



South West Neuromuscular
Operational Delivery Network

What is the South West Neuromuscular ODN?

**A guide for people living with a
neuromuscular condition**



What is the SW Neuromuscular Operational Delivery Network?

The South West Neuromuscular Operational Delivery Network (SWNODN) is a clinically driven network consisting of doctors, allied health professionals (physiotherapists, occupational therapists), NHS managers, commissioners, patients, carers and relatives.

Our aim is to develop and establish world class and equitable care for people of all ages living with rare neuromuscular conditions in the South West of England and to improve their quality of life and overall experience of NHS services.

To achieve this we will work with health and social care professionals to develop the appropriate services and increase the knowledge and skills required to manage these complex conditions. We will also ensure the patient/carer voice is central to providing the best services possible.



What does the South West Operational Delivery Network do?

The SWNODN is commissioned by NHS England to deliver an overall strategic direction for neuromuscular services in the South West. We directly employ a team of neuromuscular specialists who deliver clinical services across the South West. See map (page 2) and team members (page 5) for further details or visit our website.

What Neuromuscular conditions does the Network cover?

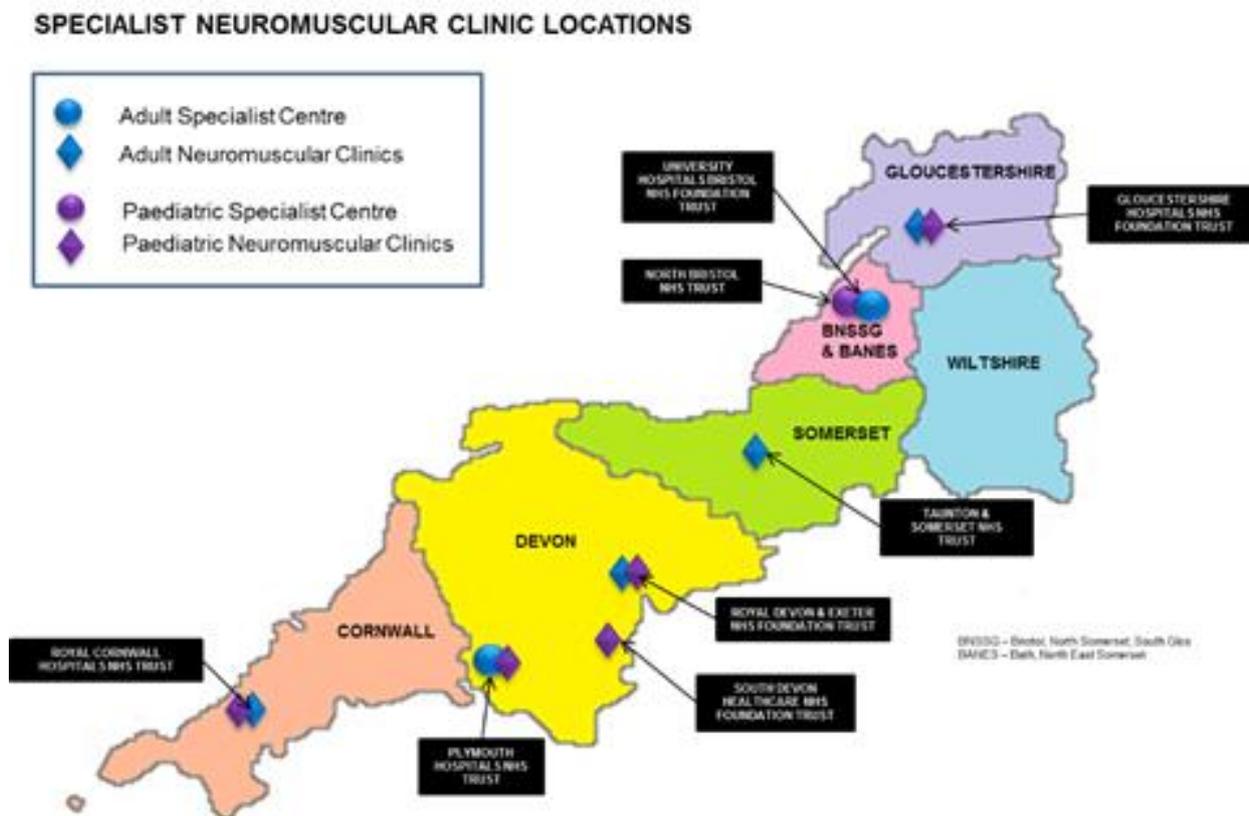
We cover 60+ neuromuscular conditions, so for a full list please visit our website or call the Network office.

- Muscular Dystrophy
- Neuropathy & Myopathy
- Myasthenia
- Spinal Muscular Atrophy
- Myotonic Dystrophy
- Inclusion Body Myositis

Please note that we do not cover Multiple Sclerosis, Parkinson's Disease, Cerebral Palsy or Motor Neurone Disease.

What Geographic area does the Network cover?

The SWNODN can offer a specialist service to people with a neuromuscular condition living in the following counties:



How can the Network help me?

The SWNODN is staffed by a team with expertise in neuromuscular conditions. They provide a multi-disciplinary approach to care which means you will be able to get a more holistic assessment of your condition and access to specialist advice during a consultant led clinic. Some members of the team can see you outside of the clinic and below is some further information about what each member of the team can provide.

Neuromuscular Physiotherapists — The Neuromuscular Physiotherapists attend paediatric and adult neuromuscular clinics around the region, providing specialist physiotherapy assessment, advice and support. They will also work with community therapists in your area so your care can be provided closer to where you live if necessary. The Neuromuscular Physiotherapists are also an expert resource for therapy teams around the South West, providing education and advice in the assessment and management of neuromuscular conditions.



Neuromuscular Advisors — As well as attending specialist clinics, the Neuromuscular Advisors can be a consistent resource for patients in the community. An Advisor is allocated to you based on your geographical location (page 5). They will work with you from the point of diagnosis of a neuromuscular condition, or from when you register with the SWNODN, and maintain contact at key stages throughout your life to ensure you can access the help and/or services you require as your circumstances change. They can provide advice over the telephone, undertake home visits and pass on specialist knowledge and advice to you and your family about a wide range of non-clinical issues such as:



- Provide more time to chat about your condition and answer any questions you may have that you may not have been able to ask during a clinic appointment.
- Help you manage your condition and make the best use of the services available to you.
- Liaise with other health and social care services, educational institutions and work places to ensure they have a clear understanding of your needs.
- Provide information on what services are available to provide advice about access to work, eligibility for benefits, access to specialist equipment such as home adaptations and specialist wheelchairs.
- Visit schools and talk to teachers about your child's neuromuscular condition and any long-term planning that is needed.
- Provide advice on managing the emotional impact of living with a neuromuscular condition and discuss options for counselling or further psychology support if required.

Psychologists — The Psychologists are often available during adult neuromuscular clinics and can see you separate to, or following, your appointment with a Consultant Neurologist. They can work with patients during transition from paediatric to adult neuromuscular clinics and will work with other psychology teams around the region to offer support and specialist knowledge in respect of neuromuscular conditions.

How can I access the SWNODN Services?

Referrals to see a Consultant Neurologist in a specialist neuromuscular clinic must be made by your General Practitioner or hospital doctor. When you attend the specialist clinic and have a confirmed diagnosis of a neuromuscular condition covered by the SWNODN, you will gain access to the Specialist Physiotherapist, Psychologist and Neuromuscular Advisor covering your area.

Depending on your needs, you may be offered a follow-up clinic appointment and/or continued support from the team who will work with you and your local health and social care organisations.

If you are not currently having active medical treatment for your neuromuscular condition, and the condition is covered by the SWNODN, you can arrange to see your Neuromuscular Advisor at any time for non-clinical support as described on page 4. You can do this by calling the Network office. Alternatively, other professionals or family members, with your knowledge and permission, can contact us on your behalf.

What does the SWNODN do with my information?

Once you have a confirmed diagnosis of a neuromuscular condition, and have been seen by a member of the Network team either in clinic or in the community, your demographic details (ie, name, address, date of birth) will ordinarily be recorded by the SWNODN along with some basic information about your neuromuscular condition (type, when diagnosed, etc). We collect this information to help us plan services and aid with audits to look at improving existing services. All information we hold will be kept securely on an NHS server and will only be accessible to SWNODN staff. Any information used as described above will be anonymised (please see our leaflet "*What do we do with your information?*" for further information).

Patient & Public Engagement

You can give your consent to join our mailing list. The benefits of being on our mailing list include:

- A twice-yearly SW Neuromuscular News Bulletin which includes some informative articles, details of other sources of support and updates on what the SWNODN is doing and the latest research
- Notification of patient events and workshops which we provide to support you in managing your neuromuscular condition (these may be organised by the network or other organisations)
- An opportunity to get involved in shaping services in your area

If you have not been seen by a member of the SWNODN team as described above, you can still join our mailing list by completing the "Keeping in Touch — Registration Form" on page 6 or via our website. You can also use the form in this leaflet to change your registration details or opt out of the mailing list. Whatever you decide, this will not affect your medical care or support from the SWNODN team in any way.

Who's who in the Network?

Paediatric Neurologists	Adult Neurologists
Dr Arni Majumdar Bristol Royal Hospital for Children	Dr Andria Merrison / Dr Clare Wood-Allum Southmead Hospital, Bristol
Dr Archana Murugan Bristol Royal Hospital for Children	Dr Clare Wood-Allum Mount Gould Hospital, Plymouth
Paediatric Physiotherapists	Adult Physiotherapists
Emily Milton (North of Network) Bristol Royal Hospital for Children	Nicola Grose (North of Network) Southmead Hospital, Bristol
Francis Belcher (North of Network) Bristol Royal Hospital for Children	Gemma Martin (North of Network) Southmead Hospital, Bristol
Jackie Watson (Cornwall) Royal Cornwall Hospital	Laura Shenton (Cornwall) St Austell Community Hospital, Cornwall
Claire Frimpong-Ansah (Devon) Plymouth Child Development Centre	Georgina Grimshaw (Devon) Mount Gould Hospital, Plymouth
Neuromuscular Advisors	Areas covered
Elaine Burrows Southmead Hospital, Bristol	BANES, Gloucestershire, South Gloucestershire, Swindon & Wiltshire
Ann Morgan Southmead Hospital, Bristol	Bristol, North Somerset & Somerset
Clare Stayt Mount Gould Hospital, Plymouth	Devon
Tamara Higgins Mount Gould Hospital, Plymouth	Cornwall
Specialist Psychologist (Adults)	Paediatric Clinical Nurse Specialist
Dr John Ashworth Southmead Hospital, Bristol	Hayley Smith Bristol Royal Hospital for Children
Network Manager	Network Co-ordinators
Sarah Collett Southmead Hospital, Bristol	Jo McTiernan Southmead Hospital, Bristol
	Lynne Ferris Mount Gould Hospital, Plymouth
Medical secretaries (Adults)	Medical secretaries (Paediatric)
Karen Parker Southmead Hospital, Bristol	Jane Berry Bristol Royal Hospital for Children
Laura Martin Southmead Hospital, Bristol	Ann-Marie Day Bristol Royal Hospital for Children

Keeping in Touch—Registration Form

Please tick all relevant boxes to highlight your preferences:

- I wish to register my details with the Network and join the mailing list
(to receive newsletters and information about events and activities)
- I do NOT want to be on the SWNODN mailing list
- I wish to update the details you already hold
- I wish to be notified about research trials for which I may be eligible

TITLE:	FIRST NAME:	SURNAME:
If child, please provide parent/guardian details:		
DOB:	GENDER:	NHS NO (If known)
ADDRESS:		
POSTCODE:		
TEL:	MOBILE:	EMAIL:
TYPE OF NEUROMUSCULAR CONDITION:		DATE OF DIAGNOSIS:
GP DETAILS (Name, Practice)		
I PREFER TO RECEIVE INFORMATION BY (please tick): <input type="radio"/> POST <input type="radio"/> EMAIL		
DATE FORM COMPLETED:	SIGNATURE:	



South West Neuromuscular Operational Delivery Network

If you would like further information, please contact us:

Post: South West Neuromuscular ODN
Office 7, Gate 18, Level 1, Brunel Building
Southmead Hospital
BRISTOL
BS10 5NB

Tel: 0117 41 41184

E-mail: swneuromuscularodn@nbt.nhs.uk

Web: nbt.nhs.uk/swnodn

Twitter: [@SWNODN](https://twitter.com/SWNODN)

The South West Neuromuscular Operational Delivery Network is hosted by North Bristol NHS Trust.

Specialist clinics are held at the following Trusts:

- Cornwall Partnership NHS Foundation Trust
- Gloucestershire Hospitals NHS Foundation Trust
- North Bristol NHS Trust
- Royal Cornwall Hospitals NHS Trust
- Royal Devon University Healthcare NHS Foundation Trust
- Somerset NHS Foundation Trust
- Torbay and South Devon NHS Foundation Trust
- University Hospitals Bristol & Weston NHS Foundation Trust
- University Hospitals Plymouth NHS Trust