

Myotonic Dystrophy (DM1) - Symptoms and Overview

Brain: The brain can be affected in many ways and excessive daytime sleepiness is one of the most common consequences. Reduced motivation can also be a common problem.

Children with myotonic dystrophy may have learning difficulties, even if they have no muscle problems.

Eyes: It is very common for cataracts to form across the lens of the eye in people with myotonic dystrophy, but they usually cause few symptoms because they appear so slowly. However, early onset cataracts can be easily treated.

Facial Weakness: Facial weakness and myotonia (difficulty relaxing the muscle) is often mild or absent.

Throat: Swallowing muscles are affected, swallowing can often lead to coughing and spluttering when eating or drinking.

Chest: Due to swallowing issues food or drink can go into the lungs rather than the stomach, this leads to 'aspiration pneumonia', which is a severe chest infection.

Heart: Heart problems can occur but are usually less severe than in DM1.

Bowel Issues: The lower bowels are also typically affected by irritable bowel syndrome-like symptoms, with a mixture of constipation, crampy abdominal pain and diarrhoea.

Finger, hips and elbows: weakness tends to occur in muscles close to joints (proximal muscles), such as those in the fingers, elbows and hips.

Overview of Myotonic dystrophy

There are two problems that may affect muscles of movement or 'skeletal muscle'.

The first is a gradual weakening of certain muscles, over time, caused by a 'muscular dystrophy'. The muscles in the face, eyelids, jaw and neck are commonly affected. The muscles in the forearm that enable us to grip objects are often affected early on. The muscles around the ankles are also commonly affected, causing 'foot drop', which causes people to catch their toes and trip. The large, weight-bearing muscles of the legs and thighs are usually affected much later.

The second problem affecting skeletal muscles is an electrical problem, called 'myotonia'. Myotonia causes muscle stiffness (difficulty relaxing the muscle), which especially affects the hands and jaw. This can be helped with medication supplied by your specialist but usually does not need treatment.

Please note: The rate of deterioration in muscle strength is typically slow over many years. Some people never have significant muscle weakness.

Some people, who are more severely affected, may need a wheelchair, but many people with myotonic dystrophy do not.

Scan me for more
information

