Anaesthetics and surgery
Certain anaesthetic drugs can cause problems for people with myotonic dystrophy. It is important to inform your surgeon and anaesthetist about your myotonic dystrophy before an operation that involves a general anaesthetic.

Alert cards
People with myotonic dystrophy should carry an alert card, 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.

Work, employment and mobility
If those affected by myotonic dystrophy struggle to work or get around they may be entitled to benefits. More information can be found via a local Citizens Advice Bureau, a Muscular Dystrophy Campaign family care officer or the Benefits Agency.

Pregnancy
Pregnant women with myotonic dystrophy require additional care in pregnancy and during labour.

If you have myotonic dystrophy and become pregnant, please call the Clinical Genetics Service as soon as you find out, to ensure you are offered the appropriate information and care.

Prenatal genetic testing is available during pregnancy to women with myotonic dystrophy. More information can be found from your local Clinical Genetics Service.

Further information and support
Muscular Dystrophy Campaign
61 Southwark Street, London SE1 0HL
Tel: 0800 652 6352
www.muscular-dystrophy.org

Myotonic Dystrophy Support Group
19-21 Main Street, Gedling, Nottingham, NG4 3HQ
Helpline: 0115 987 0080
www.mdsguk.org

Benefits enquiry line
Helpline: 0800 88 22 00
www.direct.gov.uk/disability-money

Feedback
We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 183 0204
From a mobile or abroad:
0115 924 9924 ext 65412 or 62301
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR
www.nuh.nhs.uk

Myotonic dystrophy
Information for patients
Clinical Genetics

This document can be provided in different languages and formats. For more information please contact:

Clinical Genetics Service
City Hospital
The Gables, Gate 3
Hucknall Road
Nottingham NG5 1PB

Tel: 0115 962 7728
Email: nuhnt.clinicalgenetics@nhs.net
Myotonic dystrophy can cause muscles to weaken over time. It mainly affects the muscles used for movement but it can also affect other parts of the body.

**What causes myotonic dystrophy?**

As a genetic condition, myotonic dystrophy is caused by a change in a gene (sometimes called a mutation or expansion). Our genes are instructions which tell our bodies how to grow and function.

**Inheritance**

The myotonic dystrophy gene change runs in families in a dominant pattern. This means that if someone has the gene change, there is a 50:50 or 1 in 2 chance of passing it on to each of their children.

Myotonic dystrophy can affect both men and women, but women with the condition are more at risk of having a severely affected child.

Not everyone with the gene change will develop all the symptoms and some people with the gene change may have virtually no symptoms at all.

**Muscle weakness**

Muscle problems are often the first symptom of myotonic dystrophy. The muscles may feel weak or stiff, especially in cold weather. This 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. 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’.

**Genetic testing**

If someone has symptoms of myotonic dystrophy, they may be offered a diagnostic genetic test. Alternatively, if an adult is unaffected with a family history of myotonic dystrophy, they can consider having a predictive genetic test, if the genetic diagnosis in the family has been confirmed. This will tell them if they have inherited the condition or not.

**Symptoms of myotonic dystrophy**

Symptoms of myotonic dystrophy can present from birth to old age and they can vary in how much they affect one person to the next. In general, the later the symptoms start, the milder it will be. It is unlikely that one person will have all of these symptoms.

- Muscle weakness: ranging from mild to severe. Particularly affecting the face, jaw, neck, lower arms and lower legs
- Muscle stiffness: especially in fingers and hands with difficulties relaxing muscles after use
- Cataracts: clouding of the lens in the eye
- Heart rhythm issues
- Hormonal problems: increased risk of diabetes and thyroid problems
- Excessive daytime sleepiness
- Breathing problems: especially after anaesthesia
- Premature balding: mainly in men
- Reduced fertility
- Irritable bowel syndrome
- Reduced motivation
- Learning problems

**Treatment and management for myotonic dystrophy**

**Eyes** - Individuals with myotonic dystrophy should have regular eye checks at the optician, as cataracts are common. Cataracts can be easily treated.

**Heart** - As the heart’s conduction system can be affected, annual heart checks by ECG and Echocardiogram are important.

**Muscles** - Due to muscle weakness and stiffness affecting different areas of the body a referral to neurology will be made to ensure appropriate supportive management is in place.

**Lungs** - Day time sleepiness and an increased risk of chest infections (especially after general anaesthetic) are due to respiratory issues. Keep up to date with vaccinations including flu and pneumococcal vaccines.