SELECTIVE DORSAL RHIZOTOMY

PATIENT & CARER INFORMATION

Produced by LTHT Spasticity Management Team March 2012
For review: March 2013

Selective Dorsal Rhizotomy (SDR) in Leeds

Background
SDR in Leeds is delivered by a multidisciplinary team approach. The team comprises:
Mr John Goodden Consultant Paediatric Neurosurgeon
Dr Michael Clarke Consultant Paediatric Neurologist
Alec Musson Superintendent Physiotherapist
Sharron Peacock Specialist Nurse

Mr Goodden has been trained in the techniques of SDR by Dr Park at St Louis Children's Hospital, St Louis, Missouri, USA.

Your child will first be seen in the joint Spasticity Management Clinic. They will be assessed by all the team members for a thorough assessment. During that clinic appointment a recommendation will be made about what the most suitable treatment would be. As well as going forward for SDR, there may be recommendations that orthopaedic surgery to lengthen tendons may be required. It is also sometimes necessary to recommend a period of muscle strengthening before SDR can be considered.

If your child is a suitable candidate for SDR, we will then make an application to your local Primary Care Trust (PCT) for funding for the surgery and initial physiotherapy whilst in hospital. We will also ask the PCT to increase the amount of community physiotherapy provide after discharge. Until we have confirmation of funding from the PCT we cannot place your child on the active waiting list for surgery. Once funding is confirmed, we will write to you and confirm the details with you.

What to expect during your child’s admission

Day Before Surgery
Your child will be admitted to the children’s neurosurgical ward the day before the operation. They will be assessed to ensure that they are fit for the anaesthetic and surgery; this will involve taking blood samples. You will be given the times when your child can last have something to eat or drink before the operation. Parents can visit anytime and the ward can accommodate one parent to stay with their child at the bedside overnight. The physiotherapist will see your child either on the ward or in the rehab room to carry out an assessment of their muscles and movement abilities.
Your child will have an evening meal and then be fasted for the night before surgery.

Day of Surgery
Your child will go to theatre in the morning with yourselves and anaesthetised by an anaesthetist. You will then leave your child in the safe hands of the team. During the surgery, the theatre staff will phone through to the ward with progress updates.
The surgery itself is done through an incision centred over the L1 level of the back of the spine – the same minimal-access incision that Dr Park has pioneered at St Louis Children’s Hospital, Missouri. The operation will take approximately 3-4 hours. The wound will be closed with an absorbable stitch that is buried under the skin, and dressings are applied over the top.
After surgery your child will be woken up in the recovery room in theatre, and then transferred to the children’s Intensive Care Unit or High-Dependency Care unit (PICU or HDU) where you can visit them. Following the operation, it is normal for your child to be attached to several intravenous lines and monitoring equipment. They will be given pain-kllers and muscle relaxants through an intravenous line in their arm. Whilst on PICU/HDU, the nurse looking after your child will be looking after a maximum of one other child. Due to space restrictions, and the need for quiet and privacy of other patients, only 2 visitors can be at the bedside at any one time.
Post-Op Day 1 and 2
After 24 hours on PICU and depending on your child's progress they will be moved back to the ward for the reminder of their stay. They may continue to be a little sleepy and uncomfortable at times but they will be allowed to start eating and drinking again although their appetite may be reduced until the medicines are reduced. The nurse caring for your child will also be caring for a number of other patients on this ward. One adult can sleep on the ward at night with your child.

Post-Op Day 3
Your child should now be fully awake and the intravenous medicines may be stopped although painkillers will continue orally. The physiotherapist will visit you and your child to escort you to the rehab room where they will start the exercises to strengthen your child's leg and body muscles. It is important that your child has their painkillers half an hour before the physiotherapy session. The physiotherapist will check that this has happened. Your child is also allowed to sit up in bed and the physiotherapist will show you how to do this correctly. Your child should only spend 1-2 hours in their wheelchair today as they will tire easily and rest is important.

Post-Op Day 4 onwards
Your child will continue to receive physiotherapy daily whilst they are with us in hospital. The physiotherapy Technical Instructor will lead most of the session once the physiotherapist is happy with your child’s progress. It is important that your child continues to receive painkillers half an hour before any physiotherapy sessions for the first week or so. Your child may continue to tire easily and regular rest periods continue to be important but activity in between rest periods is also to be encouraged.

General Considerations
1. Wheelchairs - if your child already has a wheelchair please bring it with you to hospital. If you do not have one, use of a nurses wheelchair will be sufficient during your stay.
2. Walking aids - if your child uses a walking aid such as a Kaye-Walker, bring it with you to hospital, as they will need to walk during their physiotherapy sessions. We would expect children to return to their pre-operative level of walking after one month.
3. Foot and knee splints - If your child has any splints for their legs and feet please bring them to hospital, as they will need them after the operation. If they do not use splints, they may be assessed by the hospital physiotherapist and orthotist to see if they would benefit from them after the operation. As your child progresses their splint prescription may change. This will be dealt with by your local physiotherapy team once you have left the hospital.
4. Foot Hypersensitivity - after the operation your child’s feet may be more sensitive and they may report tingling, itching or funny sensations in their feet. This is normal and usually wears off after a couple of weeks. Socks, shoes and standing can help reduce this.
5. “Lump” on the back - you may notice a "lump" on your child’s back above or below the incision site. This is normal and may look more prominent when they bend forwards. This "lump" is due to the stitches used to close the wound, and generally flattens down over the month after surgery.
6. Muscle spasms - your child may experience muscle spasms after an active day. Adequate painkillers and a muscle-relaxing drug may be required so please inform your doctor.
7. Activity and Play - your child should return to activities quite quickly but it may take longer for them to walk due to muscle weakness. It is important to encourage your child to be active on the floor (crawling, rolling, sitting) and participate with any exercise programmes advised. Following surgery, hydrotherapy should be avoided for 4 weeks, to allow full healing of the wound. Other forms of physiotherapy are not usually a problem.
8. Home Programme of Exercises - the hospital physiotherapist will provide you with a programme of exercises to follow at home on a daily basis. Your local physiotherapy team will be aware of any recommendations made and should continue to provide input once you are home. Local physiotherapy teams may not be able to increase their input once you are home so it is important that you carry out any exercises on a daily basis and incorporate strengthening activities into your daily routine.
9. Follow Up Appointments with the Hospital Team - you will be invited to attend an out patient appointment at 4, 12 & 24 months post operatively. It is important that you attend these appointments so the team can monitor your child's progress and give advice if required. If you do have any concerns or questions once you are home you can always phone the team for advice.

For further information please contact:
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