



Heart Check

As with other muscles in the body, there is potential for the disease process in muscular dystrophy to affect the heart. This is important for certain types of muscular dystrophy including Duchenne, Becker, Emery-Dreifuss and myotonic dystrophy. In most patients involvement of the cardiac muscle will be slight as to cause no symptoms at all and no action may be necessary. However, in a few patients involvement of the heart may need treatment.

The heart can be affected in one of two ways:

- ▶ The conduction tissue may be damaged, resulting in abnormal heart rhythms. These can lead to symptoms such as dizzy spells, palpitations or blackouts. The diagnosis can usually be made with a 24 hour ECG. Fast rhythms can be treated and prevented, in susceptible individuals, with drug therapy. Slow rhythms are usually caused by a heart block and treatment may require insertion of a pacemaker (a minor operation carried out under local anaesthetic). A heart block means that the heart's system for regulating the speed of the heartbeat degenerates. This can cause the heart to beat very slowly, causing blackouts. Patients with myotonic dystrophy and Emery-Dreifuss dystrophy are more prone to develop this sort of problem and should be under regular hospital review.
- ▶ There may be a problem with the pumping action of the heart, called a cardiomyopathy, symptoms such as breathlessness may occur. Cardiomyopathies are more likely to affect people with Duchenne or Becker MD. Those with Duchenne are, to a certain extent, protected by the lack of mobility and the cardiomyopathy will often be mild and without symptoms so treatments is rarely required. On the other hand, patients with Becker MD may develop a moderate to severe cardiomyopathy even when they are still physically active and mobile.

The diagnosis is made by a simple ultrasound examination of the heart called an echocardiogram, which may be repeated to monitor the effects of treatment and progress of the disease. Drug treatment is given to improve the heart's pumping action.

In patients with a cardiomyopathy from other causes there is now good evidence to show that early treatment improves the long-term outcome. The same may be true for these types of neuromuscular conditions although this has not yet been proven.

What can you do?

- ▶ If you are a patient with any of these conditions, it is important that you are receiving regular hospital follow-up, even if you feel well.

This factsheet is under review, due for updating later in 2017. If you have any queries, please contact us.

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- ▶ Don't smoke. Smoking is known to cause cardiovascular disease, which is likely to worsen the effects of the dystrophy.
- ▶ Keep your weight down and eat a healthy diet, low in fat and cholesterol. If you are mobile take regular gentle /moderate exercise.
- ▶ Report any unusual symptoms such as breathlessness, palpitations, chest pain or dizzy spells to your doctor.

We're here for you at the point of diagnosis and at every stage thereafter, and can:

- ▶ give you accurate and up-to-date information about your or your child's muscle-wasting condition, and let you know of progress in research
- ▶ give you tips and advice about day-to-day life, written by people who know exactly what it's like to live with a muscle-wasting condition
- ▶ put you in touch with other families living with the same muscle-wasting condition, who can tell you about their experiences
- ▶ tell you about – and help you get – the services, equipment and support you're entitled to.

If you have feedback about this factsheet please email info@muscular dystrophyuk.org.

Disclaimer

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or info@muscular dystrophyuk.org from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org

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