

## Myotonic Dystrophy (MD)

MD is a rare condition that runs in some families causing muscles to weaken over time. It is most commonly diagnosed in adulthood. There are two main types; type 1 (MD1) and type 2 (MD2) – but anaesthetic drugs can have adverse effects on patients suffering from either type.

**How common is it:** it 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 available to treat symptoms of MD such as the muscle stiffness or irregular heart beat.

**Testing:** MD is hereditary; therefore it can be passed from parents to children. It affects both men and women. An affected parent has a 50/50 chance of passing it on to their children.

A special test on your DNA is the only reliable test for MD. This can be done via 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 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 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:** please see the following website for many different information resources for patients, relatives and professionals:

[myotonicdystrophysupportgroup.org/leaflets](http://myotonicdystrophysupportgroup.org/leaflets)

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## Disclaimer

We try very hard to keep the information in this leaflet accurate and up-to-date, but we cannot guarantee this. We don't expect this general information to cover all the questions you might have or to deal with everything that might be important to you. You should discuss your choices and any worries you have with your medical team, using this leaflet as a guide. This leaflet on its own should not be treated as advice. It cannot be used for any commercial or business purpose.

For full details, please see our website: [rcoa.ac.uk/patientinfo/resources#disclaimer](https://rcoa.ac.uk/patientinfo/resources#disclaimer)

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We welcome suggestions to improve this leaflet.

If you have any comments that you would like to make, please email them to:

[patientinformation@rcoa.ac.uk](mailto:patientinformation@rcoa.ac.uk)

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