

For more information about myotonic dystrophy:

Myotonic Dystrophy Support Group

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Seen in clinic by.....

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Myotonic Dystrophy



Information for
family members

Myotonic dystrophy

You have been given this information sheet because you or a relative of yours has been diagnosed as having myotonic dystrophy. This is an inherited condition. If you have myotonic dystrophy, you may have relatives who would like to find out whether or not they have inherited the abnormal gene that causes it.

If you have an affected relative who is a parent, brother/sister, or a child of yours, then there is a 50% possibility that you might have inherited 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 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

The main problems

The main problems associated with myotonic dystrophy are listed in the box opposite - any of these can be the first sign of the condition. Three issues are of particular importance to those who unknowingly carry the abnormal gene that causes the condition:

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 heart beat, 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 and are concerned, then there are tests that can be offered to see if a baby will be affected or not, so that people can decide if they want to plan to have healthy children.

What should you do?

If you decide that you would like further information about testing for myotonic dystrophy for yourself or your relatives, you could do one of the following:

- If you live in Scotland, you can contact your local genetics department. The addresses are overleaf.
- Alternatively, you could take this form to your GP and ask to be referred to your local regional genetics centre.