

# Selective Dorsal Rhizotomy: Yours Rights to NHS Funded Treatment Explained

## Guidance with strength and sensitivity

On 25th July 2012, the National Institute for Clinical Excellence (“NICE”) published their long awaited guidance on the use of Selective Dorsal Rhizotomy in the management of spasticity for children with cerebral palsy.

Polly Sweeney, solicitor in the Public Law department at Irwin Mitchell, who specialises in ‘cutting edge’ healthcare cases explains what this new guidance will mean for children who may need this surgery and their rights to NHS funded treatment.

Selective Dorsal Rhizotomy (SDR) is a specialist neurosurgical procedure which involves the cutting of selected sensory nerves in the lower spine to improve spasticity. The procedure is routinely used in the USA and is currently available at two specialist centres in England and Wales. It is understood to cost the NHS approximately £25,000 for each surgery, including the costs of the intensive post-operative rehabilitation that the surgery requires. It has been shown to have significant impact on the walking ability and the quality of life in some children and young people with cerebral palsy.

SDR surgery has already been the subject of initial guidance by NICE in December 2010 on when and how this new procedure can be used in clinical practice in the NHS. This guidance reviewed the safety and clinical effectiveness of the procedure and recommended it for routine use in the NHS in treating people with spasticity in cerebral palsy provided that parents or carers understand that the complications can be serious and the results of the procedure are monitored. However, the guidance did not consider or make any recommendations on whether or not the surgery should be funded by the NHS. The decision on whether to fund was, therefore, left to local commissioners to consider funding on a case by case basis through the Individual Funding Request Process.

Since then, NICE has undertaken an extensive consultation and on 25th July 2012, issued further guidance in relation to the use of SDR in its clinical guidelines *‘Spasticity in children and young people with non-progressive brain disorders - Management of spasticity and co-existing motor disorders and their early musculoskeletal complications’* (‘the Guidelines’). The remit of these guidelines includes evaluation of the clinical and cost effectiveness of SDR.

Having considered the available evidence, current clinical practice and existing NICE guidance, this guidance recommends the use of Selective Dorsal Rhizotomy.

In particular it states:

1.8.1 Consider Selective Dorsal Rhizotomy to improve walking ability in children and young people with spasticity at GMFCS level II or III:

- Patient selection and treatment should be carried out by a multidisciplinary team with specialist training and expertise in the care of spasticity, and with access to the full range of treatment options.
- Discuss the irreversibility of the treatment, the known complications and the uncertainties over long-term outcomes with children and young people, and their parents and/or carers (see also Selective Dorsal Rhizotomy for spasticity in cerebral palsy, NICE interventional procedure guidance 373).
- Teams offering Selective Dorsal Rhizotomy should participate in a coordinated national agreed programme to collect information on short- and long-term outcomes on all patients assessed for Selective Dorsal Rhizotomy, whether or not Selective Dorsal Rhizotomy is performed. These recorded outcomes should include measures of muscle tone, gross motor function, neurological impairment, spinal deformity, quality of life and need for additional operations, with nationally agreed consistent definitions.

Whilst the guidance is not Technology Appraised Guidance “TAG” and, therefore, not strictly binding on PCT’s, all PCT’s are still required to give careful consideration to this guidance which recommends clinical use as a treatment to improve walking ability in appropriately selected children and young people.

The guidance goes on to identify six clinical criteria for identifying children and young person’s for SDR:

- abnormal tone (pure spasticity)
- good leg muscle strength
- straight legs and minimal muscle shortening
- good selective motor control in the legs
- good cognitive skills
- not overweight.

The guidance confirms that children and young people in GMFCS level II or III were thought likely to derive the clinical benefit of improved walking ability through undergoing SDR and that SDR is more likely to be effective if spasticity is judged to be the major factor impairing movement.

### Your Options

There are a number of options available for securing funding of SDR surgery for child with cerebral palsy.

PCT’s will now have to review their policies, taking into account these guidelines and decide whether or not they will make this procedure available routinely. It is important to check what the policy of your particular PCT is for funding this surgery as it is likely to vary dependent on where you live. If you are not sure which process applies to your local PCT you should ask your child’s treating clinician who should be able to advise you. It is important that the correct appeal route is followed to avoid delays.

The main options for funding are as follows:

1. Where PCT's have a policy to fund the procedure then the decision to carry out the surgery should be made by the multi-disciplinary team in accordance with the NICE guidelines.
2. Where PCT's still have policies not to routinely fund treatment, a funding application for treatment on the NHS can still be made to the local PCT on the grounds of clinical exceptionality. This is known as the Exceptional Funding Request process.
3. For PCT's that don't have a policy at all, the request for funding should be made via the Individual Funding Request route, which will consider the specific circumstances affecting the child or young person, including relevant clinical factors and impact on their daily living and functioning.
4. The surgery is paid for privately, for instance through fundraising or charitable support. The specialist centre would still need to assess the child and be satisfied that they were appropriate for surgery, even if carried out privately.

### The Exceptional Funding Process

The Exceptional Funding Request Process requires an application to be made by the child's treating clinician and should set out why there are exceptional benefits from the treatment. You should request a copy of your PCT's policy for funding and ensure that the request addresses the criteria which your PCT applies when making its decision.

Each PCT has its own exceptionality policy which you can request a copy of, but generally, the application will need to demonstrate that:

- The patient is significantly different to the general population of patients with the condition in question and as a result of that difference;
- The patient is likely to gain significantly more benefit from the intervention than might normally be expected for patients with that condition.

In essence, the PCT needs to be able to justify why it should fund the procedure for a particular patient, but not patients with cerebral palsy generally. This may include factors such as all other treatments which have been tried have failed, or that the child's particular clinical features make them more likely to benefit from the treatment.

The application for specialist treatment would then be considered by a panel of professional and lay members on a case by case basis and the patient has the right of appeal to an appeal panel if funding is refused. It is important that your treating clinician gathers as much evidence which shows why your case is exceptional. You should provide supporting letters from physiotherapists, occupational therapists and any other professionals who are involved in your child's treatment.

If you are unhappy with the outcome of the PCT funding appeal, or consider that a PCT is not applying their funding procedures and policies fairly, then you may be able to bring a legal challenge the decision, through a procedure known as judicial review.

This procedure would look at the lawfulness of the decision of the PCT and whether they had applied their policy properly. It can also look at whether the PCT's policy for funding SDR surgery is in accordance with the law. You should be aware that bringing a judicial review has strict time limits and any challenge must be brought promptly and within 3 months of the decision to refuse funding. It is therefore important that you seek specialist public law advice as soon as possible. Legal aid is likely to be available to eligible children to bring such a challenge.

At Irwin Mitchell we have been able to help many other patients across the region and the country to receive the NHS treatment their clinician supported, such as the breast cancer drug Herceptin and the eye treatment Lucentis.

If you would like further advice in relation to your legal rights in seeking NHS funding for SDR surgery then please do not hesitate to contact

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