Myotonic Dystrophy
SUPPORT GROUP

Relatives Information

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Myotonic Dystrophy

You have been given this information sheet because a relative of yours has been diagnosed as having Myotonic Dystrophy. This is an inherited condition and because of your family relationship it is possible that you may also have inherited the faulty gene that causes it. If your affected relation is one of your parents, a brother or sister, or one of your children, then there is a 50% possibility that you might have the abnormal gene.

Myotonic Dystrophy varies enormously in severity. Some people who inherit the gene may have no symptoms - so why worry about it? The reason is that sometimes there can be serious consequences even for people with no obvious symptoms, and that many of those consequences can be avoided given adequate knowledge.

The main problems associated with Myotonic Dystrophy are listed in the table below - any of these can be the first sign of the condition.

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Three issues are of particular importance to those who unknowingly carry the abnormal gene that causes the condition:

The main problems with Myotonic Dystrophy

- Weak muscles (especially the fingers/hands)
- Muscle stiffness (especially the fingers/hands)
- Cataracts
- Heart Rhythm problems (not angina or heart attack)
- Breathing problems (especially after anaesthesia)
- Excessive daytime sleepiness
- Premature Balding (mainly in men)
- Reduced Fertility
- Irritable Bowel Syndrome
- Intellectual problems
- Having a child who is more severely affected

- **Anaesthetic Problems:** People with Myotonic Dystrophy have an increased risk of problems with anaesthetics. These can be prevented if the diagnosis is known and taken into account when an anaesthetic is planned.

- **Heart Problems:** The electrical system of the heart, which is responsible for controlling the speed of the heartbeat, can be affected even when there are no other symptoms. In some people this can cause dizzy spells and blackouts, but a problem with the heart rhythm can be there even without symptoms and may need to be treated to stop it getting worse.

- **Affected Children:** This is perhaps the most important potential problem. The condition tends to be more severe in the next generation. So, a person with few or no symptoms can have a child who is more severely affected. This is particularly true for women. Even women who are not aware of

any problems themselves can have a child who can be severely affected at birth (a condition called Congenital Myotonic Dystrophy). These children might not survive, or might have major physical and educational difficulties later in childhood. If people know that they have this risk then there are various options that can be discussed with them that would ensure that they have a healthy child.

What Should You Do?

It is not an easy decision to decide to be tested for a condition when you have no symptoms. The reason for looking, is to know if you are at risk of the problems noted previously, so that they could be treated or prevented.

If you decide that you would like further information, then please take this booklet to your GP. Your GP is not an expert on

Myotonic Dystrophy and cannot perform diagnostic testing. If after discussion you may decide that you would like to be assessed, then your GP will refer you to a local specialist (e.g. a genetics or neurology specialist).

Further information about Myotonic Dystrophy can be obtained from:

- **Myotonic Dystrophy Support Group**
  19/21 Main Road,
  Gedling,
  Nottingham.
  NG4 3HQ

  Tel/Fax: 0115 987 5869
  Email: contact@mdsguk.org
  www.myotonicdystrophysupportgroup.org

Other publications available from the 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 Eye
- Myotonic Dystrophy Support Group
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?

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