

**South West Neuromuscular  
Operational Delivery Network**



**A Guide for Health & Social  
Care Professionals**

## What is the South West Neuromuscular Operational Delivery Network (ODN)?

The SW Neuromuscular Operational Delivery Network (ODN) is a clinically driven network of NHS Clinicians, Allied Health Professionals, NHS Managers, Commissioners and service users. Its aim is to develop and establish world class and equitable NHS services for children and adults living with rare neuromuscular conditions in the South West. We will achieve this through engagement, interaction and commitment of the above stakeholders.

## Who's Who in the SW Neuromuscular ODN

The SW Neuromuscular ODN is funded by NHS England and hosted by North Bristol NHS Trust. It employs the following specialist staff who are based in various acute and community trusts across the South West.

<b><i>Paediatric Neurologists</i></b>	<b><i>Adult Neurologists</i></b>
Dr Anirban Majumdar Bristol Royal Hospital for Children	Dr Andria Merrison Southmead Hospital Bristol
Dr Kayal Vijayakumar Bristol Royal Hospital for Children	Vacant Post Devon
<b><i>Paediatric Physiotherapists</i></b>	<b><i>Adult Physiotherapists</i></b>
Victoria Selby Bristol Royal Hospital for Children	Nicola Doran Southmead Hospital Bristol
Jackie Watson Royal Cornwall Hospital	Janet McCay St Austell Community Hospital, Cornwall
Claire Frimpong-Ansah Plymouth Child Development Centre	Vacant post Devon
<b><i>Neuromuscular Advisors</i></b>	<b><i>Ages and Areas covered</i></b>
Elaine Burrows Southmead Hospital Bristol	Children & Adults: Gloucestershire, BANES, Swindon, Wiltshire and S Glos.
Ann Morgan Southmead Hospital Bristol	Children & Adults: Bristol, N Somerset & Somerset

<i>Neuromuscular Advisors</i>	<i>Ages and Areas covered</i>
Clare Stayt Derriford Hospital Plymouth	Adults & children: Devon
Tamara Eaton Derriford Hospital Plymouth	Adults & children: Cornwall
<i>Neuromuscular Specialist Psychologists</i>	
Dr John Ashworth Southmead Hospital Bristol	Vacant Post Devon
<i>ODN Co-ordinator</i>	<i>ODN Manager</i>
Sharon Standen Southmead Hospital Bristol	Jo Smart Southmead Hospital, Bristol

### What neuromuscular conditions does the SW Neuromuscular ODN cover?

The SW Neuromuscular ODN has a clear remit on the conditions it covers. Our specialist neuromuscular clinics and staff can only provide services for individuals with the conditions listed under the ICD-10 codes relating to neuromuscular conditions. Some of the less rare conditions are listed below, but a full list of the 60+ conditions are detailed on our website.



- \* Muscular Dystrophy
- \* Spinal Muscular Atrophy (SMA)
- \* Charcot-Marie-Tooth (CMT) disease
- \* Myotonic Dystrophy
- \* Myasthenia Gravis
- \* Many neuropathies and mitochondrial conditions
- \* + many more—please see our website for full list of conditions

We **do not** cover:

- \* Multiple Sclerosis
- \* Parkinson’s Disease
- \* Motor Neurone Disease
- \* Cerebral Palsy

## What geographical area does the SW Neuromuscular ODN cover?

The SW Neuromuscular ODN staff can only see individuals who live in the following areas:



People who attend out of region neuromuscular clinics, but live in these areas, can still access our services.

Please note that people living in Dorset are now covered by NHS England (Wessex) and have access to their Neuromuscular Advisor and Physiotherapist based in Poole and Southampton.

## How will the SW Neuromuscular ODN develop and support specialist neuromuscular services around the South West?

The SW Neuromuscular ODN will operate, and support, a culture of collaboration across the South West. It will rely on the engagement, interaction and commitment of stakeholders and member organisations to deliver service developments agreed by the ODN's Board. The ODN will also deliver clinical services as detailed below:

### *Specialist Neuromuscular Clinics*

The SW Neuromuscular ODN Neurologists hold multi-disciplinary neuromuscular paediatric and adult clinics in Plymouth and Bristol. Each clinic gives patients access to an ODN Physiotherapist, Neuromuscular Advisor and Psychologist.

The ODN Neurologists also hold a number of additional specialist clinics across the region. These may be in collaboration with a local paediatrician or with clinicians and allied health professionals who specialise in other areas of medicine such as respiratory, cardiac and genetics to ensure patients receive the best treatment and medical care possible across specialities.

Paediatric clinics:	Adult Clinics:
<ul style="list-style-type: none"> <li>• Royal Bristol Hospital for Children</li> <li>• Royal Devon &amp; Exeter Hospital</li> <li>• Torbay Hospital</li> <li>• Royal Cornwall Hospital, Truro</li> <li>• Vranck House School, Exeter</li> </ul>	<ul style="list-style-type: none"> <li>• Southmead Hospital, Bristol</li> <li>• Mount Gould Hospital, Plymouth</li> <li>• Musgrove Park Hospital, Taunton</li> <li>• Gloucestershire Royal Hospital</li> <li>• Royal Devon &amp; Exeter Hospital</li> <li>• Royal Cornwall Hospital, Truro</li> </ul>

### ***Non-clinical specialist advice and support in the community***

As well as attending specialist clinics, the ODN Neuromuscular Advisors can be a consistent resource for patients in the community. An Advisor is allocated to an individual based on their geographical location. They will work with individuals from the point of diagnosis of a neuromuscular condition, or from when they register with the SW Neuromuscular ODN, and maintain contact at key stages throughout the individual's life to ensure they can access the help and/or services they require as their circumstances change. They can provide advice over the telephone, or undertake home visits, and can pass on specialist knowledge and advice to individuals and their families about a wide range of non-clinical issues such as:



- \* Supporting individuals to access other health and social care services
- \* Working with schools, colleges and employers to improve understanding
- \* Assist in the transition from childhood to adulthood neuromuscular services
- \* Working with wheelchair services
- \* Working with other professionals, such as Occupational Therapists, Nurses and Social Workers, to ensure appropriate equipment, adaptations and care packages are arranged.

### ***Neuromuscular Physiotherapists***

The ODN Neuromuscular Physiotherapists attend paediatric and adult neuromuscular clinics around the region, providing specialist physiotherapy advice and support to patients. Community therapists are very welcome to attend these clinics with their patients to help facilitate communication and collaboration. ODN Neuromuscular Physiotherapists are also a resource to therapy teams around the South West for training in various aspects of assessment and treatment of neuromuscular conditions, as well as offering joint visits and ongoing advice and support .

### ***Specialist Psychologists***

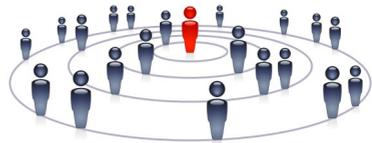
The ODN Specialist Psychologists are available during neuromuscular clinics for adults and can also offer telephone consultations. They offer a service to patients over 16 (18 + in Plymouth Hub) and will work with Psychology teams around the region to offer support and specialist knowledge in respect of neuromuscular conditions and transition from paediatric to adult neuromuscular services.

### ***Specialist Training and Education***

The SW Neuromuscular ODN delivers a free South West Interest in Muscles (SWIM) conference twice a year which is open to health and social care professionals who have an interest in neuromuscular conditions. There is also a twice yearly SW Neuromuscular ODN Bulletin to keep you updated with service developments across the region and to bring you the latest developments in neuromuscular clinical pathways and research.

### **How to access the SW Neuromuscular ODN services**

Referrals to the Specialist Consultants' neuromuscular clinics must be made via the patient's GP or hospital doctor. During clinic appointments patients will be able to access a Specialist Physiotherapist and Psychologist (adults) as appropriate who will then work with local physiotherapy or psychology departments to ensure appropriate support is provided closer to where the patient lives. The Psychologists can only accept direct referrals from the ODN Consultant Neurologists, Neuromuscular Advisors or Physiotherapists.



Once an individual has a confirmed diagnosis of a neuromuscular condition covered by the SW Neuromuscular ODN, and they live in the area covered by the ODN, they are able to use the services of a Neuromuscular Advisor. Individuals will usually meet a Neuromuscular Advisor in the neuromuscular clinic. However, for those individuals who do not attend specialist neuromuscular clinics, but meet the above criteria, Advisors will take referrals from GPs, Clinicians, AHPs and other health and social care professionals. If an individual needs specific non-medical advice, please ask them to call the Network's office and we will arrange for an Advisor to contact them.

## How can you get involved with the SW Neuromuscular ODN?

The SW Neuromuscular ODN is governed by the SW Neuromuscular ODN Board which consists of representation from NHS organisations, Commissioners, Specialist Healthcare professionals and patient representatives from across the South West. The Board often requires wider specialist input in developing services.

If you would be interested in being involved in developing specific patient pathways for people with a neuromuscular condition, please e-mail the Network for further information.

## Key medical issues to remember if an individual with a neuromuscular condition is hospitalised

Individuals with a neuromuscular condition may be at risk of various complications which hospital staff need to be aware of:

- \* There are known respiratory and cardiac complications associated with some muscle diseases. Oxygen administration may reduce respiratory drive in patients with hypercapnia.
- \* Some muscle problems are associated with risks during anaesthesia.
- \* If a person with a muscle problem is immobilised due to fracture or other reasons, there may be a risk of permanent loss of mobility. Early mobilisation may be indicated.
- \* If a person is on steroids, steroid cover and all precautions must be considered.



Please contact the SW Neuromuscular ODN if you require specific specialist advice or have concerns relating to a patient's neuromuscular condition.

## Useful Guidelines

- \* [BTS Guidelines-Respiratory Management of Children with Neuromuscular Weakness Guidelines](#)
- \* [BTS Guidelines-Respiratory Management of Children with Neuromuscular Weakness Quality Standards](#)
- \* [Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management](#)
- \* [Diagnosis and management of Duchenne muscular dystrophy, part 2: implementation of multidisciplinary care](#)
- \* [Consensus Statement on Standard of Care for Spinal Muscular Atrophy](#)
- \* [Consensus Statement on Standard of Care for Congenital Muscular Dystrophies & Family Guide](#)

# PLEASE KEEP IN TOUCH

If you would like to become an affiliate member of the SW Neuromuscular ODN, please either post the registration slip below or e-mail the details listed to us.

## NETWORK OFFICE:

SW Neuromuscular Operational Delivery Network  
Office 7, Gate 18, Level 1, Brunel Building  
North Bristol NHS Trust  
Southmead Hospital Bristol  
Southmead Road  
Westbury-on-Trym  
BRISTOL BS10 5NB

E-mail: [nbn-tr.neuromuscular-odn@nhs.net](mailto:nbn-tr.neuromuscular-odn@nhs.net)

Tel: 0117 41 41184

Website: [www.swneuromuscularodn.nhs.uk](http://www.swneuromuscularodn.nhs.uk)

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I would like to become an affiliate member of the SW Neuromuscular ODN. Please add my details to your affiliate membership mailing list.

Title	First Name	Surname
Job Title		
Organisation		
E-mail		
Tel No.		