



Neuromuscular paediatric clinic

Information for parents



Welcome to the specialist neuromuscular service for children

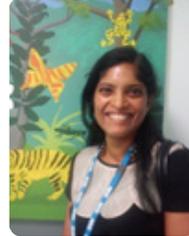
This is a holistic service provision for all children affected by a neuromuscular condition. Your child has been referred for ongoing assessment and care by your neurologist, paediatrician or GP. Your child will be seen by the neuromuscular team who are part of the South West Neuromuscular Operational Delivery Network (ODN). The network involves a team of healthcare professionals specialising in assessing children aged up to 16 with neuromuscular and other associated conditions.

Introduction to the team

When you come to clinic, you and your child may meet the following people from the South West Neuromuscular ODN as well as clinic nurses:



Dr Arni Majumdar
Consultant paediatric
neurologist



Dr Kayal Vijayakumar
Consultant paediatric
neurologist



Elaine Burrows
Neuromuscular advisor



Ann Morgan
Neuromuscular advisor



Beverly Toms
Specialist paediatric
physiotherapist

Your child's care will be overseen by a consultant paediatric neurologist. However, you may also meet other members of the clinical team as appropriate, including junior doctors and registrars. As we are part of a teaching hospital, sometimes medical students may sit in on clinic visits, with your permission.

What to expect at an appointment

Physiotherapy assessment

The specialist paediatric physiotherapist will complete an assessment of your child, which will last 45 to 60 minutes. If your child is able to wear or bring shorts, that would be helpful. Please also bring any splints, braces or other orthotic devices your child wears.

The physiotherapy assessment will include some questions about things such as your child's mobility, wheelchair, splints, therapy, leisure activities and any issues or concerns at home or school. Your child will then have a physiotherapy assessment looking at their range of joint motion, muscle strength, and spinal posture. They may also be assessed (if appropriate) on how they perform some everyday activities such as rolling over, sitting up, getting off the floor, standing up, walking etc. This will be tailored to your child's current abilities. The physiotherapist will also check your child's splints and wheelchair (if applicable).

Completing as much of the assessment as possible gives us a baseline for your child, helps to highlight any problems and helps identify any changes when repeating the assessment at a later date, should this be necessary. However, your child is always free to choose not to do any part of the assessment. At the end of the assessment, the physiotherapist may offer some advice or treatment suggestions and can answer any questions you may have.

There is a hoist available should it be necessary to hoist your child onto the therapy plinth. If your child has their own sling, it would be helpful to bring it with you.

After the clinic, the physiotherapist will liaise with your child's own physiotherapist (if they have one) and possibly other therapists involved in your child's care. Please say if you are not happy for the physiotherapist to do this, otherwise it is assumed you give your consent for this.

The clinic nurse will:

- weigh your child
- measure their height
- and may do some simple breathing tests.

If there is anything you would like to discuss without your child present, a nurse may be available to look after your child.

Consultation

A consultant paediatric neurologist, who has a specialist interest in neuromuscular conditions, will see your child. They will have the referral letter from your GP, neurologist or paediatrician. They will ask you questions about your child's health, their symptoms, your family history and any tests that have already been done. They may also conduct a physical examination.

It would be helpful if you could bring along a list of your child's current medication to the appointment. We would also be grateful if you could bring your personal child health record (PCHR), also known as the 'red book', along with any other correspondence which you think may be relevant for the consultation.

After the assessments, and looking at the results of any tests that have already been done, the consultant (or another specialist colleague) will give you a diagnosis for your child, information about the condition, talk about treatment options, or suggest further tests (if appropriate) to try to get a diagnosis. You may get a referral to another doctor or hospital for further tests.

They will tell you which tests they think your child should have and where. You will be sent a letter with details of any appointments that are made for your child.

Neuromuscular advisors

All people diagnosed with a neuromuscular condition are allocated to a neuromuscular advisor. A neuromuscular advisor may also be at the appointment. However, if you need more time to talk things over, a home visit can be arranged for a later date. You can speak to the advisor about a range of non-clinical issues, for example:

- any concerns you have following a diagnosis
- how to access other health and social care services
- talking to teachers about your child's condition
- what financial support may be available
- where to go for further information or professional support.

Other professionals that your child may need to see in the future

Your child may need to see doctors who are specialists in the heart, bones, muscles, lungs, or genetics. They may also need to see a speech and language therapist, dietician, occupational therapist or social worker. The consultant will discuss any referrals to other specialists with you.

Follow up appointment

The consultant paediatric neurologist may want to see your child again so that they can check on their progress. However, it may be more appropriate for your child to see a local paediatrician so that any other tests, care and support that are needed can be managed closer to your home. The consultant will discuss these options with you and make arrangements for an appointment letter to be sent to you in the post.

Outreach clinics

If coming to the Bristol Royal Hospital for Children is difficult for you and your family, we may be able to offer you an alternative appointment at one of the outreach clinics in Plymouth, Torbay, Truro or Exeter. Although these are not on such a regular basis as the Bristol clinics, you are welcome to discuss the option of attending one of these in the future.

Cancelling or re-arranging clinic appointments

If you are unable to attend the appointment you have been given, we would be very grateful if you could contact the consultant neurologist's secretary on **0117 342 0502**. This will enable us to offer you another appointment at a more convenient time for you and your family and ensure that we can allocate your appointment to someone else.

Further tests

Occasionally in clinic, the consultant may want to do further tests. They will be happy to discuss this with you and your child.

These tests are not usually done in clinic and may need a separate appointment.

Some of the tests include:

- a muscle biopsy – this involves taking a small amount of muscle and testing it to see if there are any abnormalities
- a sleep study – this includes the child wearing a small piece of equipment on their finger overnight to see how efficient their breathing is
- an ECG/echocardiogram – these are tests that allow the doctor to see if there are any problems with the heart
- a swallowing assessment to see if there are any problems with swallowing
- blood test – there may be many reasons that a blood test is taken. The consultant will tell you what test is being done

- nerve conduction tests – a simple electrical test to see if your child’s nerves work
- muscle MRI – a special scan which helps identify exactly which muscle is involved in your child’s condition.

The South West Neuromuscular Operational Delivery Network

The team you see in the specialist neuromuscular clinic are part of the South West Neuromuscular Operational Delivery Network (ODN). The Network aims to work with patients and their families to obtain their views on services and keep them updated on developments locally.

Now that you have been in contact with the Network team, your details will be added to our Network patient registry. We respect your privacy, so your details will be kept secure and will only be accessible to Network staff. This will help us improve NHS services in the South West and any data used will be anonymised. We will also add you to our mailing list to enable us to keep you informed of Network activities, events and service developments in your area. If at any time you would like your details to be removed from our mailing list, please contact the Network Office on **0117 414 1184** or email: **nbn-tr.neuromuscular-odn@nhs.net**.

Further information about the Network is available on our website at: **www.swneuromuscularodn.nhs.uk**.



**South West
Neuromuscular
Operational
Delivery Network**

Further information

You may also wish to look at the websites below, which may provide useful additional information:

- **Muscular Dystrophy UK**
<http://www.muscular dystrophyuk.org/>
- **Myasthenia Gravis Association (Myaware)**
<http://www.myaware.org/>
- **Spinal Muscular Atrophy Support UK**
<http://www.smasupportuk.org.uk/>
- **Action Duchenne**
<http://www.actionduchenne.org/>
- **Duchenne Family Support Group**
<http://dfsg.org.uk/>
- **Charcot-Marie-Tooth (CMT) UK**
<http://cmt.org.uk/>
- **South West Neuromuscular Operational Delivery Network**
<http://www.swneuromuscularodn.nhs.uk.>

Notes/questions:

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While your child is under our care, you may be approached about them taking part in research. To find out more please visit: www.uhbristol.nhs.uk/research-innovation or call the research and innovation team on **0117 342 0233**.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print, audio or PDF format, please call the patient information service:



0117 342 3728 / 3725

