

Selective Dorsal Rhizotomy

Information for parents / carers



Leeds children's
hospital

caring about children

What is Selective Dorsal Rhizotomy?

Selective Dorsal Rhizotomy (SDR) is an operation that helps children with stiffness (spasticity) in their legs due to cerebral palsy. The procedure involves cutting a number of the sensory nerves in the lower spine. The reason for cutting the sensory nerves is that the messages from these nerves are abnormal in children with cerebral palsy leading to stiffness (or spasticity). The procedure is usually performed by a paediatric neurosurgeon.

Although SDR has been around for over 100 years in various forms, we now have a much better understanding of what SDR can and cannot help with. As a result, SDR is a safer and more effective operation. The version of SDR offered by Mr Goodden in Leeds involves only a small cut over one level of the spine (single-level technique), rather than the long cut technique, which has been used in some other centres. In 2010, Mr Goodden travelled to St. Louis (Missouri, USA) to learn the surgical techniques from Dr Park. He has also built on contacts with other leading neurosurgeons in Canada and South Africa. Alec Musson (Paediatric Physiotherapist) also travelled to St. Louis to learn the physiotherapy techniques required for the post-operative rehabilitation. They then developed the systems and pathways required to deliver SDR and then started performing SDR operations in 2012. We have now completed over 150 cases with excellent results.

From July 2014 to March 2016, NHS England undertook an SDR evaluation called "Commissioning through Evaluation" (CtE). They examined our set-up and results, and selected the team in Leeds as one of their few chosen hospital teams to deliver SDR surgery. Mr Goodden and the team were major contributors to this NHS evaluation.

Following a lot of hard work and data analysis, on 5th July 2018 NHS England announced routine funding of SDR for children aged 3 - 9 years. The team in Leeds were confirmed as one of their chosen providers.

Our son is without doubt a much happier boy after SDR. He can do things that we never thought possible as he says "I love my new legs that Dr John has given me!"

SDR in Leeds is offered as one of the potential treatments for spasticity for children. We also offer other treatments such as physiotherapy, orthotic splinting, oral medications, Botulinum Toxin injections, Intrathecal Baclofen Therapy, Orthopaedic surgery and Plastic & reconstructive surgery.

Who are the SDR team in Leeds?

SDR in Leeds is delivered by a multidisciplinary team which offers expertise in spasticity management, surgery and post-operative rehabilitation. The team comprises:

Mr John Goodden - Consultant Paediatric Neurosurgeon

Kate McCune - Highly Specialised Paediatric Physiotherapists

Katie Davis

Catherine Wilsmore

Ms Adelle Fishlock - Consultant Paediatric Orthopaedic Surgeons
Mrs Laura Deriu
Mr John Davies
Mrs Elaine Robinson
Andie Mulkeen - Spasticity Clinical Nurse Specialists
Sharron Peacock

Who might benefit from SDR?

SDR is an option for children with cerebral palsy mainly affecting their legs (previously called spastic diplegia) and typical MRI scan changes called Periventricular Leucomalacia (PVL), or white matter injury of prematurity.

The children who benefit most from SDR tend to be those who can mobilise with or without the help of frames, rather than those who cannot. There is a classification system used to define different levels of mobility, which is called the Gross Motor Function Classification System (GMFCS). Children who are in GMFCS levels 2 and 3 usually get the most benefit from SDR surgery.

There are some children who should not undergo SDR as they may find movements harder as a result. These include children who have problems with poor control of movements (dystonia) or have significant weakness in their legs, which is unlikely to improve with rehabilitation after SDR.

Children with spasticity of their legs should normally be receiving regular input from Community Physiotherapists. The Leeds Physiotherapy Team will speak to your local community physiotherapist to get background information before the clinic appointment and surgery. They will also keep in touch with your physiotherapist to ensure there is a good handover at the end of the SDR treatment process.

Finally, in addition to all the above things, it is also important to check x-rays of the hips and spine to confirm that there are no major problems. This is routinely done before SDR surgery and then repeated, once per year, afterwards.

Going through with the SDR surgery was the best decision for our son. He used to wake up 10 times a night screaming in pain with cramps. But, since having the operation, he now sleeps through. The spasticity is gone and we know with a lot of hard work, we will see all the benefits that SDR offers.

What are the criteria for SDR surgery?

1. Cerebral Palsy with spasticity mainly affecting both legs - affecting function and mobility.
2. Typical signs of spasticity in the lower limbs on examination.
3. Age 3 - 9 years for NHS-funded surgery - although we would be happy to review children outside this range in clinic.
 - a. We are willing to review children outside this age range and to then discuss them with NHS England but the NHS Commissioners may not be willing to fund their surgery.

- b. If your child is 10 or over, we would be willing and able to perform SDR surgery for them; however, if the NHS will not pay for the surgery, you will have to fund this yourselves. Many people have successfully raised charitable funds to achieve this in the past and we would be happy to advise you about details of charities to work with.
4. MRI shows typical cerebral palsy changes with no evidence of damage to key areas of brain controlling posture and coordination.
 5. GMFCS level 2 or 3.
 - a. Children functioning at GMFCS 4 - 5 can be seen in clinic to consider the best options for their treatment, including SDR but please bear in mind that NHS England does not fund SDR for this group (see later).
 6. No dystonia (poorly controlled, often flailing limb movements).
 7. No evidence of genetic or progressive neurological illness.
 8. Mild to moderate lower limb weakness with the ability to maintain antigravity postures. The stronger the better pre- op.
 9. No significant spinal deformity or hip dislocation.

What does the SDR surgery involve?

Once your child is asleep with the anaesthetic, they are positioned face-down on the operating table in the theatre. The level for the incision is confirmed using ultrasound or x-rays. SDR surgery in Leeds is performed through a single lamina approach at the L1 level - a point just below the middle of the back. This is the point where the spinal cord ends, finishing in a cone shape, with the nerves hanging down off it.

The skin incision is made on the back and a small section of bone is then removed to allow access to the nerves. Ultrasound is used during surgery to continue to check the position of the tip of the spinal cord.

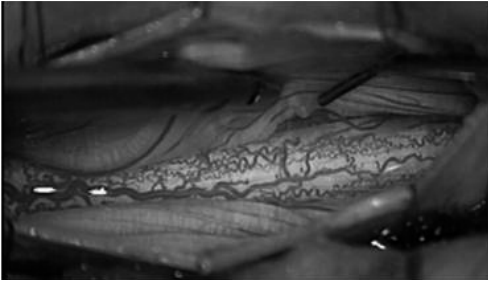
The sensory nerves are identified and special nerve monitoring is used to ensure that the selected nerves do not contain any motor (movement control) nerves. The sensory nerves are then divided into smaller portions and each one is tested with the nerve testing equipment to decide which are the most abnormal nerves. The most abnormal ones are then cut. In total, approximately two-thirds of the sensory nerves from the L1, 2, 3, 4, 5 and S1 levels of the spine will be cut.

The bladder and bowels are controlled by the S2, S3 and S4 nerves so these nerves are not cut during surgery.

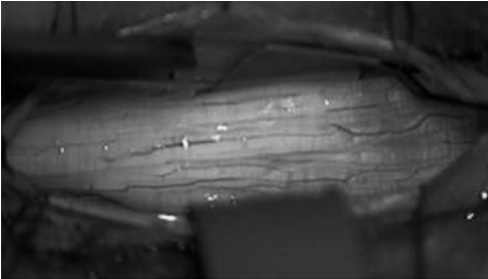
Because the nerves are cut, the SDR surgery cannot be reversed. Also, SDR surgery cannot be repeated in the future.

At the end of the operation, the wound is closed with an absorbable stitch that is buried under the skin and dressings are applied over the top.

Was great to get a video clip of the surgery too!



Separating the motor & sensory nerves



The sensory nerves now separated and ready for testing



Testing one of the nerve divisions

What does SDR do for my child?

By taking away most of the stiffness in the legs, SDR makes it easier for your child to move their legs and usually makes it easier for them to stand and walk.

When SDR is first performed, you will notice that your child appears to have weaker legs. This is because the stiffness (spasticity) in the muscles is significantly reduced or removed altogether. This stiffness used to provide some support, giving a false impression that the muscles were stronger than they really were. Once the stiffness is removed, the muscles do not have this help anymore and the underlying weakness is then seen. The physiotherapy your child receives after SDR is essential to strengthen the muscles and enable your child to stand and walk better. We expect most children to return to their pre-operative level of walking by 4 - 8 weeks after surgery.

If your child usually walks with the aid of a frame, the initial target will be to walk with sticks. If they walk with sticks, the target will be walking without aids. This does not happen overnight and takes months to years of physiotherapy after the SDR surgery.

In our experience, all children having SDR in Leeds have had a significant reduction in their spasticity. So far, we have not seen any signs of spasticity returning on those coming back for post-operative reviews, up to and including, 5 years after SDR.

What are the risks of SDR?

The National Institute for Health and Care Excellence (NICE) has detailed the risks of SDR surgery in their documents. These are quoted on page 10.

Because SDR is an operation on the nerves of the spine, there are potentially serious problems that can occur; however, a central and crucial part of the SDR surgical technique is to use specialist nerve monitoring during surgery to ensure the right nerves are cut and that nerves are not damaged by accident. This way, the movement control nerves (motor nerves) can be safely identified and preserved during surgery.

The overall risks of surgery include infection, bleeding or bruising, CSF leak, spinal deformity, paralysis, weakness, numbness, pain, bladder or bowel problems (including incontinence or impotence), return of spasticity in the future, the risks of general anaesthesia and the potential need for orthopaedic surgery in the future.

As mentioned above, the nerve monitoring makes SDR surgery much safer to perform. The monitoring involves special wires and needles inserted into the leg muscles. We also monitor the nerves for the bladder and bowel, with a wire to check the sphincter is working. This way, we can minimise any risk of damage to the bladder and bowel nerves (called S2, S3 and S4).

It is common for there to be some patches of numbness after SDR but these are usually small patches and improve over a few weeks or months after the surgery. Similarly, many children report alterations in sensation or hypersensitivity of the feet, which usually settles over a few weeks or months after SDR. Socks, shoes and standing can help reduce this.

Some patients may have temporary problems with bowel control in the first week or two after SDR surgery because of temporary irritation to the nerves that control this function. This settles down soon after surgery. In Leeds, none of our children have had any long-term problems with this.

In our experience, we have had no major complications following SDR surgery in Leeds. We have had some children requiring antibiotics for wound infections; however, we have not had any children with major problems like paralysis, incontinence or spinal deformity.

How do I get a referral to see the team in Leeds?

We will accept referrals from consultant paediatricians (including community, neurodisability or neurology), GPs or consultant orthopaedic surgeons. All referrals are discussed in our specialist multidisciplinary spasticity meeting before patients are listed for an outpatient appointment. If further information is required, this will be requested before the referral is finally accepted.

We then write to you to confirm we have received the referral and request you to complete a form about the history of your child's cerebral palsy and their treatment so far.

The Assessment and Outpatient Clinic

We see children in a multidisciplinary team (MDT) spasticity clinic, which is held on Monday's. The clinic involves an appointment with the physio team in the morning with a long and detailed assessment, which is also videoed.

We then have an MDT meeting and discuss our recommendations before then seeing you again in the afternoon to discuss our recommendations for treatment. This afternoon appointment will either be with the neurorehabilitation doctor, the neurosurgeon or both.

Whilst the clinic is set up to review patients for SDR, the team are involved in providing other anti-spasticity treatments like botulinum toxin injections and intrathecal baclofen, so we may also consider those treatments when we see you. You will see several different specialists over a 4 - 5 hour period.

During these appointments, we perform a thorough assessment to ensure that we cover all the necessary tests and examinations of function and spasticity, and also discuss the goals of treatment.

We recommend you bring a pair of shorts for your child to wear during the clinic assessment. Please also ensure that you bring your child's splints, walking aids and wheelchair with you to clinic as they will be required during the assessment.

Your child will be assessed by all the team members. During the appointment, a recommendation will be made about which treatment is most suitable for your child. This decision / recommendation will be given towards the end of the final consultation, allowing time to discuss the reasons for our decision.

The assessment may also find a need for orthopaedic surgery operations to be done after the SDR operation; for example, tendon lengthening surgery. If this is felt to be necessary, arrangements will be made for a review by a specialist children's orthopaedic surgeon before SDR surgery can be planned. **Please note: where a specialist orthopaedic opinion is required, this is likely to be in a separate clinic appointment at a later date.**

Before SDR, our son was often uncomfortable and in pain moving around during the day, this is now a thing of the past.

It is also, sometimes necessary to recommend a period of muscle strengthening before SDR can be considered. If this is the case, you will be given a repeat appointment and your physiotherapy team will be contacted to arrange the required physiotherapy.

If SDR is felt to be the best option for your child, we will explain whether your child will be able to have this surgery as part of the NHS funded pathway.

The main reason that a child may not qualify for NHS funded SDR surgery will be their age. If your child is too old for the NHS to fund the surgery, we would be happy to discuss this with NHS England; however, if they will not fund the SDR, you will have the option to fund the surgery yourself. We have treated a number of self-funding patients, many of whom have raised money through charities. We would be happy to provide some advice regarding this and put you in touch with some helpful charities.

So, my child is going to have SDR surgery, what happens next?

If your child fits the NHS funding criteria, once we have a confirmed that SDR is appropriate for your child, we can place them on our waiting list immediately and start planning towards the surgery.

If your child is outside the NHS funding criteria and you are fundraising for the surgery, we would generally wait for you to let us know that you have reached your target before placing them on the waiting list and planning surgery.

Leading up to the SDR surgery, a gait lab analysis (detailed recording of your child's walking) will be performed in Leeds. It is then repeated after the SDR surgery to assess changes in their walking ability.

Mr Goodden's secretary is usually in touch to confirm the date for surgery. We usually aim to plan this 4 - 8 weeks in advance. Our SDR Co-ordinator will then also be in touch to confirm whether any accommodation is required and what can be provided within the NHS funding pathway.

The time has now arrived for the SDR surgery. What happens now?

Day before surgery

Your child will be admitted to ward L52 on the day before surgery (usually, this is a Wednesday, with the surgery taking place on the Thursday). They will be assessed to ensure that they are fit for the anaesthetic and surgery, this will involve taking blood samples. Parents can visit anytime and the ward can accommodate one parent to stay with their child at the bedside overnight.

The physiotherapist will perform a detailed assessment. This will be videoed in order to allow comparison to future assessments. We may ask for your permission and consent to use the video for teaching purposes but the videos will never be used without your permission.

Your child will have an evening meal and then be fasted from midnight for surgery.

Wheelchairs - if your child already has a wheelchair, please bring it with you to hospital. If you do not have one, use of a ward wheelchair will be sufficient during your stay.

Walking aids - if your child uses any walking aids, please bring them with you to hospital as they will need to walk during their physiotherapy sessions.

Foot and knee splints - if your child has any splints for their legs, 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.

We are amazed at how much his fine motor skills have improved.

Day of surgery

Your child will be taken round to theatre with you. One parent can usually stay with them while they are anaesthetised. 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 that the nurses will pass on to you.

The surgery itself is described earlier. The SDR operation usually takes 2 - 3 hours but with the anaesthetic time, your child may be away from you for up to 5 hours. Your child will then be woken up and transferred to the Recovery Room.

After SDR surgery, your child will be either admitted to the High Dependency Unit (HDU) or to a high observation section on the Children's Neuroscience Ward (L52) for initial post-operative care. Your child will be attached to several intravenous lines and monitoring equipment. They will usually have an epidural infusion (a pump which delivers painkilling medicine beside the spine) for pain relief. They will also have a catheter (a tube which will drain their bladder).

At this time, the nurse looking after your child will typically be looking after a maximum of 2 - 3 other children. Due to space restrictions and the need for quiet and privacy of other patients, only two visitors can be at the bedside at any one time. A parent will be able to sleep overnight beside their child either on a reclining chair or a foldaway bed, depending on what is available in that ward area.

Post-Op Day 1 - 3

During this period, your child will be on bed rest, receive painkilling medicines and be given anti-sickness medicines - sickness after the anaesthetic and SDR is common.

On the first day after surgery, the focus will be on making sure their pain is well-controlled. They may continue to be a little sleepy and uncomfortable at times but they will be allowed to start eating and drinking. It is common for children to have a reduced appetite at this time. Also, they can of course watch films on your media player if they feel up to it.

On the 2nd day after surgery, the epidural will be removed and painkillers will be given orally instead. If they have been on HDU, they will be moved back to L52 after the epidural has been removed. By the end of Day 2, painkillers will be mainly be given orally.

On Day 3, they are able to start sitting up, as long as they are comfortable and even get out of bed if they want to.

The physio team were excellent and motivated our son to get back on his feet again.

Post-Op Day 4 - 22

The urinary catheter is usually removed on Day 2 - 4 (for Thursday operations, this will be Monday and for Tuesday operations, this will be Thursday).

The physiotherapist will visit you and your child and they will take you to the rehab room. They will start the exercises to strengthen your child's leg and body muscles. Your child will be given painkillers before physiotherapy to make them as comfortable as possible. 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 on the first day as they will tire easily and rest is important.

Discharge from the ward is usually on Day 4 post-operatively - for Thursday operations, this will be Monday and for Tuesday operations, this will be Friday. By this stage, your child will be comfortable and not requiring medical care. We find that our patients have preferred an earlier discharge so they can be with their family rather than in a hospital bed. If they need to stay in for another day or two, this is easily accommodated.

The wound dressing is removed by the ward nurses 1 week after the SDR surgery. This is usually done at the end of one of the physiotherapy sessions that day. We have special sticky remover spray that means they come off easily. Please do take you child to the nurses after the physio session and feel free to ask them if you are unsure about anything.

The physiotherapy team will continue to provide physiotherapy every day of the week for a total of 3 weeks after SDR surgery. This will either be two blocks of 30 minutes per day or a single block of 1 hour per day, depending on how tiring this is for your child.

Accommodation during the outpatient physiotherapy (Days 4 - 22 post-op):

- **NHS funded patients** - we book accommodation in a local hotel from the day of first admission until the end of the first week of physiotherapy. You can go home on Friday after the physiotherapy session and return to Leeds after the weekend on the Monday, in time for the physiotherapy session. For these physiotherapy weeks, the room is provided from Monday to Friday. If you wish to keep the room for the Friday, Saturday and Sunday nights, this will have to be at your expense

- **Self-funding patients** - Unfortunately, your hospital package does not include fees for accommodation. We can try to make recommendations regarding local hotels. Equally, many of our self-funding patients have chosen to book apartments within the city for a month to cover the duration of the surgery and physiotherapy.

Discharge from Physiotherapy (Day 22)

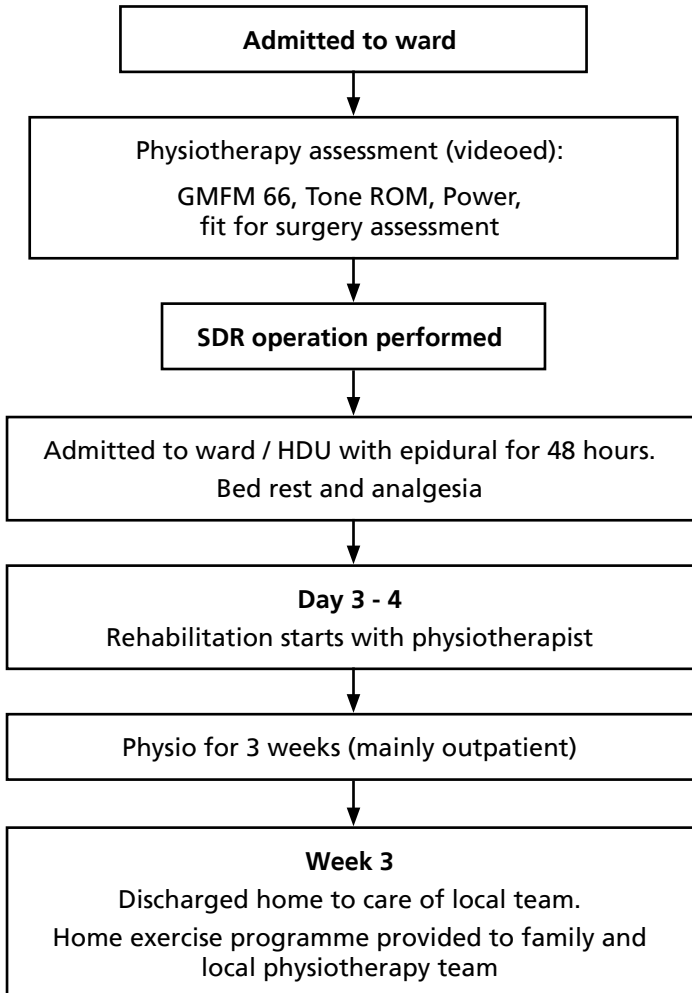
Your local physiotherapist will be invited to attend one of the final physiotherapy sessions. You will also be issued with a schedule of physiotherapy exercises and requirements for local physiotherapy rehabilitation.

Mr Goodden usually arranges to see you and your child on one of the final days of your child's physiotherapy. This is to check on progress and ensure that there are no problems before you finally leave the hospital having completed the physiotherapy programme.

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. NHS funding is in place for additional community physiotherapy for the 2 years after SDR surgery. It is very important that this is received. It is also important that you carry out any exercises on a daily basis and incorporate strengthening activities into your daily routine.

The funding for community physiotherapy is currently routed through the Leeds team as the SDR provider. Your Therapy Team Lead can contact the management team at the Leeds Children's Hospital to access the funds.

Inpatient treatment pathway



Outpatient follow-up appointments

You will be invited to attend outpatient appointments at 6, 12 and 24 months post-operatively (including physio and Gait Lab reviews). Further reviews will then occur at 5 years and 10 years after SDR.

It is important that you attend these appointments so the team can monitor your child's progress and give advice, if required. All aspects of monitoring are important - physiotherapy, Gait Lab and the neurosurgery appointments and we will try to accommodate your needs when planning the appointment times. If you do have any concerns or questions once you are home, you can always phone or email the team for advice.

The Children's Neuroscience Ward, L52

Ward L52 is a regional specialist unit caring for children and young people requiring neurosurgical and neurological care and expertise. It is staffed by qualified paediatric nurses, doctors and support workers with years of experience, and specialist knowledge. Other paediatric healthcare professionals work within the multidisciplinary team here on L52 and your child may be referred to or visited by these professionals during their stay with us.

Great nursing staff who were happy to field our queries even for non-nursing related things such as car park permit queries!

Visiting times

We understand that having your child admitted into hospital is an extremely stressful experience and can affect all aspects family life and its usual functions, and we hope that our visiting policy reflects this. Parents / main carers are encouraged and welcome to be with their child 24 / 7.

We have the facilities to accommodate one parent / carer sleeping on the ward at the child's bedside, please discuss your needs with a member of our staff.

Siblings, other family members and friends are also important and they are very welcome to visit between the hours of 11.00 am and 7.00 pm. The maximum number of visitors per bed space is four at any one time, this includes visiting children.

Time outside of these visiting hours is valuable sleep / quiet and / or rest time for the children and young people being cared for on L52.

Car parking

Car parking can often be a problem due to the hospital being in a large built-up city centre and land / space being limited.

If you can, we suggest you use the excellent public transport network that serves Leeds. If not, then please ensure you have lots of change for parking. If you are from outside the Leeds area and your child is admitted to Ward L52 more than 24 hours, then we can apply for one parking permit per family.

You can put more than one car registration on it but only have one car parked here at a time. The permits take 24 - 48 hours to process once applied for and during this processing time, you would be expected to pay the parking fees.

Things to bring from home

We want your child's stay on our ward to be as comfortable as possible for your child and yourself; therefore, we advise families planning to come to L52 to bring with them: nappies (which are essential, if still used), toothbrush and toothpaste, soap, bathing / washing products, a change of fresh clothes / nightwear, and / or any other small portable item(s) their child may wish to have with them during an overnight stay.

Medicines

If your child is on regular medication and you wish to continue to administer them to your child rather than have the nursing staff do so, then please speak to a member of staff. We will complete a short consent form with you and give you a key for the locker by your child's bedside.

Facilities on L52

Children admitted to L52 will be offered three meals during the day. Snacks and cold sandwiches are also available, **unless your child is fasting for a procedure or fed via a tube.**

Breast feeding is actively promoted and encouraged. Please ask staff for information regarding how we support breast feeding mums.

Our Play Specialist will come and visit your child during the initial part of their stay, we have a play room with toys / activities to suit all ages and development needs. We also have a range of activities and games for children who are not quite ready to venture out of their beds.

If your child is of school age and is going to be spending some time with us, we will refer your child to the Learning Zone, which is within the hospital.

The teaching and support staff from that unit will come and visit you and your child, offering learning activities to support your child's education needs and they will liaise with your child's own school.

We have a parent's room attached to the unit where adults can go and make a drink, use the microwave or just have some quiet time away from the ward. There are also several cafes and a restaurant within the hospital, and plenty of others within walking distance.

We were very happy with the whole experience and made our son feel at ease.

Infection Prevention and Control

We realise that children and young people in hospital are more at risk of infection than they may be at home or in the community. We strive to ensure that Ward L52 is clean and as safe an environment as possible. All staff adhere to hand hygiene and infection prevention policies. Hand cleanliness is paramount in the fight to stop bugs and germs spreading, and transferring from one person to another.

You can help keep your child safe by washing your hands after using the bathroom and before mealtimes, or after assisting your child with their toileting / nappy needs. Please ask visitors not to come to the ward if they are unwell.

Please also let staff know if you, your child or visiting family members develop sickness or diarrhoea symptoms.

Do not be afraid to ask anyone whether they are staff members, another parent or visitor if they have cleaned their hands before approaching your child.

What about SDR for Children functioning at GMFCS 4-5 (IV-V)?

Selective dorsal rhizotomy for children functioning at GMFCS level IV or V is a difficult question because the goals are very different than for GMFCS level II or III children. Where GMFCS level II or III children are usually looking to improve their functional mobility, for children at GMFCS levels IV or V the goals are more centred around comfort and pain relief rather than mobility - as explained below.

One of the important things for children in this GMFCS IV category is that they often rely on their quadriceps tone to help them stand, and to allow them to undertake standing transfers. SDR carries with it the likelihood of reducing the quadriceps tone; therefore, preventing standing transfers from being possible. This makes consideration of selective dorsal rhizotomy surgery much harder for this group, with a much greater likelihood that it would not be of benefit due to the loss of standing transfers. For these reasons, in general, we tend to find ourselves recommending intrathecal baclofen therapy because it can be tailored to the child's needs and can also be reversible if it is reducing their functionality.

These challenges are less with the GMFCS level V children as they tend to rely more upon hoist transfers; however, they have other complex needs that again make an SDR decision challenging.

It is also our experience that children functioning at GMFCS level IV or V often have a more complex brain injury than simply PVL - one which involves the thalami or basal ganglia. This, in turn means that they more frequently have other movement disorders such as dystonia. This is considered to be a contra-indication to proceeding with SDR.

We hope this helps in your understanding of the role of SDR for children functioning at GMFCS level IV or V. In principle, we can review information in a formal referral but, in general, have found that it has not been the best treatment choice for these children.

Other questions

How much nerve tissue should be cut during SDR?

The general opinion from research and from other teams performing SDR is that the aim should be to cut approximately $\frac{2}{3}$ (66%) of the nerve tissue. This is what we do in Leeds. This has been shown to be the best way of reducing the risk of any return of spasticity in the future.

Cutting more than $\frac{3}{4}$ (75%) of the nerves can cause numbness and problems with controlling walking. Cutting less than $\frac{1}{2}$ (50%) increases the risk of spasticity returning in the future.

Can spasticity return in the future?

Studies have shown that SDR dramatically reduces stiffness (spasticity) in the legs of children. Some studies suggest that over the 10 - 15 years after SDR surgery, some spasticity may return in a few patients. This is usually less severe than the amount of spasticity before the SDR surgery.

The best way to keep this risk to a minimum is to cut enough of the nerve during the SDR surgery. Studies have confirmed that the target should be about $\frac{2}{3}$ (66%).

I've noticed a "Lump" on my child's back. Is this normal?

Yes. It is normal to notice a "lump" on your child's back above or below the incision site. This 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.

Are muscle spasms common after SDR?

Your child may experience muscle spasms after an active day. Adequate painkillers and muscle relaxing drugs may be required so please inform your doctor.

Activity and Play – What can my child do and when?

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. Hydrotherapy or swimming are usually avoided until the wound is sufficiently healed - sometimes, 2 - 3 weeks and sometimes, 4 - 6 weeks. The team will monitor this and advise you.

When can my child return to school?

Your child may tire more easily after the operation and may not be able to manage a full day or week in school. A phased return to school may be helpful but should always be discussed with your local therapy team and school special educational needs coordinator.

If you have any concerns about your child after discharge:

- Either, please contact **Ward L52** at LGI on: **0113 3927452**
- Or, please contact one of the SDR team on the numbers over the page



John Goodden



Kate McCune,
Catherine Wilsmore and
Katie Davis



Andie Mulkeen

For further information please contact:

- **Mr John Goodden:**
Consultant Paediatric Neurosurgeon
Tel: **0113 3928413**
E-mail: valerie.allerton@nhs.net
- **Paediatric Physiotherapy Team**
Tel: **0113 3926361**
E-mail: k.mccune@nhs.net / katie.davis3@nhs.net
- **Jade-Lauren Belton:**
SDR Co-ordinator
Tel: **0113 3923113**
E-mail: jade-lauren.belton@nhs.net
- **Andie Mulkeen:**
Children's Spasticity Clinical Nurse Specialist
Tel: **0113 3922640**
E-mail: andie.mulkeen@nhs.net

After your child has been discharged, we will email you a link to our online patient experience survey. We would be grateful for any comments about our service as we strive to provide the best for your child.

Brilliant team altogether. Many thanks.

For further advice contact:

The Children's Neuroscience Ward - Ward L52

Tel: **0113 3927452**

Leeds General Infirmary

Main hospital number: **0113 2432799**

Patient Advice and Liaison Team
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