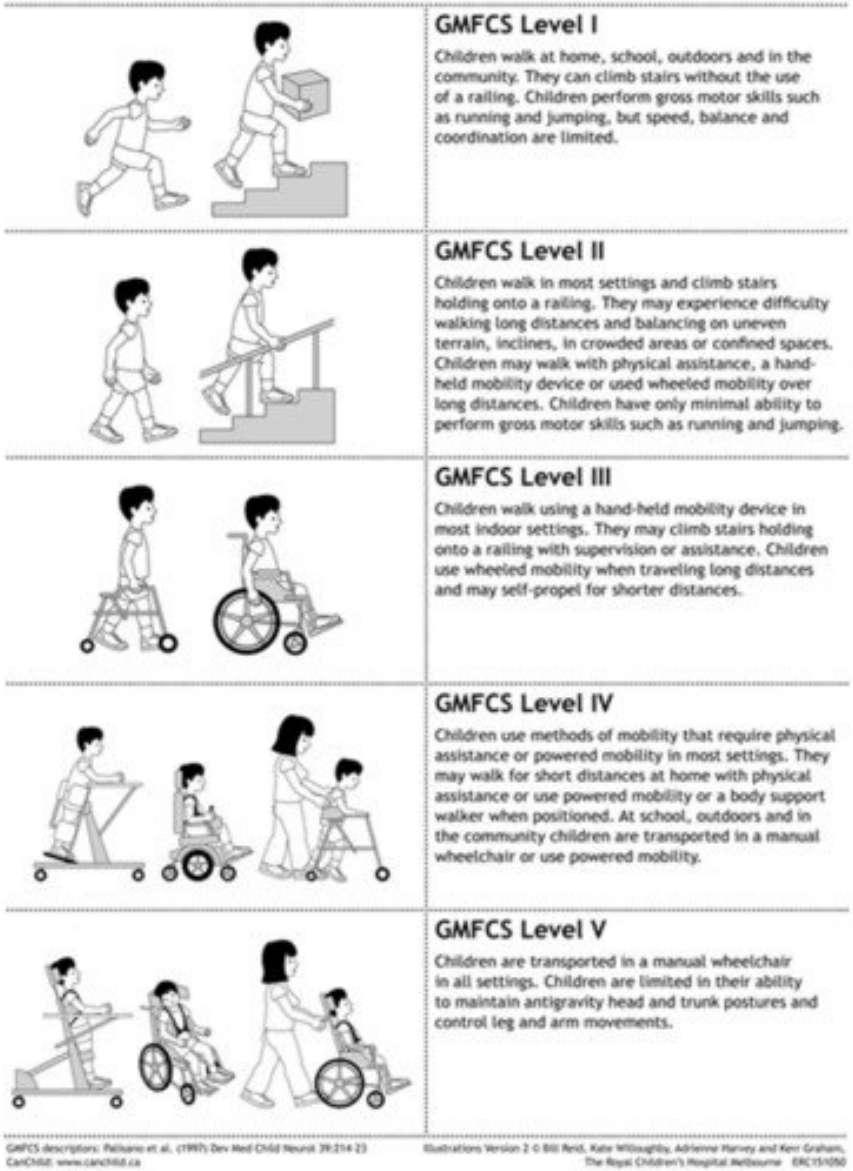
- *"velocity-dependent increased resistance to passive limb movement in people with upper motor neurone syndrome"*
- This means that when the limb arm/leg of someone who has CP is moved by someone else resistance can be felt. The faster that limb is moved the more resistance is felt.
- Lots of body muscles work in pairs; one is shortening whilst the other lengthens. The brain sends messages to the muscle to tell it to contract or relax and messages are sent back from the muscles to the brain.
- When you have CP the damage to the brain results in those messages not being sent properly and the circuit between brain and muscles is disrupted; this results in spasticity. More noticeable in one muscle of a joint than the other eg. Biceps rather than triceps.

What is dystonia?

- Sustained or repetitive muscle contractions result in twisting and repetitive movements or abnormal fixed postures.
- Dystonia is worse with intention to move.
- Can see an overflow of movement into an area of the body that isn't necessary e.g. child sitting unsupported and talking will posture their arms or lift up their big toe, or when walking fast will posture their arm.
- This is often referred to as an associated reaction.

Classifying and assessing how a child moves

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations



GMFCS Level I

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.

GMFCS Level II

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 hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III

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.

GMFCS Level IV

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.

GMFCS Level V

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.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Gross Motor function Classification Score

Gross Motor Function Measure

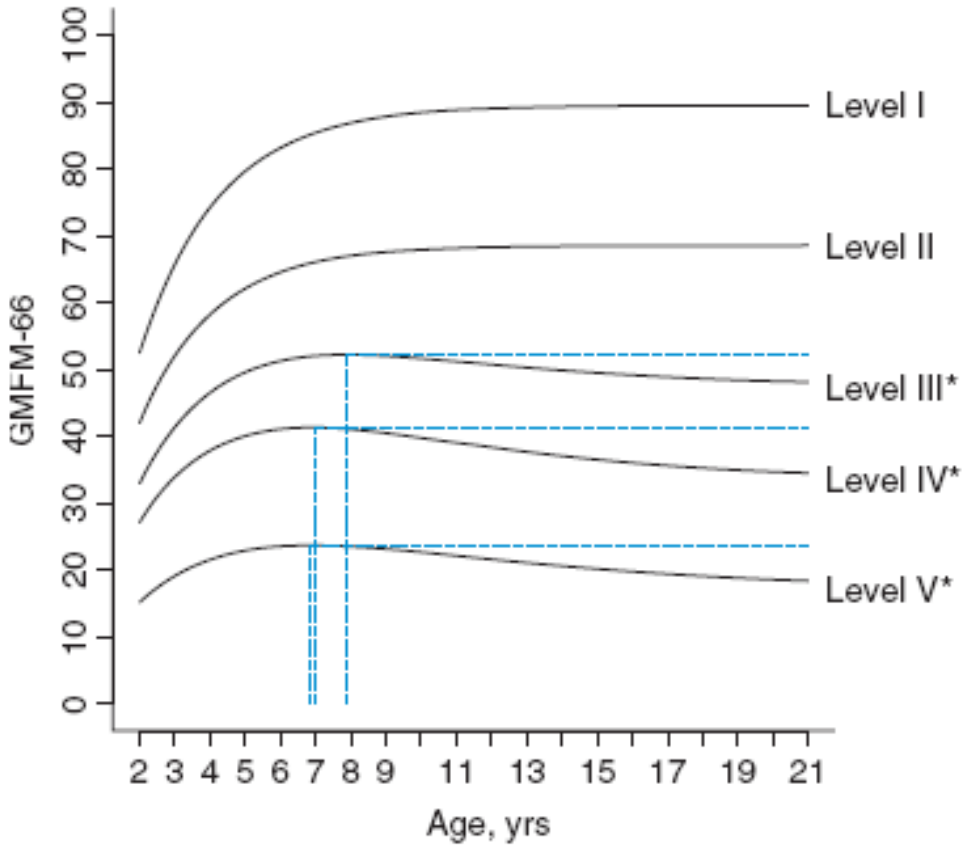


Figure 1: Predicted Gross Motor Function Measure (GMFM-66) motor scores as a function of age by Gross Motor Function Classification level. *GMFCS levels with significant average peak and decline. Dashed lines illustrate age and score at peak GMFM-66.

Treatments for spasticity in children who have CP

Spasticity management: NICE guidelines 2012 (2016)

There are different treatments for spasticity, or the consequence on the body of spasticity, depending on:

- where it is
- how widespread it is – focal or global
- how much it is interfering with function or comfort
- a child's individual goals

- Physiotherapy (and OT) – task focused therapy, muscle strengthening, postural management
- Orthotics / serial casting
- Oral medication – baclofen, diazepam.
- Botulinum toxin injections
- ITB.
- Orthopaedic surgery – muscle lengthening, bony surgery,
- SDR: "consider selective dorsal rhizotomy to improve walking ability in children and young people with spasticity at GMFCS level II or III." Also stated that further evidence was required about its efficacy.

Muscle contractures

- When a muscle is in a shortened position a lot of the time it can become difficult to stretch it out fully so range of movement at a joint is lost.
- This is common in children with CP.
- Muscle groups typically affected are:
  - Hip flexors, adductors, hamstrings, calfs.
- More time spent in sitting and less in standing so less opportunity for day to day lengthening of muscles.
- Spasticity also contributes to development of contractures.
- It is important to understand; is spasticity causing the movement pattern or posture you see or is it a contracture? Is it both? SDR may still be indicated but your child may also need muscle lengthening.

History of SDR in England

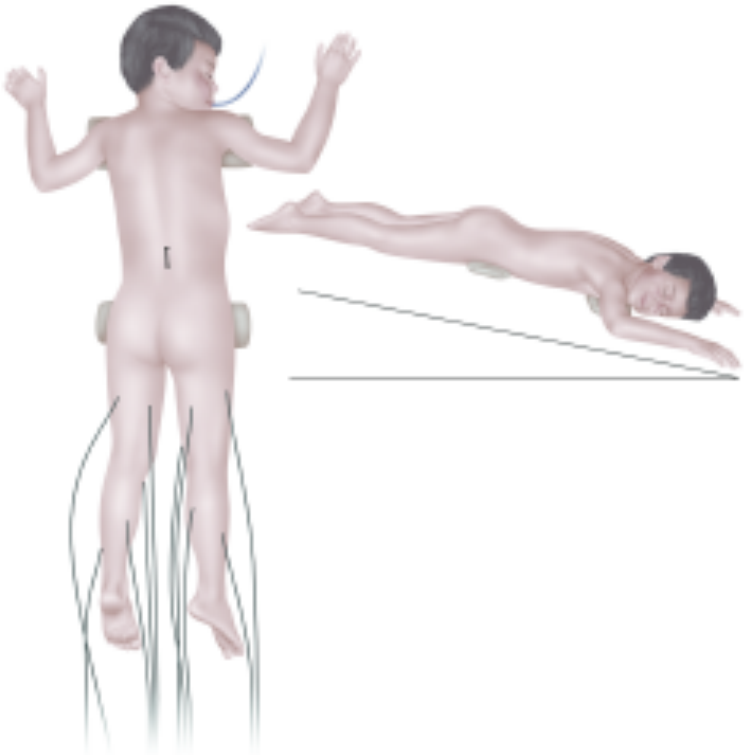
- Prior to 2014 only one centre offered SDR and they had a very limited service.
- In 2013 NHS England stated that SDR was not routinely commissioned due to lack of evidence to support the procedure.
- A number of parents were travelling to USA to access SDR for their children.
- In 2014 NHS England launched a commissioning through evaluation program at 5 English hospitals to evaluate the outcome of SDR and investigate whether there was improvement in gross motor function and quality of life after SDR at 6 months and if that was maintained or improved at 12 and 24 months.
- 137 children's outcomes were reviewed.
- In June 2018 SDR became routinely available on the NHS for children like those in that were included in the study criteria.

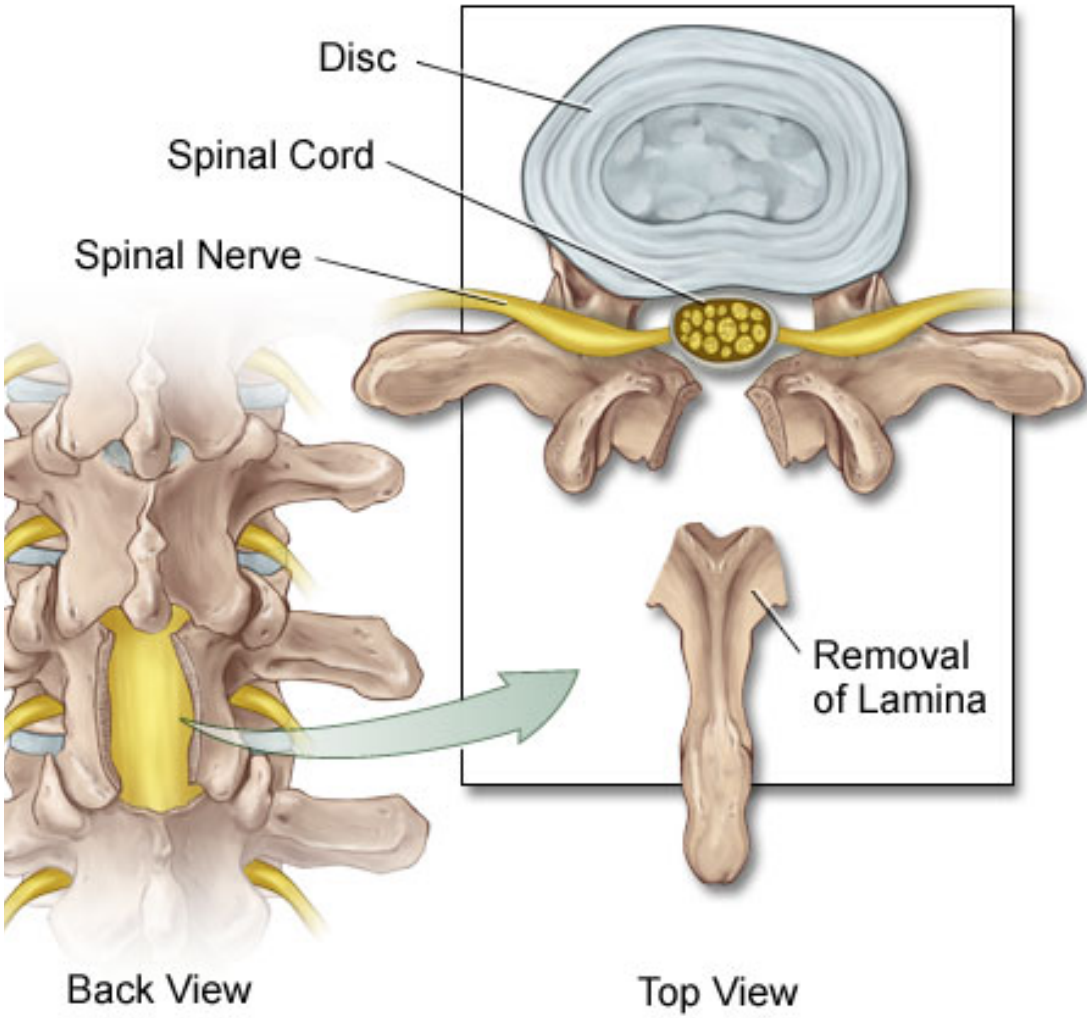
Why undergo SDR and intensive rehab?

- NHS England has found consistent evidence of:
  - Improvement in patient outcomes from pre-SDR at 2 years post surgery:
    - Reduction in spasticity
    - Improved movement
    - Improved gait
    - Improved quality of life including reduced pain for children and their carers.
- Procedure was safe.
- Anecdotal evidence of:
  - improved speech, arm function, bladder/bowel control, vision, cognitive improvements, better concentration, calmer, body positivity.
- Continued requirement for orthotics!
- Change in walking aid used for GMFCS III. Not typical to change GMFCS level.
- Goals will vary for each child and will be discussed during the assessment process:
  - Broadly split between improving walking (GMFCS II and III) and for improved comfort/care (GMFCS IV and V).

What is SDR?

- A neurosurgery where some of the sensory nerves that contribute to spasticity in the legs are cut at the point where they enter the spinal cord.
- Not the nerves that allow movement – motor nerves, it is the feedback nerves; sensory nerves which are cut.
- SDR was first performed in the early 1900's and the technique has been refined over time.
- The procedure is performed under a general anaesthetic and takes around 4 hours. A skin incision is made on the lower back.
- The bumps you can feel down your back are bones called lamina.
- During an SDR one of the lamina bones is removed at L1/2; the top of the lumbar region of the spine.
- The surgeon can gain access to the end of the spinal cord and cut open the sack around the cord.
- Here the nerve roots are separated into individual rootlets and tested electrically (EMG) to see if they are motor or sensory nerves.
- The EMG responses from the leg muscles identifies the rootlets that cause spasticity. A proportion of the abnormal rootlets are selectively cut. The normal and least affected rootlets and those to the bladder and bowel are left intact.
- At the end of the procedure the sac is closed again and the skin is closed with absorbable stitches.
- Hospital stay for 1 week plus 2 weeks intensive rehab staying in a local hotel.




Lumbar Laminectomy
Disc
Spinal Cord
Spinal Nerve
Removal of Lamina
Back View
Top View

Physiotherapy

- Proven that SDR plus intensive rehab for 2 years results in improvement.
- The study was for 2 years but rehab is for life. Transition over time from a specific exercise program to sports and activities.
- Significant undertaking for families, won't suit all children.
- NHS England funding includes money for community physiotherapy.
- Unfortunately this cannot be used for private therapy.

GMFCS level II:	Hospital discharge to 4 months post op	2x per week
	4-6 months post op	1x every two weeks
	6-12 months	1x every 3 /4 weeks
	12-24 months	monthly
GMFCS level III:	Hospital discharge to 4 months post op	3x per week
	4-6 months post op	1x every week
	6-12 months	1 x every two weeks
	12-24 months	1 x every 2-4 weeks

NHS England funding criteria for SDR

- Diagnosis of Cerebral Palsy
- GMFCS levels II and III
- Aged 3 - 9
- Spasticity mainly in the legs affecting function and mobility and no dystonia.
- The MRI brain scan shows typical cerebral palsy changes; white-matter damage of prematurity or periventricular leucomalacia (PVL) and no damage to basal ganglia or cerebellum the key areas of the brain controlling posture and coordination i.e. no dystonia/ataxia.
- No evidence of genetic or neurological progressive illness
- Mild to moderate leg weakness with ability to maintain antigravity postures
- No significant scoliosis or hip dislocation (Reimer's index should be <40%)

How can my child access SDR?

Six centres in England *presently* offer SDR via a single-level approach:

- Bristol Royal Hospital for Children
- Alder Hey Children's NHS Foundation Trust
- Great Ormond Street Hospital for Children
- The Portland - private
- Leeds General Infirmary
- Nottingham University Hospital

How do I choose where to go for an assessment?

- Convenience of location to your home for inpatient stay and to attend for follow ups.
- Experience of team.
- What feels right for your family.
- Requirement for Orthopaedic surgery.

Patient pathway

For more information on SDR including links to all the references in this presentation go to www.carolinehardakerkidsphysio.co.uk

Facebook private group: SDR UK