

Facts about Myotonic Dystrophy

Who can I talk to?



The Myotonic Dystrophy Support Group is here to help you! It is a charity that can help you to:

- Meet and talk with people of all ages who also have Myotonic Dystrophy.
- Make new friends.
- Become more aware of how Myotonic Dystrophy affects you.
- Get your Alert Card

For more information about the Myotonic Dystrophy Support Group, and how you can get involved, check out their website:

www.myotonicdystrophysupportgroup.org
or Helpline: 0808 169 1960



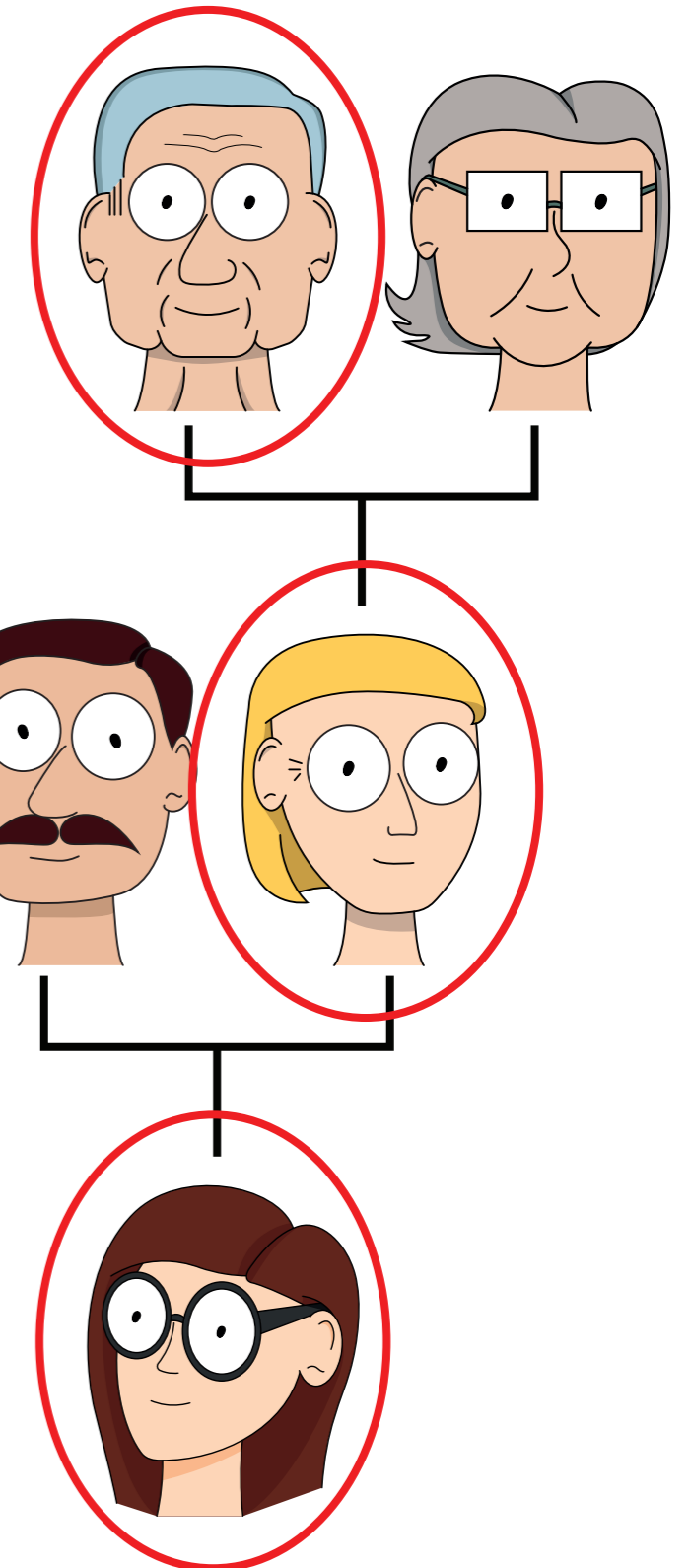
Why do I have Myotonic Dystrophy?



Myotonic Dystrophy is a genetic condition that you get from one of your parents.

There is a 50% chance that someone with Myotonic Dystrophy will pass it on to each child they have.

That means that one of your Grandparents passed it on to one of your parents, and they passed it on to you.



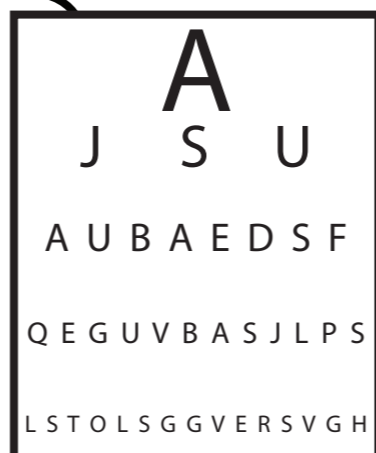
What symptoms should I expect to have?



There are a few symptoms that you could get. These include:

- Tiredness and sleeping in the daytime.
- Muscle weakness in different parts of your body.
- Myotonia – which means you may find it difficult to relax your muscles after using them e.g. after gripping a pen.
- Changes in the rhythm of your heart beat.
- Chest infections and breathing problems.
- Eye problems that could cause your vision to go blurry or dim.
- Thinking and learning difficulties.

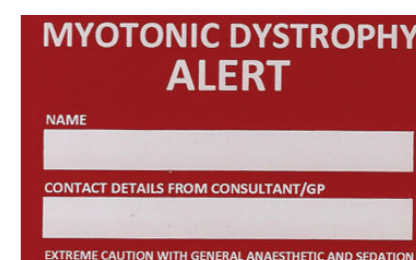
It is important to remember that it is very unlikely that you will get all of these symptoms!



What do I need to be aware of?



- You **MUST** always carry your **MYOTONIC DYSTROPHY ALERT CARD**. Having Myotonic Dystrophy means that you could react badly to some medical treatments. This card lets people know you have Myotonic Dystrophy which means that you can get the right medical care if you need it.



- Some problems can affect you without you knowing. This means that it is important that you have an ECG (heart reading), eye test and have your urine sugar levels checked every year.

- You **CAN** have children of your own. Genetic tests can be done to see if your child is likely to have Myotonic Dystrophy.
- Everyone is different – Young people with Myotonic Dystrophy usually have worse symptoms than people who get Myotonic Dystrophy when they are older. However, this is not always the case!



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