



**Patient Factsheet:
Testing for Malignant Hyperthermia (MH)**

**Patient/Relative Helpline No
0113 206 5270 (during office hours)**

This factsheet has been put together by the MH Investigation Unit at the University of Leeds, to give information for patients and relatives on all aspects of testing for Malignant Hyperthermia (MH).

What is MH?

MH is a reaction to commonly used anaesthetic drugs where the body produces too much heat. If not recognised and treated in its early stages MH can be fatal.

When someone is known to be at risk of developing MH, the condition can be managed effectively and alternative anaesthetic drugs can be used.

The risk of developing MH is associated with a change in the genes that are responsible for controlling the release of calcium in skeletal muscle cells.

MH can be diagnosed by removing small pieces of muscle in an operation called a muscle biopsy. By exposing the muscle to anaesthetics and other compounds under carefully controlled conditions in the laboratory we can find out whether MH is present or not.

Is MH a common condition?

An MH reaction during anaesthesia is a rare event, occurring in 1 in 10,000- 50,000 general anaesthetics. However, anaesthetics do not necessarily cause an MH crisis every time someone at risk is given them. We know of one patient who had 13 uneventful anaesthetics before they had an MH reaction.

Who gets MH and why?

MH is hereditary; therefore it is passed on through the family. It occurs equally in males and females and the gene changes that cause it are found in every ethnic group. Someone at risk of MH has a 50-50 chance of passing on the condition to their children.

Testing for MH

A muscle biopsy test is currently the only definitive test for MH.

In some families a gene test can be used to identify those at high risk and these people do not need the muscle biopsy. A negative gene test does not exclude MH and this can only be done using the muscle biopsy.

Muscle Biopsy

There are three common reasons for being referred to the MH unit for a muscle biopsy:

1. You experienced a reaction to an anaesthetic that raised a suspicion of MH
2. MH has been found in your family and there is no gene test available in your family
3. MH has been found in your family and you have had a negative gene test.

Other reasons for being referred to the MH unit for a muscle biopsy:

1. You or a relative have a muscle disease that may be associated with a risk of MH, such as central core disease
2. You developed heat stroke during exercise or muscle cell breakdown (rhabdomyolysis) after exercise, in which case you will receive further information.

Can I choose not to be tested?

Yes, the decision to have a muscle biopsy is entirely yours. We will provide you with as much information as you need to help you reach your decision.

If you decide not to be tested then you would have to be assumed to be at risk of MH should you require an anaesthetic.

Most anaesthetists would like to know your MH status for your safety and this may lead to postponement of non-life saving surgery or increased risk of other complications during emergency surgery.

If you choose not to be tested, your children (and possibly other relatives) will be presumed to be at risk of MH and would need to undergo testing which would be unnecessary if you had a test and were shown not to be at risk.

I live a long way from Leeds, can I have my biopsy done at my local hospital?

No. The laboratory tests are highly specialised and St James's Hospital is the only centre in the UK where they are done. The muscle samples need to be taken to the

laboratory within 15 minutes of the muscle biopsy in order for the tests to be reliable and so the biopsy must also be done at St James's.

What does the muscle biopsy test involve?

The muscle biopsy involves taking samples of muscle from the inner aspect of the lower part of your left thigh. The biopsy is a surgical procedure through an incision (cut) in the skin that is usually 5 – 7 cm long. The image below shows the position of the incision marked on the skin before the procedure.

This procedure is performed in an operating theatre and usually takes no more than 45 minutes to 1 hour.

You are required to stay in hospital the night before the biopsy, and will be fasted before surgery.

The anaesthetist will meet you the day before the muscle biopsy to discuss the procedure in detail, giving you plenty of opportunity to ask questions.

You will be taken to theatre the following morning where you will initially go into the anaesthetic room. In the anaesthetic room routine monitoring will be attached. After this, a cannula will be inserted into the back of your hand to allow for blood samples to be taken and provide access for any drugs that may need to be administered. What you feel is a scratch similar to the one for a routine blood test.



The procedure is performed under local anaesthetic meaning you will be awake throughout. If you are nervous or anxious the anaesthetist can give you medicines through the cannula; this is known as sedation and can make you feel drowsy.

The anaesthetist will inject the local anaesthetic in the groin area using the guidance

of an ultrasound scanner. Initially a small patch of skin is made numb (this will sting for a few seconds) and then local anaesthetic is placed around the nerve. At this point you may experience a tight sensation in the area of injection. Over the next 5 – 20 minutes the thigh will gradually become numb and the leg heavy. The anaesthetist will do various tests to confirm that the thigh is sufficiently numb for surgery.

The next step is for the anaesthetist to locate the precise position on the thigh for the biopsy. You may notice some tingling of the skin of the thigh or the thigh muscles twitching. This does not hurt. Once the correct position has been located, it will be marked with a marker pen and you will be ready for surgery.

In the operating room, a screen is put up in front of you to keep the surgical site sterile and this means you will not be able to see the procedure. The leg will then be covered with drapes and an antiseptic will be applied to the skin at the biopsy area. Before commencing the operation the anaesthetist will do one final check to ensure that the pain sensation has disappeared.

During the muscle biopsy you may experience muscle jumping or a pulling sensation, but you should not feel anything sharp or uncomfortable.

After the procedure, you will be taken to a ward where you will stay until the effects of the anaesthetic have worn off.

How many stitches will I have and when will the stitch come out?

You will have one single stitch running through the wound with two beads at the ends. We will give you a letter to give to your GP and you will need to book an appointment with the practice nurse to have the stitch removed 10 days after the biopsy.

When will I get the results of the biopsy?

We will have your results on the same day as the biopsy. The anaesthetist will visit you on the ward and explain the results and what steps need to be taken.

What do I do if my result is negative?

A negative result means that you are not at risk of developing MH. For any future operations no specific precautions relating to MH need be taken. If you were having the biopsy because you had a suspected MH reaction, other family members can be reassured that they also are not at risk of developing MH. However, if you are having the biopsy because a family member had a reaction, and you are given a negative result, whilst you and your immediate descendants are fine, other blood relatives may still need to be tested. It is best to check with the doctor at the time of your biopsy.

What do I do if my result is positive?

A positive result means that you are at risk of developing MH. The anaesthetist will explain in detail what this means for you. You will have the opportunity to ask any questions and will also be given information to take away with you explaining more about MH. You will be given an MH alert card for your wallet and advised to obtain a warning disc to be worn as a necklace or bracelet. MH warning discs can be obtained through the UKMHR, a registered charity that supports patients and families with MH. Please remember to ask the anaesthetist for a signed application form to join the UKMHR.

Please remember: A positive result of MH does not mean that patients can no longer have surgery. MH can be managed well. It simply means that any MH triggering anaesthetic drugs need to be replaced with alternative anaesthetics.

Is there a cure?

There is no cure for MH; the management involves avoiding the triggering agents during anaesthesia.

How long will I be in hospital for?

If you are travelling home on your own by public transport then you will be discharged on the morning of the day after the biopsy. Patients cannot drive themselves home under any circumstances.

If someone is with you and will stay with you on the night of the biopsy, then generally you can leave on the evening of the biopsy after you have seen the anaesthetist. We would prefer you not to travel so far that you could not return to St James's should a problem arise on the night after the biopsy but this rarely would require us to advise against you returning home on the evening of the biopsy.

Will I have pain following the biopsy?

The local anaesthetic will last for around 6 hours, meaning there will be weakness and numbness of the leg for this period. As this begins to wear off you will start to experience some pain or discomfort at the site of the muscle biopsy.

Pain killers will be prescribed to help ease this and patients will be advised of further pain medication on discharge. The pain is similar to that of a torn muscle and is usually manageable with routine painkillers.

How long will this last?

This varies between patients. Based on our surveys in the past, patients experience pain for an average of 6 days (ranging from 0 to 60 days) and use painkillers for an average of 3 days.

How big will the scar be?

The scar is normally around 5 – 7 cm and is located just above the knee. In our last survey, 96% of the patients described their scar as either hardly noticeable or acceptable. 4% described their scar as poor.

Are there any complications of the muscle biopsy?

We have surveyed patients 6 months after their muscle biopsy. Approximately 50% of patients reported some numbness around the scar and knee initially. This resolved subsequently in half of them. No patient has reported persistent pain or soreness around the scar.

Most patients say they have had to limit normal physical activities until the stitches came out, c. 10 days after the surgery.

It usually takes an average of 1 week after the biopsy before patients feel able to drive safely. This is when the patient has no discomfort or muscle weakness which would stop them reacting quickly in an emergency.

The average period of absence from work after the biopsy was one week.

Other uncommon problems patients reported were “knee twitches”; itchiness around the scar; difficulty in bending the knee and climbing stairs. One patient received physiotherapy to help build up the strength in the biopsied leg.

Should I be worried about further anaesthetics if I am at risk of MH?

No. It is important to realise that operations can be performed safely and effectively for patients at risk of MH.

All anaesthetists in the UK and most developed countries are aware of this condition. However, in order to anaesthetise you safely anaesthetic equipment needs to be specially prepared and a more experienced anaesthetist will often be called as some anaesthetists are less familiar with the alternative drugs required.

Although the condition may be documented in your notes, it is important for you to inform the anaesthetist of your MH status before any operation. We advise that you keep your MH warning card in your wallet or purse and wear a warning disc in case you are brought into hospital unconscious after an accident, or through illness.

Can I travel abroad if I have MH?

Most developed countries have well trained anaesthetists and the necessary anaesthetic drugs and equipment required to manage patients at risk of MH.

In less developed countries safe anaesthesia for patients at risk of MH cannot be guaranteed. Hospitals in these countries are also unlikely to be able to afford to

stock Dantrolene, which is the antidote to MH that is used to treat an MH reaction.

We can provide foreign translations and a list of foreign MH experts for use when travelling abroad.

What do I do if I need an operation in the future and am negative?

If you are negative, you can receive anaesthesia without any special precautions.

Do I need to inform any family members?

Yes. On receiving a positive result, you are advised to inform blood relatives of your diagnosis and ask them to contact the MH Unit for advice regarding testing as soon as they can.

Can I still have a local anaesthetic at the dentist or an epidural during labour?

Yes. All local anaesthetics are safe to use. However, it is still important to inform those treating you that you are at risk of MH.

Can I have a biopsy if I am pregnant?

No, we do not offer the biopsy to pregnant women.

How old do my children need to be before they can be tested?

Children must be at least 10 years of age and weigh more than 30 Kg before they can be tested.

What is recommended in terms of work/exercise after the muscle biopsy?

Returning to work depends on the type of work and the individual themselves. A more physical job may require a longer period off work, however, generally no more than a week off would be required.

In terms of exercise we would recommend that you gradually return to your normal activities after the stitch has been removed. Depending on the type and intensity of exercise you wish to do, it can take between 2 and 6 weeks to get back to normal.

How long should I avoid driving?

There is no set limit, however, patients cannot drive home following their biopsy and we advise they do not drive until they have the strength to comfortably perform an emergency stop. For most patients this usually takes a week.

I do not have MH but can MH skip generations?

No, if you are negative, your children and their children are all negative.

What if my doctor does not believe my words?

Within 2 weeks of your biopsy your GP will be sent a copy of the result. You will also be sent a letter through the post to confirm your diagnosis.

We keep your records in our unit and can be contacted to provide copies when necessary. We are available to speak to any doctor who wishes to discuss your management or future anaesthetics.

A relative of mine wants to be tested for MH, what should I do?

Please ask him to contact the MH Unit and we will advise him of the next steps for him to take.

I have been told I have Malignant Hyperpyrexia – is this the same condition?

Yes, malignant hyperpyrexia is an old name for malignant hyperthermia.

Patients and Relatives Helpline Number

If you have any further questions about MH please do not hesitate to call the MH unit on 0113 206 5270 (during office hours). We will be happy to help you in any way we can.

For more information about MH please visit www.ukmhr.ac.uk

Please use the space below to note down any questions you may wish to ask the MH team on your arrival.