

National Hospital for Neurology and Neurosurgery

Specialist Muscle Channelopathy Service

Useful information about your appointment

If you would like this document in another language or format, or require the services of an interpreter, contact us on 0203 448 8009. We will do our best to meet your needs.

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1 Introduction

This leaflet has been written for patients and their family members who have been referred to the Specialist Muscle Channelopathy Service clinic. Clinic is held every alternate week on a Tuesday afternoon from 1pm. This is a National outpatient clinic and we see people referred to us from across the UK.

Muscle channelopathies are a group of very rare neuromuscular disorders. Most general physicians may only see 1 or 2 people with these disorders during their career. Our specialist clinic was created to provide a central service that has experience and expertise in diagnosing and managing these conditions.

It is directly funded by the Department of Health to promote equality in health care for rare diseases. If a diagnosis of a channel problem has already been made then you may be referred here for advice on management.

2 Why have I been referred to the Muscle Channelopathy clinic?

You or your family member has been referred to us by your local specialist or GP because they have questioned whether you or your family member may have a muscle channel problem.

Muscle channels effectively act as “gates” in our muscle membranes. They control the movement of substances such as sodium and potassium in or out of our muscle cells. This is very important for our muscles to contract and relax properly.

Common symptoms described by people with a muscle channelopathy include episodes where the muscles are very weak or paralysed or episodes where the muscles feel very stiff or even become stuck.

Our team will assess whether you or your family member is likely to have a muscle channel problem or alternatively confirm that you don't have a problem with your muscle channels.

If after all our assessments are complete we don't think a muscle channel problem is the cause of your symptoms we will either refer your medical care back to the specialist who referred you to us or if we think you have a different condition affecting your muscles we may suggest transferring you to another of our muscle clinics.

If a diagnosis of a channel problem has already been made then you may have been referred to us for advice on the management of your symptoms.

These appointments are very specialised and a lot of resources go into organising them. If you need to reschedule or cancel your appointment, please could you contact the secretary a minimum of two weeks before your appointment? Although every effort is made to reschedule appointments where possible, failure to attend can result in you being discharged.

3 Where is the muscle channel clinic MGH02 located?

This clinic is run alternate Tuesday afternoons in the 33 Queen Square outpatient department at the National Hospital for Neurology and Neurosurgery. The outpatient department has a large wooden door and has both stepped and slope access to the department.

4 How do I get to the National Hospital for Neurology and Neurosurgery at Queen Square?

The hospital is located in Queen Square which is near Russell Square tube station for the Piccadilly underground line and Holborn tube station for the Central and Piccadilly lines.

There are a number of buses that run from Kings Cross and Euston stations as well as from Waterloo station. The buses stop on Southampton Row and it is a short walk into the square. There is limited pay and display parking in the square; however there are a number of underground car parks a short walk away, check www.ncp.co.uk for details.

For travel advice, contact Transport for London on **020 7222 1234** or at www.tfl.gov.uk.

If you are travelling to the hospital for NHS treatment under the care of a consultant you may be able to claim a refund. If you are in receipt of certain benefits you may be able to claim a refund.

Please ask at the outpatient desk if you need to claim travel costs.

5 What facilities are available?

The waiting area in the clinic has water for patients to help themselves. There is also a small coffee shop a short walk through the department into a different section of the hospital, this has step and lift access. Please ask a member of the outpatient team for directions should you wish to go to the coffee shop while you wait.

There is space for patients in wheelchairs.

If you need any assistance during your appointment please let the clinic nurse know.

There is a wheelchair accessible toilet in the department as well.

6 What should I bring with me?

- Your appointment letter
- Your current contact and GP details
- Mobility aid(s)
- A list of questions and a note pad
- All medication you are taking (whether prescription, over-the-counter, herbal, homoeopathic or traditional)
- Money for prescriptions and refreshments
- Any specimen(s) requested

- Any relevant letters from other doctors if you have them

7 Relatives, carers and visitors

We encourage patients to bring someone with them to the hospital for support.

8 The Team

The clinic team is made up of two consultant neurologists, a clinical fellow, a neuromuscular physiotherapist and a specialist nurse.

Additionally we have a Consultant Neurophysiologist, who does all of the nerve and muscle 'electrical' tests. We also have a neuro- genetics team member who comes to our biweekly multidisciplinary meetings, they perform the genetic testing.

9 What will happen during the appointment?

We will talk to you about your symptoms and examine you. You may be asked to have some blood tests and/or an electrocardiogram (ECG), this is to check the electrical activity of your heart and is not painful.

This is done in patients whom we may prescribe a particular medication and not all patients require this. You may spend some

additional time with our physiotherapist or specialist nurse if needed. If you wish to see a particular person in the clinic, please ask at reception; however you may have to wait longer to be seen. It is not always possible to see a specific doctor.

You may also be sent a separate appointment to see the neurophysiologist to have some tests done looking at how the muscles are working (EMG test). This may be earlier in the day prior to your appointment in the clinic or after your appointment. Not everyone will have an appointment for this test. If you do you will receive a separate appointment letter and a separate information sheet about the specific tests will be enclosed.

The test takes place in the Neurophysiology Department on the 3rd floor of the Albany Wing in the main hospital building (the brown building with the blue and white sign above the steps – there are steps and wheelchair access to the hospital).

10 Teaching and research

UCLH is a teaching Trust, and you may be asked if medical or nursing students can observe or assist with your care.

We are also a major centre for medical research. If you are interested in taking part in research projects, ask the person who is caring for you.

If you do not wish to take part in teaching of students and/or research, please tell us when you arrive. Not taking part in teaching or research will not harm your care.

11 After my appointment

If you are to be followed up in the clinic you will be given another appointment. You may also be booked into the nurse-led telephone clinic if you have been started on treatments, this appointment will be sent out to you by post.

You will be given the contact details for the clinical nurse specialist, whom you can contact for information and advice about your condition, appointment, medication.

We will write to you and your doctor summarising everything that took place during the clinic and what the next steps are.

12 Where can I get more information?

Muscular Dystrophy UK is a charity for people with neuromuscular disorders, they provide information, advice and support for patients, carers and health care professionals.

Website: <http://www.muscular dystrophyuk.org/>

Telephone: 0800 652 6352

For general health information and advice, contact the 24 hour, nurse-led service, NHS 111, see your GP for non-urgent problems and attend local A&E in an emergency only.

13 Contact details

Consultants for the service can be contacted via the PA:

Direct line: 020 3448 8014

Clinical Nurse Specialist: Direct line 020 3448 8009

Fax number: 020 3448 3633

Specialist Registrar for the muscle team via the hospital switchboard on 0845 155 5000, (during working hours 08.30 – 18.00)

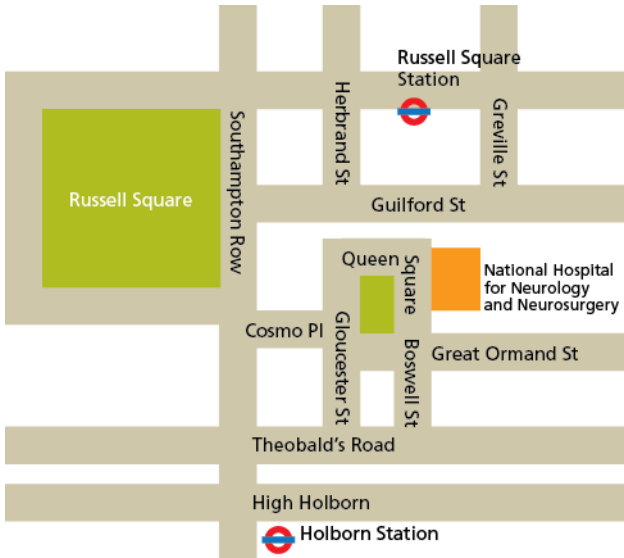
Email: uclh.enquiry.MuscleChannelService@nhs.net

Website: www.uclh.nhs.uk

If you need to alter the date of your appointment or wish to have a telephone appointment please contact either:

The HSS Service Manager on 0203 448 8030 or HSS administrator on 0203 448 8155.

Space for notes and questions



We are committed to delivering top-quality patient care, excellent education and world class research

Safety
Kindness
Teamwork
Improving

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