

# MYOTONIC DYSTROPHY

Please note that this factsheet is being discontinued. Information for patients on myotonic dystrophy and anaesthesia is available on the Myotonic Dystrophy Support Group: [myotonicdystrophysupportgroup.org/leaflets](http://myotonicdystrophysupportgroup.org/leaflets)

Myotonic dystrophy (MD) is a rare condition that runs in some families. It causes muscles to weaken over time and is most commonly diagnosed in adulthood. There are two main types: type 1 (MD1) and type 2 (MD2). Anaesthetic drugs can cause problems for patients suffering from either type.

## How common is MD?

MD is rare, only affecting 1 in 8,000 people. This number varies slightly in different parts of the world.

## Symptoms

MD can affect many different parts of the body. As well as muscle weakness it can cause:

- pain and stiffness in muscles
- heart problems
- breathing problems
- problems swallowing and with the gut
- cataracts
- infertility in men
- tiredness and sleepiness.

## Treatment

There is no cure for MD. There are, however, medicines to treat symptoms of MD such as muscle stiffness or an irregular heart beat.

## Testing

MD is hereditary, which means that it can be passed from parents to children as part of their genes. It affects both men and women. A parent with MD has a 50/50 chance of passing it on to their children. A test to look at your DNA is the only reliable test for MD. This can be done with a blood test. It is advisable to have specialist counselling before any testing. Anyone who knows or suspects

they have MD should let their family know as others may also be affected. They in turn should be tested for the condition.

## Anaesthetic management

There are extra risks from anaesthesia for patients with MD. If you have MD, it is very important to warn your anaesthetist and surgeon before your operation. They may wish to contact a specialist centre for advice. It is very important to have a careful plan for your operation, because breathing muscles are weak and are sensitive to anaesthetics and other drugs. Your anaesthetist will also need to watch out for and treat any unusual heart rhythms. Depending on your operation, you might need to go to an intensive care unit afterwards while you recover. Leaflets for particular operations are available on the MD website below.

It is also extremely important that you tell your anaesthetist and surgeon if you or anybody in your family has MD or has had a severe unexplained reaction to an anaesthetic. We advise that you keep an MD warning card in your wallet or purse available from the website below. It is also advisable to wear a warning disc or bracelet in case you are brought into hospital unconscious after an accident or through illness.

Further information is available from: [myotonicdystrophysupportgroup.org/leaflets](http://myotonicdystrophysupportgroup.org/leaflets)

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