

Neuromuscular Care Advisor

Neuromuscular Care Advisors are employed by NHS Health Boards across Scotland and are based within various adult and children hospitals.

If you are unsure who your nearest Advisor is, you can ask your hospital Doctor / Nurse or contact the Scottish Muscle Network (SMN).

An example of services available from your local Advisor can include:

- Emotional and psychological support at point of diagnosis and at crucial stages of living with a neuromuscular condition
- Coping with advancing symptoms
- Education to Schools / Universities on neuromuscular conditions
- Advice at times of change. For example: leaving school or starting a new school
- Employment issues
- Loss of mobility / becoming increasingly dependent
- Support in dealing with loss and grief
- Linking with housing departments
- Provide support / information to families regarding DLA/PIP applications

Scottish Muscle Network

The role of the Neuromuscular Care Advisor

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

How do Advisors work with people who have a neuromuscular condition?

Neuromuscular Care Advisors offer support and advice to **children** and **adults** affected by neuromuscular conditions, their families and carers. Sometimes they are there simply to listen.

It is often useful for people to have contact with an Advisor at the time of diagnosis or within a few weeks. They will discuss the effects of the diagnosis and offer support / further information as requested. This support is also available at any time in the future as the condition changes.

The Advisors are able to support children and their families carry on into adult services.

They can be available for you to meet at the **clinic** you attend or by **appointment at home**.

They can also chat via telephone if this is easier.

Working with other Health Care / Social Care professionals

The Advisors can help with education and give information to Healthcare professionals, GPs, Social Services and the Education sector.

They can be involved in group activities such as condition specific information days for people living with a neuromuscular condition alongside other charities.

An Advisor has experience in many problems that having a neuromuscular condition can cause. This means they could support you in meeting with other professionals such as teachers, social workers and local medical staff who may have limited experience dealing with rare neuromuscular conditions.

They can also suggest the nearest expert clinic for anyone who does not regularly see a Hospital Doctor for their condition.

Where are Advisors based?

The Advisor in Edinburgh is based in the Royal Hospital for Children and Young People and covers patients in the **South East of Scotland (Borders, Lothian and Fife)**.

The Advisor in Glasgow is based in the Queen Elizabeth University Hospital, Clinical Genetics, and covers patients in the **West of Scotland (Glasgow & Clyde, Lanarkshire, Ayrshire & Arran, Forth Valley, Dumfries and Highland)**.

The Advisor in Inverness has a base in Raigmore Hospital and is a part time paediatric Physiotherapist and Care Advisor who covers patients in the **North of Scotland (Highland, Tayside, Grampian, Orkney and Shetland)**.

For further information, please contact:

South East of Scotland

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North of Scotland

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Scottish Muscle Network

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