CPA FACT SHEET

Muscular dystrophy

Cerebral Palsy ALLIANCE

What is muscular dystrophy?

Muscular dystrophy is the name for a group of genetic conditions that causes weak muscles. For some people, it shows up early in life and causes serious problems. But for other people, it shows up later and doesn't cause serious disability.

Types of muscular dystrophy

There are many types of muscular dystrophy – the most common ones are Duchenne muscular dystrophy, Becker muscular dystrophy and myotonic muscular dystrophy.

Causes

Muscular dystrophy is caused by a problem with a gene. Different genetic problems cause different types of muscular dystrophy. Sometimes a problem with a gene is inherited by a parent, and sometimes it just happens for no obvious reason.

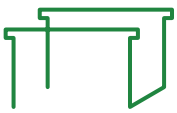
Symptoms

Muscle weakness is the main symptom. Babies with muscular dystrophy will be floppy, or will find it hard to crawl or walk. Older children, teenagers and adults with muscular dystrophy will usually notice feeling tired and weak as the first sign. Later it might affect many parts of their body.

Diagnosis

A GP can help, and will refer children with a suspected diagnosis to a specialist. They will do an examination and arrange some tests, which might include:

- genetic tests – these should be carried out with a doctor or a genetic counsellor, not online
- tests on muscles and nerves
- blood tests
- tests on the heart and lungs
- a muscle biopsy (taking a small section of a muscle and examining it under a microscope).



At CPA we help babies, children, teenagers and adults living with neurological and physical disabilities lead the most comfortable and independent lives possible. Our therapy teams work with individuals and families in many ways. Get in touch to find out how we can support you and improve your child's development.

Living with muscular dystrophy

Learning that a child has muscular dystrophy can be very distressing for the child's family. Speaking with a doctor to find out about muscular dystrophy and about the support available from organisations like the Muscular Dystrophy Foundation and Muscular Dystrophy Australia can be helpful. Over time, families might need help with:

- psychological and emotional support – talk to a psychologist, counsellor or social worker
- household adaptations – such as rails and ramps, hoists for lifting to reduce injury risk
- equipment and assistive technology – such as leg braces, a cane, walking frame, wheelchair, communication and breathing aids
- Exercise – talk to a Physiotherapist or Exercise Physiologist about recommendations
- diet and lifestyle changes
- personal and nursing care – for help with dressing, bathing, cooking and feeding

Treatment and therapy

There is plenty that can be done to help manage symptoms, improve quality of life and keep disability to a minimum. Children with muscular dystrophy are often advised to join an early intervention program.

Ideally, people with muscular dystrophy should be cared for by a multidisciplinary team. It should be led by a GP, and might include:

- specialists such as a neurologist, a cardiologist, a respiratory physician, an orthopaedic surgeon and a psychiatrist
- a physiotherapist
- an occupational therapist
- a psychologist, registered counsellor or social worker
- a speech pathologist
- a dietitian.

Interpreters are available to support you through all of your appointments. Interpreters are free of charge from the government and can be included in your NDIS plan.

Get in touch with us:

Call us on 1300 888 378

Email us at ask@cerebralpalsy.org.au

Visit cerebralpalsy.org.au

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