

Carry an Alert Card in your wallet or purse, or wear a Medic Alert bracelet or necklace at all times, in case of an accident or emergency. You can obtain a free card from the Myotonic Dystrophy Support Group – see details.

## Work, employment and mobility

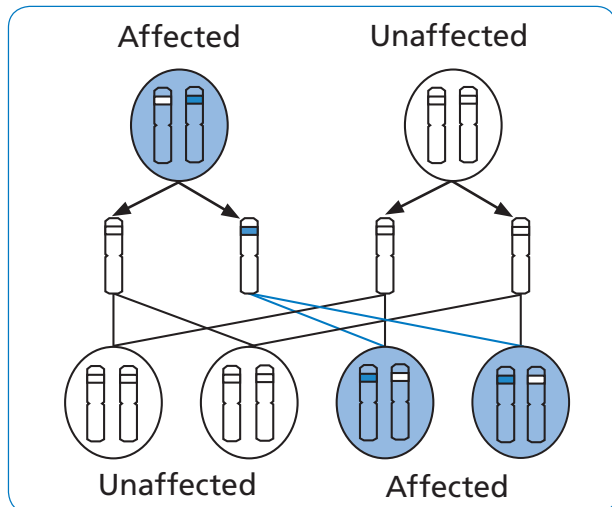
If your ability to work or get around is affected by myotonic dystrophy, you may be entitled to special benefits.

You can find out more about this from a local Citizen's Advice Bureau, a Family Care Officer of the Muscular Dystrophy Campaign or the Benefits Agency.

## Inheritance

Myotonic dystrophy is caused by a change in a gene that usually runs in families.

Any child of a person with myotonic dystrophy has a 50% (1 in 2) chance of inheriting the condition.



- It can affect and be passed on by males and females. Women with the condition

are more at risk of having a seriously affected child.

- Healthy young adults with an affected relative can have a genetic test. This will show whether they carry the gene alteration. If they do, they will develop myotonic dystrophy at a later stage in their life.
- Tests in pregnancy can tell if the baby carries the gene alteration.
- Before having a genetic test it is important to see a member of the genetics team to find out all the facts.

## For more information

Myotonic Dystrophy Support Group  
5A Carlton Hill, Carlton,  
Nottingham, NG4 1BG  
Tel (office): 0115 987 5869  
[www.mdsguk.org](http://www.mdsguk.org)  
Tel (helpline): 0115 987 0080

Muscular Dystrophy Campaign  
61 Southwark Street,  
London, SE1 OHL  
[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

**Information and Support Line:**  
0800 652 6352 (freephone)

*With thanks to the Clinical Genetics Unit,  
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NHS Foundation Trust**  
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Birmingham Women's **NHS**  
NHS Foundation Trust

# Myotonic Dystrophy

An information leaflet for  
patients and families

If you need more advice about  
Myotonic dystrophy, please contact:

**Clinical Genetics Unit**  
Birmingham Women's NHS  
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Mindelsohn Way  
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## Myotonic dystrophy has a wide range of effects

This leaflet is designed to explain how myotonic dystrophy affects people who have the condition. It lists lots of possible effects.

It is important to remember that it is very unlikely that an affected person will have all of these problems.

Some people with the condition have hardly any symptoms. Others are quite severely affected.

## What causes myotonic dystrophy?

Myotonic dystrophy is caused by an alteration in a gene. People who have this gene alteration (sometimes called a mutation or expansion) may develop a variety of symptoms. These symptoms can affect people at different ages and in different parts of the body.

## Muscle weakness

Muscle problems are often the first sign of myotonic dystrophy. The muscles may feel weak, and this weakness can range from mild to severe. It mainly involves the face and eyelids, jaw, neck, forearms and hands, lower legs and feet. If the muscles of the mouth and tongue are affected it can make it difficult to speak clearly. Weakness in the muscles of the face may make someone's face appear "droopy" or "expressionless".

## Myotonia

This means that it is difficult to relax a muscle after it has been contracted.

People with myotonic dystrophy sometimes find it difficult to release their grip on things such as shopping bags or steering wheels. This is quite common and may not cause much of a problem.

## Heart Problems

Myotonic dystrophy can affect the heart. Sometimes there are no symptoms at all. The heartbeat may be very slow or irregular. If you notice any problems or are concerned about your heartbeat we recommend that you consult your general practitioner for advice.

## Chest and breathing problems

Chest infections may result from weakness of the breathing muscles. Food may enter the lungs as a result of choking. Poor breathing during the night can lead to disturbed sleep and snoring. This might make it difficult to wake up, or cause morning headaches and daytime sleepiness.

## Digestive problems

These are common as the muscles of the digestive system may be affected. This may lead to:

- Swallowing problems (which can be a cause of food entering the lungs).
- Pains in the bowels with constipation and diarrhoea.

- Gallstones can be a problem in myotonic dystrophy. They can cause painful spasms after eating fatty food.

## Eye problems

Cataracts can cause blurring and dimming of vision. This may be the only problem that myotonic dystrophy causes. Droopy eyelids may cause a problem with reading or watching television. You should have regular checks at the optician and see a medical eye specialist if there is any concern.

## Other problems

- Problems with fertility in men.
- Diabetes (we recommend a urine test once a year).
- Pregnancy problems (the muscles in the womb can be involved, leading to a long labour).
- When myotonic dystrophy is present at birth, muscle involvement can be very severe. Babies may live only a short time.
- Children with myotonic dystrophy might have problems with speech and some difficulties with learning.

## Anaesthetics and surgery

People with myotonic dystrophy may have problems with surgery when certain anaesthetic drugs are used. Make sure the surgeon and anaesthetist know about your myotonic dystrophy before an operation. They may wish to contact a specialist centre for advice.