

**South West Neuromuscular
Operational Delivery Network**



**A Guide to using the
Neuromuscular Advisor
Service**

Background

The Neuromuscular Advisors are part of the South West Neuromuscular Operational Delivery Network (SWNODN) which is a network of professionals who specialise in providing world class services for individuals with a neuromuscular condition. Their aim is to help you achieve the best quality of life you can by ensuring you have access to the relevant professionals and services that are available in your area. This leaflet explains the Advisor's role in various settings.



Am I eligible to access the Neuromuscular Advisor Service?

The Neuromuscular Advisors offer a service to all ages. If you have a confirmed diagnosis of a neuromuscular condition covered by the SWNODN, and live in the South West (excluding Dorset), then a Neuromuscular Advisor is available to you for advice and support. Whether you are being seen in a specialist clinic or not, the Neuromuscular Advisors can be accessed from the point of diagnosis of a neuromuscular condition, or when you become known to the Network via registering your details with us.

Please note that the Neuromuscular Advisor Service does not cover Parkinson's Disease, Motor Neurone Disease or Multiple Sclerosis.

Who is my Neuromuscular Advisor?

There are four Neuromuscular Advisors in the South West. Each Advisor has a caseload of children and adults within a specific geographical region. The table on page 2 provides details of the areas covered and the contact details for the Neuromuscular Advisor covering your area.

Ages & Areas Covered	Neuromuscular Advisor
Bath and North East Somerset (BANES) Gloucestershire South Gloucestershire Swindon Wiltshire	Elaine Burrows Office: 0117 41 40246 Mobile: 0774 045 5041 E-mail: elaine.burrows@nbt.nhs.uk Based at: Southmead Hospital, Bristol
Bristol North Somerset Somerset	Ann Morgan Office: 0117 41 46447 Mobile: 0774 045 6199 E-mail: ann.morgan7@nhs.net Based at: Southmead Hospital, Bristol
Cornwall	Tamara Eaton Office: 01752 432911 Mobile: 0782 434 2827 E-mail: tamara.eaton@nhs.net Based at: Derriford Hospital, Plymouth
Devon	Clare Stayt Office: 01752 432912 Mobile: 07824 342806 E-mail: clarestayt@nhs.net Based at: Derriford Hospital, Plymouth

The Neuromuscular Advisors work in the community, so if you are unable to make contact via their office or mobile numbers above and need to speak to someone urgently, please call the Network office on 0117 41 41184 / 0117 41 41185 and we can arrange for an Advisor to call you back.

How can a Neuromuscular Advisor help me?

There are over 60 different types of neuro-muscular conditions, some of which may be very rare. It is the Neuromuscular Advisor's role to offer advice and support to anyone with a neuromuscular condition covered by the Network. They are also available to help other health and social care professionals to understand your neuromuscular condition and how this may affect you in your daily activities.



The Neuromuscular Advisors work as part of a multi-disciplinary team consisting of Consultant Neurologists, Specialist Physiotherapists and Psychologists, all of whom have a specialist interest in neuromuscular conditions. Together, the team provides a holistic approach to the overall clinical management and care of individuals with a neuromuscular condition.

Where can I see a Neuromuscular Advisor?

The Neuromuscular Advisors can support you in the following settings:

In the Out Patient Clinic

The Neuromuscular Advisors are part of a multi-disciplinary team that attend neuromuscular out-patient clinics across the South West which are led by the Network's Consultant Neurologists or a local Consultant with a specialist interest in neuromuscular conditions.

The Advisors are there to support you when you are first given a diagnosis of a neuromuscular condition, ensuring you have a good understanding of your illness and helping to address any concerns you may have. They are also available during follow-up clinic appointments to facilitate on-going referral to other healthcare professionals such as Occupational Therapists, Speech and Language Therapists, Dieticians and Social Care Services.



During Emergency or In-Patient Admissions

The Neuromuscular Advisors are available as a resource to other healthcare professionals who may not have an in-depth knowledge of your neuromuscular condition. We would encourage you to inform any healthcare professionals you come into contact with about the Network and Neuromuscular Team, especially during a hospital admission. The Neuromuscular Advisors can provide advice to the hospital staff about your condition and with planning your discharge from hospital.

In the Community and in your Home

The Neuromuscular Advisors are accessible between clinic visits and can provide help and advice over the phone or arrange a home visit if necessary.

During this time, they can:

- ◆ 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.



How can I access my Neuromuscular Advisor?

You must have a confirmed diagnosis of a neuromuscular condition covered by the Network and live in the South West (excludes Dorset). Details of the conditions covered are listed on our website or you can call the Network office for advice on 0117 41 41184.

If you have not met a Neuromuscular Advisor in clinic, you can refer yourself via phone, e-mail or post. Parents and Carers can also refer to a Neuromuscular Advisor with the knowledge and permission of the individual with a neuromuscular condition.



Alternatively, your GP, hospital doctor or other health or social care professional can refer on your behalf. We would encourage them to use the Neuromuscular Advisor Referral Form available on our website.

About the South West Neuromuscular Operational Delivery Network

The Neuromuscular Advisors are part of the South West Neuromuscular Operational Delivery Network (SWNODN). The Network aims to work with patients and their families to obtain their views on services and keep them updated on developments locally. When you are seen by a Neuromuscular Advisor, your details will be added to the Network's database which is used to help us improve NHS services in the South West. Please be assured that the Network respects your privacy. Your details will be kept secure and will only be accessible to Network staff. Any information used for service development will be anonymised.

Keeping you Informed

We would like to keep you updated on Network activities, events and service developments in your area and occasionally ask for your opinion about the NHS services you use. Therefore, you will be automatically added to our mailing list. However, if you would like your details to be removed from our mailing list at any time, please contact the Network Office. This will not affect any of the services you receive from the Network's specialist staff.

Network Office Contact Details:

South West Neuromuscular ODN
Office 7, Gate 18, Level 1, Brunel Building
North Bristol NHS Trust
Southmead Hospital Bristol
Southmead Road
Westbury-on-Trym
BRISTOL BS10 5NB
Tel: 0117 41 41184
E-mail: nbn-tr.neuromuscular-odn@nhs.net
Website: www.swneuromuscularodn.nhs.uk
Twitter: [@SWNODN](https://twitter.com/SWNODN)



South West Neuromuscular
Operational Delivery Network



**South West Neuromuscular
Operational Delivery Network**

Host Trusts: **North Bristol** 
NHS Trust

Plymouth Hospitals 
NHS Trust

University Hospitals Bristol 
NHS Foundation Trust

Royal Cornwall Hospitals 
NHS Trust

Northern Devon Healthcare 
NHS Trust



Partner Trusts:

Gloucestershire Hospitals 
NHS Foundation Trust

Taunton and Somerset 
NHS Foundation Trust

South Devon Healthcare 
NHS Foundation Trust

Royal Devon and Exeter 
NHS Foundation Trust