

Additional Support for Patients with Neuromuscular Disease

Offering advice and support to people affected by nerve and muscle conditions

The Scottish Muscle Network aims to signpost patients across Scotland to their local support services

Many NHS staff help care for people with neuromuscular conditions. This includes doctors, physiotherapists / orthotists, dieticians and other specialists. There are also **Neuromuscular Care Advisors** and **Specialist Nurses** who can be a key resource for patients and families.

These staff can offer support and advice to **children** and **adults** as well as their families and carers. Depending on their particular role, sometimes they are there simply to listen.

How do support staff work with people who have a neuromuscular condition?

- Children and Young People: Neuromuscular Care Advisors are available across Scotland. Their details are at the end of this leaflet.
- It is often helpful to speak to a Care Advisor when you first get a diagnosis. They can explain what it means and offer support and information.
- Adults: may be supported by a local Specialist Nurse or Care Advisor. Your Neurologist or Geneticist may suggest an Advocacy Officer, usually from the support group, MDUK.

Neuromuscular Care Advisors or Specialist Nurses can also help children and their families as they transition into adult services.

You can meet them at your clinic, at home (by appointment) or online. You can also phone them if that is easier.

Working with other Health Care / Social Care professionals

Advisors and support staff understand the challenges of living with a neuromuscular condition. They can:

- Share advice with schools, GP's, social workers, and healthcare staff who may not know much about these rare conditions.
- Help with education and support in school.

- Link in with group events, like information days, often with charities.
- Suggest the nearest specialist clinic if you don't already see a hospital doctor.

If you are not sure who your nearest **Neuromuscular Care Advisor** or **Specialist Nurse** is, you can ask your hospital Doctor or contact the **Scottish Muscle Network (SMN)**.

The support available from your local team may include:

- Emotional and psychological support at diagnosis and at key points when living with a neuromuscular condition.
- Guidance on managing symptoms as they progress.
- Providing schools, colleges or universities with information about neuromuscular conditions.
- Advice during times of transition, such as moving from school to further education or starting a new school.
- Support with employment or workplace issues.
- Help with reduced mobility or increasing dependence on others.
- Support around loss and grief.
- Linking with housing services if required.
- Information and advice for families about child and adult disability payments

Where are Advisors based?

For further information, please contact:

South East of Scotland

Gill Mitchell

Neuromuscular Care Advisor for Children, Adults and families

Available Tuesday to Thursday 0800 to 1600

Royal Hospital for Children & Young People, 50 Little France Crescent,
Edinburgh. EH16 4TJ

Tel: 0131 312 0611/(50611)

Mobile: 0771701113

Covers patients in the **South East of Scotland (Borders, Lothian and Fife)**

East of Scotland (Tayside)

Rather than a Care Advisor, for Adults in Tayside, support can be found with

Kirsten Patterson

Genetics Specialist Nurse

Clinical Genetics, Ninewells Hospital, Dundee DD1 9SY

Admin team: 01382 632035 email : Tay.clinicalgenetics@nhs.scot

Covers Adult patients in **Tayside and North East Fife**

North of Scotland

Julie Burslem

Neuromuscular Care Advisor for Children and Paediatric Physiotherapist
Care and Learning Service, Highland Council, The Pines, Drummond Road,
Inverness. IV2 4NZ

Mobile: 07909 891756 email : jule.burslem2@nhs.scot

Covers patients in the North of Scotland (**Highland, Tayside, Grampian,
Orkney and Shetland**)

West of Scotland

Wilma Stewart, MSc RGN NDN

Neuromuscular Care Advisor for Children

Queen Elizabeth University Hospital, Clinical Genetics, Floor 1, Laboratory
Medicine Building, 1345 Govan Road, Glasgow. G51 4TF

Available Wednesday **or** Thursday 9 - 4.30pm

Mobile: 07771 701114

Covers paediatric patients in the **West of Scotland (Glasgow & Clyde,
Lanarkshire, Ayrshire & Arran, Forth Valley, Dumfries and Highland).**

Muscular Dystrophy UK (MDUK)

While MDUK are NOT an NHS Scotland organisation, they do offer an
advocacy service and many patients have found MDUK a great local support
with a growing team here in Scotland.

- **Phone:** 0800 652 6352 (Monday to Friday, 9am–5pm). If you call outside these hours, please leave a message and we aim to get back to you within five working days.
- **Email:** info@musculardystrophyuk.org

Scottish Muscle Network

Email: nss.smn@nhs.scot

Website: www.smn.scot.nhs.uk

