



Myotonic Dystrophy
SUPPORT GROUP

Anaesthesia and Sedation for patients with Myotonic Dystrophy

by

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Myotonic Dystrophy

People who are affected by Myotonic Dystrophy (DM) may need to have operations and medical procedures, and so will require anaesthesia or sedation. We know there are certain problems associated with DM which affect the way patients with DM tolerate or react to the anaesthetic. Unfortunately we may also know someone with DM who has had an unexpected complication after an operation, which can be life-threatening.

One of the problems that occurs is that there can be a lack of understanding of the condition by the patient, the GP, the surgeon or the anaesthetist. 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.

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Potential problems for patients with DM having surgery:

- Heart and lung complications are more common
- Sensitivity to sedatives or painkillers
- Myotonia during surgery
- Abnormal reaction to muscle relaxing drugs

Anaesthetists are involved in all areas of the hospital, not only in the operating theatres. Areas where anaesthetists have expertise include:

- Treating acute and chronic pain
- Resuscitation and trauma management
- Obstetric pain relief and anaesthesia
- Intensive care
- All types of anaesthesia and sedation

Pre-operative Assessment

The first time you commonly come across the anaesthetist is the pre-operative assessment, which can be on the night before your operation, but may be in a clinic a few weeks before your surgery. This is your opportunity to ask any



questions, so remember that this consultation should be a 2 way exchange of information, not

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just a string of questions fired by the anaesthetist. 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 does tend to go blank in these stressful situations, write down a list of questions beforehand to help you.

Key Facts that the anaesthetist needs to know:

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

The anaesthetist will also look at any investigations that have been performed, to ensure that there are no reasons why you should not have the anaesthetic at that time. They include:

Blood tests - to look at kidney and liver function,

blood sugar level, and blood count. You may also need a blood test from an artery to assess your blood oxygen level.

Heart Tracing - this is called an Electrocardiograph 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 surgery.

Chest X-ray - this should show up potential problems with the breathing muscles, especially the diaphragm. It may also help if you have problems with choking or 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

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you are having cataract surgery or if it is a minor procedure.

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 heart surgery or operations on the head, brain or neck. The anaesthetist will explain the most suitable type of anaesthetic for you, and may offer you a choice, and will explain if choices are limited. If

there is anything you are concerned about, it is better to ask.

- **Risks / Benefits**

The anaesthetist should then tell you what he or she thinks the risks are to you from the anaesthetic point of view. (The surgeon should tell you about surgical risks when they ask you to sign the consent form.) Occasionally 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.

The acceptable risk will vary depending on the type of surgery and what it is for. For example, surgery for cancer would be viewed differently to surgery for varicose veins.

- **Explanation**

The anaesthetist should then explain exactly what you are likely to expect, in terms that you should understand. This will include explaining where they will put a drip, or tubes in your

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Hip Replacement Surgery using Spinal anaesthetic

mouth or throat. They will also explain how you might feel after the operation, what sort of pain relief you should expect, and if you will go to the high dependency or intensive care ward. Patients with DM are much more likely to need a higher level of care after an operation. This is routine and nothing to worry about.

Emergency Surgery

The problem with emergency surgery is that all the preparation before an operation has to be shortened or even missed out. It is therefore vital that you or your family let hospital staff know that you have Myotonic Dystrophy if you are taken ill suddenly or have an accident. In these situations you do not need to give details, simply tell the doctors about DM, or better still, give them your Alert Card or Care Card. Further information can then be found from the helpline or website.

<p>Emergency Contact</p> <p>Name: _____</p> <p>Address: _____</p> <p>Phone: _____</p> <p>Mobile: _____</p> <p>Emergency Contact: _____</p>		<p>Personal Details</p> <p>Name: _____</p> <p>DOB: _____</p> <p>Address: _____</p> <p>Phone: _____</p> <p>Mobile: _____</p>	
<p>Medical Alert</p> <p>The bearer of this card has MYOTONIC DYSTROPHY, a neuromuscular condition that may cause the following:</p> <ul style="list-style-type: none"> A. muscle weakness and stiffness B. extreme tiredness C. speech difficulties D. adverse reaction to commonly used anaesthetic agents. E. Abnormal heart rhythm 		<p>Myotonic Dystrophy CARE CARD</p> <p></p>	

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Medical procedures under sedation

As medicine advances, more and more procedures can be done using “magic eye” technology or xray, so formal surgery and anaesthesia are not necessarily required. Examples include:

- Insertion of pacemakers or stents in the heart
- Examinations of the bowel - endoscopy, colonoscopy
- Dental procedures under sedation
- Examination of the lungs - bronchoscopy
- Cardioversion

One of the potential problems with these procedures is that the sedation is often provided by a doctor with no training in anaesthesia, for example the same person who is performing the procedure. They therefore have less expertise in dealing with sedation than an anaesthetist, and may not realize that patients with DM can be sensitive to the sedative drugs.

It is therefore very important that an anaesthetist is available for these procedures if sedation is to be used.

Key Facts about Anaesthetic Drugs

- 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 they do occur
- People who have DM tend to be sensitive to most of the drugs used for general anaesthesia and strong painkillers (drugs like morphine).
- One drug that relaxes the muscles (Suxamethonium) should be avoided.
- Other types of muscle relaxing drugs can again be used safely if their effects are monitored carefully.

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- The local anaesthetic drugs are safe to use in DM as long as one of these techniques is suitable. Spinal and epidural anaesthesia 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.

Post-operative Care

After surgery patients with DM can run into problems with their lungs, especially after major operations. 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 them in a High Dependency or Intensive Care Unit, for the first 24-48 hours after their operation. This enables the doctors and nurses to monitor things like blood pressure, oxygen levels and the heart, and for you to have oxygen and physiotherapy easily.

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Intensive Care

Summary

There are several potential problems that can occur if a patient with DM needs surgery or sedation for a medical procedure, but these can be anticipated in many cases if the surgeon and anaesthetist are made aware of the condition in advance. The onus is on the patient and their family to start this communication. Problems and complications may still arise, as there are risks involved in any surgical or anaesthetic procedure, which cannot be anticipated. With knowledge and awareness the avoidable, expected complications will be minimised.

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Anyone requiring further information regarding Anaesthesia and Myotonic Dystrophy can contact Dr Ian Bowler at Llandough Hospital on 02920 716860.

For further information:

www.cardiffandvale.wales.nhs.uk

Royal College of Anaesthetists **www.rcoa.ac.uk**

Association of Anaesthetists **www.aagbi.org**

Further information about Myotonic Dystrophy can be obtained from:

Myotonic Dystrophy Support Group

19/21 Main Road,

Gedling,

Nottingham.

NG4 3HQ

Tel/Fax: 0115 987 5869

Email: contact@mdsguk.org

www.myotonicdystrophysupportgroup.org

Other publications available from the Myotonic Dystrophy Support Group:

- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Excessive Daytime Sleepiness and Myotonic Dystrophy
- Facts for patients, family members and professionals
- Just Diagnosed
- Lungs and Breathing
- Myotonic Dystrophy and the Brain
- Myotonic Dystrophy and the Eye
- Myotonic Dystrophy Support Group
- Myotonic Dystrophy Type 2
- Painkillers and Myotonic Dystrophy – what is safe?
- Relatives Information
- Strategies for Managing Excessive Saliva

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- Swallowing Difficulties in Myotonic Dystrophy
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?

Your Notes:



Myotonic Dystrophy
SUPPORT GROUP

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