

SELECTIVE DORSAL RHIZOTOMY in Ireland

Information for Parents, Children and Families

Background:

Selective Dorsal Rhizotomy (SDR) is one of a number of treatment options to manage spasticity (increased tone) in children with cerebral palsy. Children with cerebral palsy have varying degrees of spasticity, weakness, poor selective motor control and poor balance – all of which impact on motor function. The impact of interventions for spasticity can be affected by the presence of other factors such as weakness. Spasticity can cause pain (which impacts on quality of life) and contribute to muscle contractures which leads to deformities. Interventions for spasticity include stretching, splinting, serial casting muscles, anti-spasticity medication such as baclofen and botulinum toxin, orthopaedic surgery and selective dorsal rhizotomy. Interventions are planned specifically for the individual child. Less invasive interventions occur as a rule before escalating to more invasive interventions. There are plans that SDR surgery will occur in Ireland in due course. Meanwhile children who are felt to be suitable for this procedure are referred to Leeds General Infirmary in the UK, and this is funded by the Treatment Abroad Scheme: www.hse.ie/eng/services/list/1/schemes/treatmentabroad

Not every child with cerebral palsy is suitable. There is a multi-disciplinary team of professionals in Ireland (Irish SDR MDT) with expertise in cerebral palsy who meet several times a year to review approve suitable children for onward referral to the UK. This process is further explained below

What is SDR?

The following link from Leeds describes the procedure: www.leedsneurosurgery.com/sdr

Who is suitable for consideration for surgery?

The Irish SDR MDT, on review of literature and consultation, has established the following criteria:

- 1) Children require a diagnosis of spastic diplegic (bilateral) cerebral palsy.
- 2) Children with MRI brain changes of periventricular leucomalacia (PVL). PVL is often associated with being born prematurely and can result in spasticity.
- 3) Children are considered from the age of three to ten years. Formal Gait Analysis is a key component of the assessment in Ireland and this is not performed until the child turns four but children can be referred for this at the age of three.
- 4) Children who are capable of walking independently or with a hand held mobility device which correlates with GMFCS Levels II-III. GMFCS refers to Gross Motor Function Classification System which describes the gross motor skills of children with cerebral palsy.
- 5) There must be adequate muscle strength in the legs and trunk. Children must be able to hold their posture against gravity in standing.
- 6) Children who have SDR performed need to have regular physiotherapy post-operatively to obtain the best results. This requires their input, motivation and cooperation and significant input from the parent at home.
- 7) Unsuitable. Examples of cases where SDR is not suitable include a child with dystonic cerebral palsy, significant scoliosis or hip dislocation

Referral process:

This selection process is a fundamental part of successful SDR. Careful selection of suitable candidates to be referred for surgery is essential if optimal outcomes are to be achieved and goals attained. A multidisciplinary SDR team was established in Ireland in 2012. It meets throughout the year to review and assess suitability of cases of children referred for consideration of SDR. The team includes specialists from Paediatrics, Physiotherapy, Neurosurgery and Gait Analysis. Referrals are accepted from the child's local paediatrician.

When each child is reviewed the process is as follows:-

- 1) The individual case is discussed in liaison with the child's local team.
- 2) Clinical information specific to each child is reviewed. This includes review of functional ability, muscle tone, joint range, muscle power and gait analysis data.
- 3) The MRI brain scan is reviewed to ensure there is no evidence of damage to other areas of the brain involved in the control of balance and posture.
- 4) Goals of intervention and possible functional or qualitative benefits of SDR are discussed. Consideration is given to the individual family circumstances, goals and expectations of outcome along with ability for regular physiotherapy after SDR.

If the child is felt to be suitable for consideration for surgery he/she is then referred to Leeds. Over 20 children have been referred to the UK to date. The child is called for a consultation with the multi-disciplinary SDR team in Leeds. The team in Leeds makes the final decision regarding whether to proceed with SDR. If a child is found to be a suitable candidate for SDR the ensuing process will be discussed with the child and family, along with information regarding potential complications and the importance of following up with the intense physiotherapy and home exercise programme in the post-operative period.

Post-operative physiotherapy:

For information on post-operative physiotherapy: www.leedsneurosurgery.com/sdr

There is intensive physiotherapy in the UK for the first three weeks following surgery, which is funded. Following this, upon return to Ireland, an individualised physiotherapy and home exercise programme is implemented. This will have been planned in advance of surgery by the local physiotherapist in conjunction with parents.

Evaluation of outcome:

In the UK SDR is part of NHS England's Commissioning through Evaluation programme. This programme evaluates the effectiveness of a procedure at a time when the evidence base for it is still emerging and sometimes conflicting. New clinical and patient experience data are collected within a formal evaluation programme. SDR is currently in the evaluation phase. This process of evaluation will be helpful in contributing to the growing evidence base with respect to SDR. In Ireland we have been collecting and evaluating data since establishment of the team. This is through feedback from local team reviews and serial Gait Analysis.

A parent's perspective:

"For us 4 years post-op, our recommendation to families is to do as much strength building pre-op as possible, and be prepared to work extremely hard post-op. SDR is not a cure - it opens a door which allows muscles to be built which previously were held by spasticity. Often families' goal is to see their child walk, and of course this is important, but our feeling four years on - seeing our child's body free from spasticity has changed our child the most. SDR is not for every child, and maybe not for every family, but for those children or adults who meet the criteria and their families that engage in the process it definitely changes lives."

This document has been approved by the Irish SDR MDT. If you would like further information regarding this procedure please raise this with your paediatrician and physiotherapist.