Selective Dorsal Rhizotomy (SDR) Scotland Service Pathway

This pathway should to be read in conjunction with the attached notes. The number in each text box refers to the note that relates to the specific step of the pathway.

- All decision points assume full involvement and agreement with the child and their family or carers.
- Only referrals made through specialist MDT, that meet the Scottish Clinical Criteria, and who have identified funding for community physiotherapy, will be accepted for consideration.
- There are three Annexes to the this pathway:
  
  Annexe 1   Clinical Criteria  
  Annexe 2   Note for families about commitment to the rehabilitation programme  
  Annexe 3   Referral form (to be developed as an electronic referral page)
1. **Local Team to assess merit against agreed Clinical Criteria** \(^1\) [Annexe 1]

   - **Clinical Criteria Met**
   - **Clinical Criteria Not Met**

   If clinical criteria NOT MET - LOCAL TEAM to assess and provide ongoing care/support as required for the child and their family/carers

   Discuss local physiotherapy provision with local physiotherapy/tone management team AND physiotherapy lead for patient’s board of residence: **confirm resources are available for rehabilitation.**

2. **Local Team to arrange for specialist reviews, Imaging and Gait Analysis. Multi professional discussion and if consensus, onward referral.** \(^2\)

3. **Presentation at Regional MDT:** \(^3\)
   - (Local team present)

   If unsuitable for SDR - LOCAL TEAM to assess and provide ongoing care/support as required for the child and their family/carers.

(Annexe 3 Referral form to SDR Co-ordinator)

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\(^1\) Clinical Criteria Met

\(^2\) Clinical Criteria Not Met

\(^3\) If clinical criteria MET - LOCAL TEAM to assess and provide ongoing care/support as required for the child and their family/carers

Version 1.0
4. Presentation at National MDT: Quarterly meeting

5. SDR Neurosurgeon Clinic Visit
   Glasgow and Lothian
   Assessment by Neurosurgeons, Anaesthetists, Physiotherapists and Orthotists and discussion for surgery.

6. Admission for Surgery
   Pre-operative assessments by Physiotherapy and Orthotics.
   **Glasgow:** Admit Thursday for Friday list
   **Lothian:** Admit Tuesday for Wednesday list

7. Inpatient stay and intensive physiotherapy (3 weeks post–operative stay initially)
   Pain team review, orthotics review.

8. Provider/Local Team discussion
   Patient reviewed and programme of intensive physiotherapy agreed during last week of inpatient stay. Handover to community physiotherapy and orthotics during week 3. Assessment of other support/care needs and access to school/education.
9. Early return clinic visit \(^9\)
(Three months post-operatively) trouble shooting, wound healing etc.

10. Six month return visit for physiotherapist’s assessment of progress \(^9\)

11. Twelve month review, Orthopaedic/Neuro surgeon and physiotherapy, clinical assessment of outcome \(^9\)

12. Gait Lab assessment at 2 years post-operatively. \(^9\) (Earlier if clinically indicated)

13. National MDT to ensure all agreed outcome measures have been recorded on database \(^9\)


15. Interim provider unit physiotherapy assessment of progress at 10 years.

16. Regional Gait Lab assessment at skeletal maturity (around 16 years of age) \(^9\)
Notes to accompany the SDR Pathway

1. **Access to the SDR pathway** will be managed by a LOCAL TEAM led by a locally agreed lead clinician. It is recognised that parental request for consideration of SDR is a common starting point and the pathway works on an assumption that the child will already be known to the LOCAL TEAM and in particular to the Community Paediatric Physiotherapist and Community Paediatrician. The Family will be regarded as key partners throughout the pathway and will be involved in making the key decisions. The Scottish Clinical Criteria as advised in ANNEXE 1 must be adhered to. Arrangements for community physiotherapy must be confirmed prior to referral.

2. Whilst the **LOCAL TEAM** will have an understanding of the child being considered for SDR it is necessary to undertake a number of specialist assessments which will ensure there is a robust baseline to assess future progress and to ensure consistent decision making regarding the likely benefit from SDR. The minimum data set is advised in the Clinical Criteria ANNEXE 1. **Gait Analysis**, as advised in the Scottish Clinical Criteria, is regarded as a mandatory assessment. In children too young for a full gait analysis a minimum of video capture demonstrating level of mobility is required. This to offer a baseline to assess the benefit from the care provided whether this includes SDR or not.

3. At the Regional MDT all information will be reviewed. In addition the physiotherapist and orthotist will undertake some final checks prior to referral to the National MDT. All referrals (Annexe 3) should be sent to the SDR MDT Co-ordinator.

4. The **National MDT** will consist of the following professional staff - Orthopaedic Surgeon, Neurosurgeon, Physiotherapist and Orthotist with interest in managing spasticity and muscle tone; and Paediatric Neurologist if available. The Neurosurgeon has the final decision on whether or not it is appropriate to offer SDR surgery.

5. In NHS Scotland, SDR surgery will be provided in two **surgical centres** (NHS Lothian and NHS Greater Glasgow and Clyde) and will provide a package of care to include initial assessment, the surgical procedure, and immediate post-operative care and rehabilitation.

6. The SDR surgical provider team will be encouraged to accept the clinical assessment undertaken under the supervision of the National MDT. Whilst it is recognised that there may need to be some **reassessment or additional assessment of the child**, it is expected that this will be kept to a minimum and will be funded within the overall package of surgical care agreed with the provider.

7. In line with other specialist care it is intended that the child should be **discharged to local care** in their own community as soon as clinically appropriate, with a clear expectation that detailed information will be provided timeously by both the surgical team and the post-operative rehabilitation team.

Families may choose to self fund access to SDR surgery from surgical providers’ out with NHS Scotland, however they must be advised that they will **need to include community physiotherapy in their fundraising efforts**.

8. A comprehensive care package will be provided after surgery by the **LOCAL TEAM** in collaboration with the National MDT team. This will include a package of **INTENSIVE SPECIALIST PHYSIOTHERAPY** which will be delivered in partnership with the child’s family or carers. It is highlighted that one of the criteria for acceptance for SDR is an assessment of the family’s commitment to participate in the delivery of the essential rehabilitation and care which follows SDR surgery. (Annexe 2)

9. The progress of all children who are being considered for SDR, all who have SDR as a surgical procedure, and all who are in post SDR rehabilitation will be reviewed on an ongoing basis by the Specialist Regional MDT(s). This will be based on the collection of an agreed minimum dataset.
which is expected to be incorporated into the wider data collection and audit programme CPIPS developed for specialist musculoskeletal review (for all children with CP). The National MDT for Tone Management/SDR will ensure that additional Gait Analysis are undertaken and reported when required.

National MDT(s) will contribute to the development of an **Annual Report** which will advise NHS Scotland of the level of SDR activity by NHS Board, of the benefits identified for the children referred for the procedure, and will provide a benchmark against the progress achieved by children with similar levels of difficulty who did not or who chose not to access SDR. The annual report will also provide information regarding the quality of the service provided by the SDR provider unit.

**Additional commissioning notes**

**A**  
If a referral for SDR is planned, the NHS Board of residence of the patient must be notified by the consultant making the referral. The NHS Board of residence of the child is required to confirm funding for the community physiotherapy component of the pathway is in place and agree to support travel and subsistence costs for the family.

**B**  
National funding cannot be provided to access SDR care out with Scotland.

**C**  
All clinical communication regarding referral and discharge is between the referring team and the SDR provider team.
Annexe 1

Scottish Clinical Criteria for referral for Selective Dorsal Rhizotomy (SDR)

The clinical criteria below have been developed in partnership with Paediatric Neurologists, Orthopaedic Surgeons, Orthotists, Physiotherapists and the Allied Health Professional National Lead for Children and Young People at Scottish Government. The criteria have been developed to be used in discussion with families and to provide equitable access for this procedure that is based upon clinical decision making. Although developed for SDR it is envisaged that they could be used for the management of tone using a variety of modalities. The pre- and post-physiotherapy management must be discussed at the outset.

History

1. Age: children should have a confidently established GMFCS level (usually between 5-10 years old).
2. Evidence of capacity for the child to participate and co-operate in physiotherapy, wearing of orthotic devices and with no past history of non-compliance with therapy.
3. Family understanding and agreement to commitment in active participation in the rehabilitation programme following surgery.
4. Absence of chronic conditions that may contra-indicate anaesthesia or adversely affects rehabilitation e.g. broncho-pulmonary dysplasia, refractory epilepsy and scoliosis.
5. Absence of significant concerns about weight management and obesity.

Examination

7. Spastic diplegia
8. Have clearly demonstrable spasticity (moderate to severe spasticity).
10. Movement control - isolate hip flexion (minimum), isolate knee extension (better), isolate dorsiflexion (best).
12. MRC 3 lower limb muscle power particularly in knee extensors and hip flexors, preferably also hip abductors.
13. SDR would be unlikely to be considered in the presence of significant joint contracture or abnormal torsional profile for which orthopaedic surgery was likely. Such surgery would not be undertaken simultaneous to SDR and so its timing would be important to establish if referral was being considered for SDR.
14. The co-existence of significant upper limb dysfunction that could impair a child’s ability to use walking aids independently should be identified and discussed in case this should compromise the potential benefit of SDR.

15. Ambulant: GMFCS II-III (possibly high functioning IV), a gait assessment should be conducted as part of the MDT assessment.

**Investigation**

17. MRI – brain and spine

18. <33 % Reimers index for hip displacement or surgical plans to address this before SDR.

The above list is intended as a guide which will evolve with experience. It should be recognised that many of the criteria are subjective and when viewed in isolation are not necessarily absolute. Discussion is anticipated with the centre when referral is being considered and uncertainty exists.
Annexe 2

Physiotherapy for children who are having SDR

This is a statement about physiotherapy provision to share with parents who may be considering the option of their child with cerebral palsy undergoing SDR (or any other surgery). It applies to the whole of Scotland.

The Paediatric physiotherapist will take the lead for rehabilitation following SDR, however it is imperative that parents are committed to active participation in this and that our partners within educational establishments are supported to ensure that they are able to include activity as part of their curriculum particularly post-operatively. This must also include discussions with the orthotic service and where appropriate occupational therapists.

Every child has different needs and physiotherapists must ensure that they are safe, healthy, respected, included, nurtured, responsible, achieving as well as active. Therefore this statement is not prescriptive, rather it provides guidance to ensure a child’s needs are met holistically based upon a clinical assessment and the clinical reasoning of the physiotherapist.

A physiotherapy assessment should be conducted as part of the multi-disciplinary assessment, if possible 6 weeks prior to surgery.

This will include:

- Gross Motor Function Measure
- Assessment of muscle tone
- Range of movement
- Muscle Power

At this point in time the child’s current physiotherapy programme will be reviewed and clarity provided to parents and child on their active participation in the rehabilitation process.

Once the child returns to local service providers following a surgical procedure a physiotherapy review will take place. As autonomous practitioners the physiotherapist will synthesise the outcome of their assessment, combined with current evidence-based practice to advise upon appropriate physiotherapy intervention. Following this the physiotherapist will agree joint goals with the child and family for the post-operative period and identify how this will be achieved. Integral to this will be active participation of the parents and liaison with educational establishments to maximise opportunities for activity.

The guidance for the management of ambulant children with neurological conditions including orthopaedic single event multilevel surgery (NHS Greater Glasgow and Clyde 2011) may be used to provide further detail on protocols and pathways and this can be accessed [here](#).
Annexe 3

Electronic Referral form for National MDT Clinic (link to web-based form)
Selective Dorsal Rhizotomy (SDR) Service Scotland

Referral Form

Date: 

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Has the patient had Botox treatment:

- [ ] Yes (Please Select Date of last treatment):
- [ ] No

Response to Botox treatment:

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Copy of Reports Attached

- [ ] Yes
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Gait Lab wmv file attached

- [ ] Yes
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**Details of Other Surgery:**

- [ ] Select...
- [ ] Other (Please specify)

Orthopaedic Surgery (Please specify)

Please provide a brief statement on the aims of SDR Surgery for the patient:

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