If you would like this document in another language or format or if you require the services of an interpreter contact the Clinical Nurse Specialists or the ward directly. We will try our best to meet your needs.

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Your neurologist has recommended that you have a muscle biopsy to help make a diagnosis of your condition. This may also help decide what the best treatment is for you.

This booklet has been written by the neuromuscular team at The National Hospital for Neurology and Neurosurgery. Our aim is to explain what a muscle biopsy is, how it is performed and what you are likely to experience.

This booklet is intended for patients, their family and carers, who may be offered this procedure. This booklet is not intended to replace discussion about muscle biopsy with your consultant. If you have any questions about this procedure please contact a member of our team.

After you have agreed to have the muscle biopsy, we will request the biopsy for you. The biopsy will be done by one of the neurosurgery team in a surgical theatre. You should have a date within 3 months of the request. If you have not heard, please contact your consultant’s secretary.

If the date and time you are offered is not suitable, please contact the admission team to find a suitable date.

**What is a muscle biopsy?**

A biopsy is a procedure in which small samples of muscle tissue are removed for analysis. This tissue is examined under
a microscope for abnormalities that may reveal important information about your condition.

Three biopsy samples are taken. The first is about a centimetre in length and about the same width as a matchstick (about two millimetres), the other two are around two centimetres in length and one centimetre in width (similar to the width of a biro).

This is usually taken from the upper, outer thigh muscle (the quadriceps muscle) on the left but other muscles are sometimes selected by your doctor including the arm muscles (biceps or triceps) or the calf muscle. The biopsy will take around 20 to 30 minutes.

**How can a muscle biopsy help?**

A muscle biopsy may help in diagnosing conditions associated with muscle weakness/pain. By looking at the muscle tissue under a microscope and doing other additional laboratory tests the cause of the muscle weakness/pain can often be determined.

Sometimes a muscle biopsy is useful for investigating rare conditions that do not directly cause muscle symptoms; for example a muscle biopsy may be carried out when investigating heart problems or rare brain disorders. It can also help in the diagnosis of conditions causing inflammation of the blood vessels (called “vasculitis”).

The results of the muscle biopsy may help your doctor to make a diagnosis of your problem and this may lead to further
treatment. Sometimes the muscle biopsy results do not provide a clear answer to your problems.

What are the risks of a muscle biopsy?

All operations have risks and your doctor will discuss the risks of a muscle biopsy with you.

The commonly occurring ones are:

• Problems that may happen straight away

The most common problem is pain at the site of the biopsy after the local anaesthetic wears off. It is important that you ask your nurse for pain relief when you need it. In most cases this will stop in a few days to weeks. A small amount of bleeding or discharge from the wound may occur for two or three days. Swelling and bruising often occurs but should go away in a few days.

On extremely rare occasions an allergy to the medicines or dressings used may develop. If this happens treatment may be required in or out of hospital.

• Problems that may happen later:

Infection (although rare) may occur as with any wound. However it is more likely to occur if you have diabetes or you are taking medicines called steroids.

When infection develops, wound healing may be slow and occasionally the infection may need draining. A wound infection
may require prolonged wound dressing and antibiotics and you may be left with a larger scar.

• **Problems that are rare:**

Some people experience ongoing pain at the biopsy site or persisting numbness overlying the scar. Occasionally it is necessary to use medicines or other techniques to ease ongoing pain.

On very rare occasions, swelling and bruising at the wound site may remain for weeks after and it is possible that a hard lump (haematoma) may develop under the skin. This is generally accompanied by pain around the biopsy area.

**What will happen if I choose not to have a muscle biopsy?**

The choice to have a muscle biopsy is yours. However, decisions about future treatments may depend upon the biopsy result, especially if long term or potentially toxic treatments are being considered.

We would not wish to give you such treatments without good evidence that it is right for you.

If you are uncertain about any aspect of the procedure, the reasons for it, the benefits or the possible risks and complications, please speak to your doctor.
What alternatives are available?
Before considering a muscle biopsy your doctor will have gathered as much information as possible through blood tests (including genetic blood tests) and electrical studies.

An MRI scan of the muscles may also be helpful.

In some cases, a biopsy of skin or other body tissues can help.

How should I prepare for a muscle biopsy?
Your doctor needs to know about all medicines you are taking. It is especially important that the doctors know about medicines that affect the blood’s ability to form a clot such as anticoagulants (blood thinning) or antiplatelet medicines, as these may need to be stopped before surgery. Do not stop taking any medicines unless you are advised to do so by your doctors or clinical nurse specialist.

You may be admitted to the Day Care Unit, one of the wards or the Neuromuscular Complex Care Centre prior to your biopsy. We will send you information about the units with your admission letter.

Please bring any medicines you are currently taking with you on the day.

You will not need to fast for the biopsy as it is performed under a local anaesthetic. This means you will be awake throughout, if you would prefer to have sedation for the biopsy, please ask the team doing the procedure.
We recommend that you have someone to accompany you on your homeward journey.

**Asking for your consent**

We want to involve you in all decisions about your care and treatment. If you decide to go ahead with this procedure, by law we must ask for your consent and will ask you to sign a consent form.

This confirms that you have agreed to have the procedure and understand what it involves.

You should be able to see the doctor who is doing the biopsy in advance, and can be consented for the procedure however this is not always possible so you may have a telephone conversation with the surgeon and will sign consent on admission.

Staff will explain all the risks, benefits and alternatives before they ask you to sign a consent form.

If you are unsure about any aspect of your proposed treatment, please don’t hesitate to speak to a senior member of staff.

**What happens during a muscle biopsy?**

The doctor performing the biopsy may not be the doctor looking after you, but by a doctor who has specialised in taking a muscle biopsy.

The procedure is performed in an operating theatre under a local anaesthetic. This means you will be awake throughout the
procedure. However you are able to request sedation, if you wish for the procedure.

The surgeon doing the biopsy will ask you to lie on your back or will position you so that the muscle is easy to access.

The surgeon will sterilise the area with iodine or other cleaning solution. A local anaesthetic (numbing medicine) will be injected around the area which initially causes a stinging sensation. Once the area is numb, a five centimetre incision (opening) is made through the skin.

The surgeon then identifies the muscle before taking the biopsy. Patients experience a ‘pulling’ or ‘pressing’ sensation as the biopsy is taken and some patients find this uncomfortable/painful.

Stitches are used to close the skin and a dressing is applied.

**What should I expect after a muscle biopsy?**

After the surgery, the biopsy site will be covered with a sterile dressing and a bandage. The dressing should remain in place for three to five days and it is important that you keep the wound and dressing dry.

Generally stitches dissolve and do not need to be removed. Sometimes a stronger type of stitch is used, which will need to be removed.

You will receive instructions as to which type of stitch you have and we will give you a letter which tells you when you need to have your stitches removed. Usually this can be done by your
GP or practice nurse. We will give you a letter to take to your GP.

If the muscle biopsy has been taken from your leg you should rest for three hours afterwards ideally with your leg raised on a pillow to prevent swelling and complications and to aid healing.

If possible, on your journey home you should avoid walking for long periods and you should be able to keep your leg raised, for example by sitting in the back of a car with your leg resting on a pillow on the seat.

After 24 hours it is important to maintain mobility but try to avoid a lot of exercise or too much walking for one week.

If the biopsy was taken from the arm the main principles of care listed above still apply.

The Neuromuscular Nurse Specialists will be able to advise you further regarding exercise and wound care.

**How and when will I receive the results of my muscle biopsy?**

An initial report of the findings from the muscle biopsy is usually available four weeks after the procedure. This initial report is often sufficient but sometimes if additional special tests are required this report will take longer.

A preliminary result of your muscle biopsy may be available in seven days, and if appropriate, treatment could commence before a full report is available.
Your doctor may contact you to discuss the result if there is an urgent need. The results are usually discussed at an appointment in a future clinic.

**What should I do if I have a question or I am concerned about the biopsy wound?**

If you are at all concerned about your wound please seek medical advice. If you experience excessive pain, swelling, bleeding or drainage from the biopsy site or have any other concerns regarding your wound please see your family doctor (GP) or the practice nurse.

If your GP is closed, please contact your local out of hour’s service that deputises for your GP or go to your local Accident & Emergency department.

The on-call Neurology Registrar covering The National Hospital for Neurology and Neurosurgery can be contacted by the treating Accident & Emergency physician through the switchboard.

For non-urgent enquiries you can contact the Neuromuscular Nurse Specialists. During working hours our answer phone is checked at least twice each day. Please leave a message with your name and a contact number and we will get back to you as soon as possible.

**Where can I get more information?**

Centre for Neuromuscular Diseases www.cnmd.ac.uk
Muscular Dystrophy UK
61 Southwark Street
London
SE1 0HL
020 7803 4800
info@muscular-dystrophy.org

UCL Hospitals cannot accept responsibility for information provided by other organisations.

Contact details
The National Hospital for Neurology and Neurosurgery Queen Square
London
WC1N 3BG
Switchboard: 0845 155 5000 (There is no additional service charge for using an 0845 number. The cost is determined by your phone company’s access charge) / 020 3456 7890
Fax: 020 3448 3633
Website: www.uclh.nhs.uk/nhnn
Neuromuscular Disorders Nurse Specialists
Direct Line: 020 3448 8009
020 3448 8015
Space for notes and questions: