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Myotonic Dystrophy Support Group:

- Anaesthesia and Sedation for patients with Myotonic Dystrophy
- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Excessive Daytime Sleepiness and Myotonic Dystrophy
- Facts for patients, family members and professionals
- Myotonic Dystrophy and the Brain
- Myotonic Dystrophy and the Eye
- Myotonic Dystrophy Support Group
- Relatives Information
- Swallowing Difficulties in Myotonic Dystrophy
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?

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Myotonic Dystrophy
SUPPORT GROUP

MD

Myotonic Dystrophy
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Just
Diagnosed

by
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Myotonic Dystrophy

You have been told that you have the condition Myotonic Dystrophy – another name is Dystopia Myotonica. Perhaps you have never heard of this condition.

Myotonic Dystrophy means:-

MYO	Muscle
TONIC	Tone(stiffness)
DYSTROPHY	Deterioation

Other family members may be affected as this is a genetic condition – that means the condition is passed down from a parent from one generation to another. As the condition affects the muscles it is known as a neuromuscular condition.

The news of your diagnosis will be bewildering to you and your family. You may feel relieved at a diagnosis – at last. You may feel that you cannot talk to anyone about it. You may feel cross with your parents – afraid, lonely, isolated – especially as other people will say “I’ve never heard of the condition”. I myself had spent my working life in the nursing and midwifery field, and I hadn’t heard the words Myotonic Dystrophy until members of my family were diagnosed.

You have a genetic neuromuscular condition which affects (approx) 1 in 8000 people.

How did you come to be going to a Genetic Clinic?

Perhaps you have known for years that something had been bothering you, it may have been your hand grip, or tiredness for instance. Or maybe a baby has been born to your next generation and he or she has been diagnosed as having Congenital Myotonic Dystrophy. It is easier to diagnose a new born infant than it is a mother or grandparent.

A simple blood test is necessary to find the faulty gene and to look for Chromosome 19, where they will find the faulty gene.

What thoughts are going through your mind now?

To find out more? OR forget it!!

Please find out more in your own time.

If you want to find out more about Myotonic Dystrophy you can contact the Support Group via the telephone helpline:-

0808 169 1960

The person who answers will have experienced just what you are experiencing now, and on the phone you can talk and know that the conversation will be confidential and helpful, and it will perhaps help with the isolation that you are feeling, because you have shared your feelings with someone who really understands. There will be so many questions that you will want answering. You can also contact us via e-mail at contact@mdsguk.org or visit our website at www.myotonicdystrophysupportgroup.org where you will find up to date information and help.

As well as the following publications the MDSG also issues an **Alert Card**, a necessary card to carry with you in case of emergencies, and also a **Care Card** for you to record your clinical visits. All these leaflets are readily available on request.