

# Scottish Muscle Network

## Template Letters for Malignant Hyperthermia (MH) Referrals

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## Template Letter for Patient (Scotland)

<<Hospital logo >>  
<<Anaesthetic Department Address>>

Tel: XXX  
Email: XXX

Date: XX/XX/XXXX

Patient name: XXX

DoB: XXX

NHS number: XXX

Dear <<Patient name>>,

I am writing to confirm the information I gave to you following your anaesthetic on <<date of operation>> at <<name of hospital>>.

During the anaesthetic you developed some features of a condition called 'Malignant Hyperthermia' (MH).

MH is a rare but potentially fatal reaction to common anaesthetic drugs. MH can be a rapidly progressive reaction and so when we became concerned that it may be happening to you we treated you for MH. If we had waited until we were sure of the diagnosis it may have been too late to save you.

We have discussed your case locally with nominated link anaesthetists and / or with the UK National MH Unit in Leeds (DELETE AS APPROPRAITE) and we have concluded it is worth investigating you further for MH or I have written to the MH unit in Leeds for their clinical advice and they have agreed to review your case (DELETE AS APPROPRIATE). I have / will then (DELETE AS APPROPRIATE) consider referring you to your local Clinical Genetics Service who coordinate genetic testing for MH in Scotland and out of area referrals to the Leeds MH Unit, if required.

MH is a genetic condition, which means it can be passed on within families from generation to generation. It is important to confirm whether this was an MH reaction so that you and members of your family can have safe anaesthesia in the future. In the first instance we will send a referral to the local Clinical Genetics Service to organise genetic testing for you on a blood sample and the genetics team may also consider onward referral to the UK National MH Unit in Leeds for further testing if required. Further testing may include an overnight stay for a muscle biopsy test in Leeds.

In the meantime, should you or any of your blood relatives require a general anaesthetic you should be treated as **at risk of developing MH**. If anaesthetists know about a potential risk of MH they can provide an anaesthetic using drugs that are known not to cause MH. I enclose a letter that you may copy and distribute to your blood relatives to inform them about the potential for MH in your family.

I also in enclose an information leaflet about MH written by the specialists in Leeds. They have also produced a website ([www.ukmhr.ac.uk](http://www.ukmhr.ac.uk)) with useful information about the condition for patients, families, and doctors.

Please contact me if you have any questions about the contents of this letter.

Yours sincerely,

<<Anaesthetist's name>>

Consultant Anaesthetist

## Template Letter for Relatives (Scotland)

<<Hospital logo >>  
<<Anaesthetic Department Address>>  
Tel: XXX  
Email: XXX  
  
Date: XX/XX/XXXX

### IMPORTANT HEALTH INFORMATION ABOUT MALIGNANT HYPERTHERMIA FOR FAMILY MEMBERS (BLOOD RELATIONS) OF:

Patient name: XXX

DoB: XXX

NHS number: XXX

Dear XXX,

During a recent operation the above-named person had a suspected Malignant Hyperthermia (MH) reaction to the general anaesthetic. Investigations are ongoing to clarify if there is a genetic cause for this reaction.

MH is a genetic condition, which means that can be passed on within families from generation to generation. People who have the genetic risk for MH can have a potentially fatal, rapidly progressive reaction when they receive common anaesthetic drugs. Until it can be proven that you do not carry the genetic risk, family members should be treated as at risk of developing MH if they require a general anaesthetic.

Please let your GP know about this family history as soon as you can, as well as any doctor or surgeon who must treat you in hospital or any dentist who plans to give you a general anaesthetic. If you are waiting for surgery or hospital tests that require a general anaesthetic, depending on the urgency of the procedure, the hospital may advise postponing the procedure until your risk of developing MH has been clarified.

It is important to know that people who are at risk of developing MH may not have a reaction every time they have a general anaesthetic. This means that even if you have had many operations without a problem, you still may be at risk of developing MH in future anaesthetics.

Please be reassured that with the correct knowledge and awareness, MH is a well-managed condition.

The Leeds MH Unit have produced a website ([www.ukmhr.ac.uk](http://www.ukmhr.ac.uk)) with useful information about the condition for patients, families, and doctors.

Please send copies of this letter to any other blood relatives of the above-named person who you think may not have already received it.

Yours sincerely,

<<Anaesthetist's name>>

Consultant Anaesthetist

## Template Letter for GP (Scotland)

<<Hospital logo >>  
<<Anaesthetic Department Address>>  
Tel: XXX  
Email: XXX

Date: XX/XX/XXXX

GP name: XXX  
GP Address: XXX

Dear XXX,

**RE: <<PATIENT DETAILS>>**

During an anaesthetic on <<date of operation>> at <<name of hospital>> << patient name>> developed suspected Malignant Hyperthermia (MH).

MH is a rare but potentially fatal reaction to common anaesthetic drugs. MH can rapidly progress to death so, in line with guidelines, treatment for MH was instigated before the full clinical picture materialised. If we had waited until we were sure of the diagnosis it may have been too late. We have discussed this patient's case locally with nominated link anaesthetists and / or with the UK National MH Unit in Leeds (DELETE AS APPROPRIATE) and we have concluded it is worth investigating this patient further for MH.

MH is a genetic condition, and it is important to confirm whether there is a genetic test which can be offered to family members. Genetic testing and onward referral to the National MH Unit in Leeds is coordinated via Clinical Genetics in Scotland ([Affected Cases Pathway](#), [Family History Pathway](#)).

It is important to note that if a gene variant is identified, this can only prove MH susceptibility. Patients who do not carry a familial MH gene variant will need a muscle biopsy in Leeds to confirm they are not MH susceptible. Patients who have had a suspected MH reaction in whom no genetic variant is identified will also require referral to Leeds for a muscle biopsy.

A referral to this patient's local Clinical Genetics service has been made.

**Please place a suitable alert on this patient's electronic letters accessible by primary care & ambulance staff.**

I have / have not (DELETE AS APPROPRIATE) placed an alert on the secondary care electronic records.

I have provided your patient with verbal and written information about MH. I have also provided them with information they can distribute to family members. The Leeds MH Unit have produced a website ([www.ukmhr.ac.uk](http://www.ukmhr.ac.uk)) with useful information about the condition for patients, families, and doctors.

Please contact me if you have any questions about the contents of this letter.

Yours sincerely,

<<Anaesthetist's name>>  
Consultant Anaesthetist

## Template Letter to MH Unit

In Scotland this should be used for clinical advice as to whether an episode is MH or otherwise. Referrals for patients to the MH Unit in Scotland should come from Clinical Genetics ([Affected Cases Pathway](#), [Family History Pathway](#)).

<<Hospital logo >>  
<<Anaesthetic Department Address>>  
Tel: XXX  
Email: XXX  
Date: XX/XX/XXXX

The Leeds Malignant Hyperthermia Investigation Unit  
Level 08, Clinical Sciences Building  
St James's University Hospital  
Leeds LS9 7TF

Email: helenbinns@nhs.net

Dear Colleagues,

**RE: <<PATIENT DETAILS>>**

This patient developed a suspected MH reaction during an anaesthetic on <<date of operation>> at <<name of hospital>>. Please could you consider their case as to whether they require further investigation of their MH susceptibility. I enclose/attach the following **(DELETE AS APPROPRIATE)**:

Copies of:

- Preoperative clinical observations
- Preoperative blood test results
- Anaesthetic record
- Post-anaesthesia care unit observation chart
- ICU chart (up to 24 h after admission)
- Postoperative blood test results for 24 h post-event, including 24 h post-event
- creatine kinase
- Arterial blood gas results
- A retrospective account of the suspected reaction to aid interpretation of the clinical records.

Given this patient is resident in Scotland, if, based on your review of the case this patient requires further investigation, either by genetic testing or In Vitro Contracture testing (IVCT), the patient must be seen in Clinical Genetics in Scotland as this team coordinate the genetic testing and organise Out of Area funding for IVCT referrals. As such please copy the appropriate Clinical Geneticist (\*) into your advice letters on potentially positive cases and into positive IVCT reports.

I can confirm that I have counselled the patient and family members about MH and provided them with the Association of Anaesthetists' written information. The GP is aware of this advice referral.

Yours sincerely,

<<Anaesthetist's name>>

Consultant Anaesthetist

*\*MH Geneticists are: Glasgow / West of Scotland – Dr Cheryl Longman, Edinburgh/Fife/Borders – Dr Elaine Fletcher, Tayside – Dr Catherine McWilliam, North Scotland – Dr Alison Ross.*