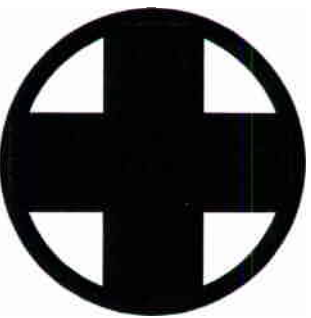


# CARE CARD



## MYOTONIC DYSTROPHY 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 commonl y used anaesthetic agents.

### Personal Details

Name  
DOB  
Address  
Phone  
Emergency Contact Name  
Address  
Phone

Form 2

### Further Information

The Newcastle Muscle Centre:  
Tel: 0191 273 8811

#### Myotonic Support Group:

a self help group, willing to provide support to families affected by Myotonic Dystrophy.  
Tel: 0115 987 0080  
Email: [mdsg@tesco.net](mailto:mdsg@tesco.net)  
Web: [www.comcom.org/mdsg/](http://www.comcom.org/mdsg/)

#### International Myotonic Dystrophy Organization

PO Box 1121  
Sunland, CA 91041-1121  
United States of America  
(866) 679-7954 (Toll Free)  
(815) 477-0047

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

#### Tiredness:

Tiredness is very common and can occur at any time of the day. Sometimes it can be extreme.

#### Muscle weakness:

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.

#### Myotonia:

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:

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:

Chest infections 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:

These 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 diarrhea, soiling of underwear particularly when stressed or excited, occasionally enlargement of the large bowel.

Gallstones, which can cause painful spasms after eating fatty food, can be a problem in myotonic dystrophy and great care needs to be taken with any surgical treatment.

#### Eye problems:

Cataracts can 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.

#### Other problems include:

male infertility; diabetes, (ask to have your blood or urine sugar checked); the muscle in the womb can be involved and lead to long difficult labour 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. Speech, educational and behavioural problems can occur.

#### Inheritance:

Other family members are frequently affected. It can affect and be passed on by both sexes, but women are more at risk of having a seriously affected child.

Genetic counselling is advised if genetic testing is being considered.

Accurate genetic tests are possible: for healthy offspring who are at risk of developing myotonic dystrophy in the future because they have an affected parent or grandparent and in early pregnancy where one parent is affected.

