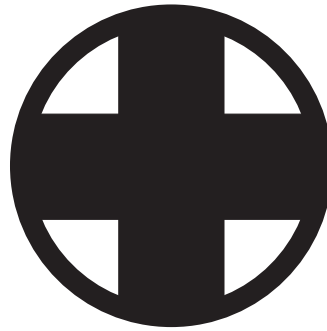


# MEDICAL ALERT

The bearer of this card has **MYOTONIC DYSTROPHY**, a neuromuscular condition that may cause the following:

- A. muscle weakness and Stiffness.
- B. extreme tiredness.
- C. speech difficulties.
- D. Adverse reaction to commonly used anaesthetic agents.
- E. Abnormal heart rhythm.

# MYOTONIC DYSTROPHY



## CARE CARD

### Personal Details

Name

DoB

Address

Phone

### Emergency Contact

Name

Address

Phone

Version 11.02 : 23/08/2010

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### Further Information

#### Scottish Muscle Network:

For specialist clinics in your area, Information leaflets, updated versions of the Card at: [www.smn.scot.nhs.uk/Myotonic%20Dystrophy.html](http://www.smn.scot.nhs.uk/Myotonic%20Dystrophy.html)

Card enquiries and suggestions to: [douglas.wilcox@glasgow.ac.uk](mailto:douglas.wilcox@glasgow.ac.uk)

#### Myotonic Dystrophy Support Group:

a self help group, willing to provide support to families affected by Myotonic Dystrophy. Tel: 0115 987 0080

Email: [contact@mdsguk.org](mailto:contact@mdsguk.org)

Web: [www.mdsguk.org](http://www.mdsguk.org)

#### Muscular Dystrophy Campaign:

a charity funding medical research and support, for people with neuromuscular conditions.

Tel: 0800 652 6352

Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

Web: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### Myotonic Dystrophy and how it could affect your health.

**Personality changes** are often the main problem reported by families and can include lack of motivation, inertia, stubbornness and liking a set routine. This can lead to relationship problems with family, friends and at school or work.

**Tiredness** is very common and sometimes can be extreme. Sleeping during the day increases with age and sleep at night is often poor.

**Muscle weakness** is very variable and can range from mild to severe. It particularly involves the face and eyelids, jaw, neck, forearms and hands, lower legs and feet. It can affect **speech** and give lack of facial expression. Handwriting may start well but become a scrawl after a few lines.

**Myotonia** is a difficulty in relaxing a muscle after it has been contracted, e.g. after gripping something, it might be difficult to let go.

**Heart problems** can cause abnormal rhythm of the heart might require treatment. This can affect adults, even those without symptoms. Regular ECGs (heart tracings) of affected adults are advised to detect problems at an early stage.

**Chest and breathing problems** include chest infections. These may result from weakness of breathing muscles, including the diaphragm, or from food entering lungs as a result of choking. Inadequate breathing during the night might lead to disturbed sleep, snoring, difficulty waking, morning headaches and daytime sleepiness.

**Digestive problems** are common as the muscle throughout the digestive system may be affected. This may lead to: swallowing problems (which can also be a cause of food entering the lungs); pains in the bowels with constipation and diarrhoea; soiling of underwear particularly when stressed or excited and occasionally enlargement of the large bowel. Gallstones, which can cause painful spasms after eating fatty food, can be a problem in myotonic dystrophy (even in young adults) and great care needs to be taken with any surgical treatment. Many patients have reported that medicines containing codeine cause severe constipation.

**Eye problems** include cataracts which cause blurring and dimming of vision. This may be the only problem caused by myotonic dystrophy, particularly in the first affected generation of a family. Droopy eyelids can cause a problem with reading and watching television. You should have regular checks at the optician and see a medical eye specialist if there is any concern.

**Anaesthetics and surgery:** myotonic dystrophy can cause problems with your recovery after an operation 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. Carry this document or an Alert Card in your wallet or purse at all times, in case of an accident or emergency. **Anaesthetic Guide:** [www.smn.scot.nhs.uk/Myotonic%20Dystrophy.html](http://www.smn.scot.nhs.uk/Myotonic%20Dystrophy.html)

**Other problems include:** Diabetes, male infertility; in females the muscle in the womb can be involved and lead to long difficult labour (possibly with bleeding afterward), and obstetric help may be required; the brain can be affected causing thinking and learning difficulty, especially when onset is in childhood.

**Special difficulties in affected children:** Muscle involvement can be more severe, especially when myotonic dystrophy is present at birth. Sometimes severely affected babies may live only a short time. However, if an affected baby survives infancy, parents and doctors are often surprised by the good progress the child subsequently makes but speech, educational and behaviour problems are common.

**Inheritance:** Other family members are frequently affected. It can affect and be passed on by both sexes, but affected mothers are more at risk of having a seriously affected baby than affected fathers. Genetic counselling is advised if genetic testing is being considered. Accurate genetic tests are possible: for healthy people who are at risk of developing myotonic dystrophy because they have an affected relative and in early pregnancy where one parent is affected.

**Note: it is very unlikely one person would develop all these problems.**

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