

Dear

I am writing to let you know about a problem _____ had when undergoing an operation because, as a blood relative, it could possibly affect you.

During the operation ----- had a reaction to the anaesthetic, which might have been caused by a condition called malignant hyperthermia (MH). It is important I inform all close relatives because some people die during a reaction. MH is inherited, by both males and females, so it may affect you too.

Obviously we need to trace the MH links in the family so if you know about any anaesthetic reactions you or others in the family have had or if anyone in the family died during or shortly after surgery, would you let me know.

----- is going to be tested to see if the reaction was due to MH. These screening tests will be done at St James's Hospital in Leeds. I will let you know what the result was. If it is shown that ----- does have MH, other people in the family will be offered testing. Not everyone in the family will need to be tested, to begin with only very close relatives eg children, brothers and sisters and parents.

I have enclosed a sheet which gives you a bit more information about MH and what we all need to do until ----- has been tested. Please read it carefully and please take it seriously.

In the meantime please remember to tell everyone about ----'s problem.

Best wishes,

Malignant Hyperthermia

The main points are:

- Those who are susceptible to MH are often unaware of the risk until they or a family member are exposed to anaesthetics that lead to a crisis. It does not affect your general health. Should an MH reaction occur it can be brought under control if the operating team act quickly but it could result in death or have serious complications.
- The anaesthetic agents that trigger a MH event are known so, once susceptibility is suspected or confirmed, it is possible to have an operation by avoiding the use of triggering anaesthetics and using safe alternatives.
- Importantly, susceptible people can have operations without the problem occurring on every occasion. So even if you have had previous 'untroubled' operations you cannot assume that you do not have MH.

In the population overall MH is quite rare and not everyone in the family will be affected. However, once it is identified in a family all the family members who are directly linked to the affected person must be considered susceptible until it is proved otherwise.

Here are a few things you might want to do now:

- Notify your own doctor about your family history of MH and ask for the front of your medical notes to be annotated clearly stating that you have a "Family history of Malignant Hyperthermia under anaesthesia"
- For children remember to notify all those involved in their care such as the school, sports coaches etc. and make sure that they know what to do if the child has to go to hospital (see below).
- If you or your children are going to have an operation requiring a general anaesthetic ensure that the anaesthetist is warned about the family history of MH. MH is a rare condition and often is unfamiliar to hospital staff other than anaesthetists. As the anaesthetist is usually the last person you see before an operation, insist that the nurse/surgeon informs them beforehand, so they can be prepared.

If you have access to the internet you might look at the site of the British Malignant Hyperthermia Association, www.bmha.co.uk which has lots of useful information.

Also you might like to get a warning card or an engraved necklace that in emergency would let medical teams know you have a family history of MH, it also gives a 'hotline' number they can call if necessary. The details are on the BMHA website or you can phone the association secretary, Mrs Alison Winks 01773 717901.