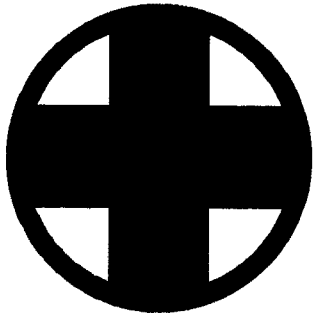
MEDICAL ALERT

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 anaes-thetic agents.
E. Abnormal heart rhythm.



MYOTONIC DYSTROPHY

CARE CARD

Personal Details

Name

DoB

Address

Phone

Emergency Contact

Name

Address

Phone

Version 10.02 : 06/06/02

Fold 2

Fold 3

Further Information

Regional Muscle Clinic:
Address/contact details.

Myotonic Dystrophy Support Group:
a self help group, willing to provide support to families affected by Myotonic Dystrophy.
Tel: 0115 987 0080
Email: mdsg@tesco.net
Web: www.mdsguk.org

Muscular Dystrophy Campaign:
a charity funding medical research and support , including Family Care Officers, for people with neuromuscular conditions.
Tel: 0207 720 8055
Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

Scottish Muscle Network:
information, regional and updated versions of the Card at: www.gla.ac.uk/muscle/dm.htm
Card enquiries and suggestions to:
d.e.wilcox@clinmed.gla.ac.uk

Fold 1

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 diarrhea; 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 guidelines are at: www.gla.ac.uk/muscle/dmanaesthesia.htm**

Other problems include: Diabetes, (ask to have your blood or urine sugar checked); male infertility; 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.

GP	ECG	Blood/urine glucose
	✓	✓

Optician	Family Care Officer
✓	

Occupational Therapist	Physiotherapist

Other specialists who might be able to help you, (or your child), with some of the problems of myotonic dystrophy include: anaesthetist, cardiologist, obstetrician, ophthalmologist, paediatrician, paediatric neurologist, physician, respiratory physician, social worker, surgeon and speech therapist.

Development of the Care Card:

The best management of myotonic dystrophy is difficult to assess because of the small number of patients compared to common disorders such as heart attacks. At the Scottish Muscle Network meeting in September 2000 the Myotonic Dystrophy Support Group voiced concern that the majority of their members did not have access to specialist clinics and the concept of a patient held Care Card was discussed. The MDSG then sponsored a meeting, in London in December 2000, of a multi-disciplinary team of 33 UK experts in the management of neuromuscular disorders. After local trials, the Care Card was appraised at a UK national meeting sponsored by the Muscular Dystrophy Campaign in Cambridge in March 2001. The Care Card was further developed at the 99th European Neuro Muscular Centre "Workshop on the management of myotonic dystrophy" in the Netherlands in November, 2001.

Geneticist	Neurologis

✓ **A number of Good Practice Points emerged from the development discussions an include:**

The diagnosis of myotonic dystrophy in an affec person should be confirmed by DNA testing.

Healthy adults at risk of inheriting myotonic dystrophy should be offered genetic counselling before DNA testing.

Healthy children, at risk of inheriting myotonic dystrophy, should be allowed to make their own decision about testing when they are adults and c consider implications for insurance, employment and having children.

Affected mothers, whose babies are at risk, shou give birth in a specialist maternity hospital with access to a neonatal intensive care unit.

Affected adults should have an ECG and urine sugar checked every year and visit an optician fo an eye test every 2 years.

Anaesthetists should seek advice before treating people with myotonic dystrophy, or their apparently unaffected relatives. Anaesthetic guidelines at:

www.gla.ac.uk/muscle/dmanaesthesia.htm