



MYOTONIC DYSTROPHY
SUPPORT GROUP
Charity Number 1073211

**ANAESTHESIA AND
MYOTONIC DYSTROPHY**

BY

DR IAN BOWLER MB BCH, FRCA

Myotonic Dystrophy Support Group
National Co-ordinator: Mrs M A Bowler SRN, SCM
175a Carlton Hill
Carlton
Nottingham
NG4 1GZ
Tel: 0115 987 0080
Fax: 0115 987 6462
Website: www.mdsguk.org
e-mail: MDSG@tiscali.net

Patron: Prof. J. David Brook
Professor of Human Molecular Genetics, Nottingham University

Anaesthesia and Myotonic Dystrophy

Dr Ian Bowler MB BCh, FRCA

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Anaesthesia and Myotonic Dystrophy

Many people who are affected by Myotonic Dystrophy (DM) need to have operations, and so require an anaesthetic. As we all know there are certain problems associated with DM which affect the way in which the anaesthetic is administered and tolerated. Unfortunately we all probably also know someone who has an unexpected complication after an operation, which can be life threatening. One of the main problems that occur is that there seems to be a lack of communication between the patient, the GP, the surgeon and the anaesthetist. Remember, the anaesthetist is usually the last person in this chain of people, and like Chinese whispers information second or third hand can become distorted to say the least. So, if you are worried or concerned about having an anaesthetic, ask your GP or surgeon to make an appointment for you to see the anaesthetist personally before you go into hospital so that you can discuss your worries.

Pre-operative Assessment

The first time you come across an anaesthetist is the pre-operative visit, which is usually on the night before your operation. This can be a very anxious time for you, being in an unfamiliar place, not knowing exactly what is going to happen, and with so many questions to ask. Isn't it typical that as soon as the anaesthetist appears, you forget all you were going to ask! If this tends to happen to you, remember.....

Don't worry, it's not an interrogation!

The pre-operative visit by the anaesthetist should be a 2 way exchange of information, not a string of questions fired by the anaesthetist without stopping to draw breath. There will be things he/she will need to know from you, but also things that you need to

know from them. If your mind tends to go blank in these situations, write down a list of questions beforehand to help you.

What the anaesthetist needs to know - key points

- That you have *or may have* Myotonic Dystrophy
- Specific problems with heart, chest or swallowing
- About previous anaesthetics
- *All* the medicines you take
- About other relevant medical conditions

The anaesthetist will also look at the investigations that you have had done, to see if there are any reasons why you should not have the anaesthetic at that time. They include:

Blood tests

To look at the kidney and liver function, blood sugar level, and blood count. If you have problems with your chest you may also need a blood test from an artery that tests your blood oxygen level.

Heart Tracing

This is called an Electrocardiogram or ECG. 30-80% of patients with DM have some abnormalities on the ECG, some being very minor and requiring no treatment, but some needing attention before you have an anaesthetic.

Chest Xray

This should show up potential problems with the breathing muscles, especially

the diaphragm. It may also help if you have problems with food going down the wrong way.

What the anaesthetist should tell you

Options

The anaesthetist will discuss with you the relevant types of anaesthetic which are possible for the surgery you are having. These may include having a local anaesthetic, especially if you are having a cataract done or if it is a relatively minor procedure, for instance on an arm or a leg. There is also the possibility of a spinal or epidural anaesthetic, which can be used for operations on the abdomen, pelvis or legs. Epidurals have the added advantage that they can be used for pain relief after the operation. However, some types of surgery will require that you have a general anaesthetic, for example open heart surgery or operations on the head, brain or neck. In these cases it is important that there is extra time allocated for you to recover from the anaesthetic, and usually a bed on a High dependency Unit or Intensive Care Unit, as problems can occur up to 3 or 4 days after the operation.

Risks/Benefits

The anaesthetist should tell you what he or she thinks the risks are to you if you have the operation from the anaesthetic point of view. (The surgeon should tell you about the surgical risks when they ask you to sign the consent form). Sometimes it may be that the risks outweigh the benefits, and the anaesthetist will tell you if they consider it unsafe for you to have an anaesthetic.

Anaesthetic Knowledge

In 1988, when the support group was very small, it seemed that hardly any doctors had even heard of DM, and the level of knowledge appeared to be very low. However, there have been several good reviews of the anaesthetic management of DM in high profile anaesthetic journals, the most quoted being from 1985, which is before the support group was formed. I therefore cannot explain the apparent problem, but there is increasing awareness in the anaesthetic world which is reflected in the management of DM being asked in the anaesthetic diploma examinations.

Anaesthetic Management - keypoints

- Most anaesthetic drugs have some effect on breathing and blood pressure
- Usually it is *how and how much* is given that is important
- Knowing what to expect can reduce the problems, even if the do occur

People who have DM tend to be sensitive to most of the sedative drugs that are given as pre-medication, drugs used for general anaesthetics and strong painkillers (drugs like morphine). However, as long as this is recognised and the drug given slowly and carefully, all these drugs can be used safely. One drug that relaxes the muscles (Suxamethonium) should be avoided, but other types of muscle relaxing drugs can again be used safely if their affects are monitored carefully. The local anaesthetic drugs are safe to use in DM as long as one of these techniques is suitable, spinal and epidurals have been used

successfully for operations commonly done under general anaesthetic such as having your appendix out, Epidurals can also be used for pain relief after surgery, minimising the amount of painkillers required.

After surgery patients with DM can run into problems, especially after major operations, with their lungs. They are much more likely to get chest infections and are sensitive to painkillers so that they are less likely to be able to cough and clear their chest. It can therefore be necessary to look after you in a High Dependency or Intensive Care Unit, for the first 24-48 hours after your operation. This enables the doctors and nurses to monitor things like blood pressure, oxygen levels and heart tracing, and for you to have oxygen and physiotherapy easily.

Summary

A lot of problems that do occur usually happen due to a breakdown in communication somewhere along the line, and the onus is on you to start this communication going. Problems and complications will still arise, as there are small risks involved in any surgical or anaesthetic procedure, which cannot be anticipated. With increased knowledge and awareness I hope that the avoidable, expected complications can be minimised.