

MUSCULAR DYSTROPHY

This fact sheet has been written by parent carers for parent carers.



What is muscular dystrophy?

Muscular dystrophy, or MD, refers to a group of genetic conditions that cause muscles to gradually weaken, leading to increasing levels of disability. It is a progressive condition, which means it gets worse over time. It usually affects a particular set of muscles before spreading to other muscle groups. Around 70,000 children and adults in the UK have MD. The most common form is Duchenne muscular dystrophy – it is estimated that around 100 boys are born with this form of MD every year in the UK.

Characteristics of muscular dystrophy

Symptoms usually appear from age 1-3. Typical symptoms include difficulty walking, standing and sitting. Other physical characteristics might be apparent, for example, curvature of the spine, which is known as scoliosis, or enlarged leg and pelvic muscles.

Types of muscular dystrophy

There are many different forms of muscular dystrophy, each with varying symptoms and degrees of muscle weakness. The most common forms that affect children are:

- **Duchenne muscular dystrophy** – the most common and severest form, it particularly affects boys. Boys with Duchenne MD usually only live into their twenties or thirties.
- **Becker muscular dystrophy** – similar to Duchenne MD but develops later in childhood and differs in having less severe symptoms and a longer life expectancy.
- **Myotonic dystrophy** – can develop in childhood or adulthood. It is characterised by muscle weakness and stiffness and affects smaller muscle groups, such as those in the face. In severe forms of the condition life expectancy is reduced.
- **Facioscapulohumeral muscular dystrophy** – this slow progressing form of MD affects the face, shoulders, upper back and calves. It does not tend to affect life expectancy.
- **Limb-girdle muscular dystrophy** – a group of conditions that cause weakness in muscles at the base of the arms, legs and hips. Symptoms usually develop in late childhood. Some variants of the condition can be life-limiting, others develop more slowly.
- **Emery-Dreifuss muscular dystrophy** – a form of the condition that develops in late childhood or adolescence and is characterised by shortened and tightened muscles in the arms, neck and feet. Most people with the condition live until middle age.

Types of treatment

There is currently no cure for Muscular Dystrophy but there are a number of treatments that can manage and slow down the progress of the condition:

- **Cardiology** – MD can cause problems with heart muscles and those used for breathing. Treatment may involve monitoring, medication and/or the fitting of a pace-maker.
- **Corrective Surgery** – surgery may be performed to correct problems such as scoliosis and to treat droopy eye lids, tight joints or weak shoulder muscles.
- **Occupational Therapy (OT)** – if your child finds everyday tasks difficult, such as dressing, bathing or



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using the toilet, a therapist can identify solutions and help your child to develop skills to maximise their independence.

- **Physiotherapy** – low impact exercise and physiotherapy can help maintain muscle strength and flexibility and preserving stiff joints. Various splints may be helpful.
- **Steroids** – in people with Duchenne MD, steroids may be used to improve muscle strength and slow down the process of muscle weakness.

Ask about

- **Information, Advice and Support (IAS)** – Amaze supports families of children and young people with SEN and disabilities in Brighton and Hove. We have a helpline, publications and a website. We also run workshops and courses and can offer one-to-one support with EHC planning and making DLA and PIP claims. Call Amaze on: **01273 772289** or visit: **www.amazebrighton.org.uk**.
- **Chailey Heritage Clinical Services** – a range of services and therapies available to children with complex physical or neurological physical disabilities. Call: **01825 722112**.
- **Compass Card** – a free leisure discount card administered by Amaze for 0 to 25 year olds registered on The Compass who live or go to school in Brighton and Hove or West Sussex, or who are looked after by social services in these areas. Call Amaze on: **01273 772289**.
- **Independent Support** – Amaze's Independent Supporters provide extra advice and support to young people and parent carers who are going through the process of getting an EHC Plan in Brighton and Hove and Sussex. For Brighton and Hove Independent Support, call: **01273 772289**. For Sussex Independent Support, call: **0300 123 7782**.
- **Integrated Child Development and Disability Centre (Seaside View)** – where many children are diagnosed and where services work together to support and treat your child. Referrals will usually be via a health or education professional but you can contact Seaside View direct on: **01273 265780**.
- **Kaleidoscope** – a group for parents and carers of children with physical disabilities. Little Wheels is for 0 to 8s and provides early support and info, regular swimming sessions and meet-ups. Wheels is for 8 to 16 year olds and they organise regular leisure activities. Contact Gillian on: **07788 924940** (Little Wheels) or Sandra on: **07946 344220** (Wheels).
- **Making a claim for DLA** – if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim Disability Living Allowance for them. Find out more at: **www.gov.uk**. Amaze can give you advice and practical support with making a claim. Call the helpline on: **01273 772289** or email: **helpline@amazebrighton.org.uk**.

Further reading and useful links

- **Through the Maze** – Amaze's handbook for parent carers of children and young people with SEN and disabilities (0-14) includes lots of information on education, money matters, social care, health, leisure and more. It's free to parent carers of children who live or go to school in Brighton and Hove. Call the Amaze helpline to request a copy on **01273 772289**.
- **Action Duchenne** – **www.actionduchenne.org**.
- **Becker United** – **www.beckerunited.com**.
- **Duchenne Family Support Group** – **www.dfsg.org.uk**, helpline: **0800 121 4518**.
- **Muscular Dystrophy Campaign** – **www.muscular dystrophyuk.org**, helpline: **0800 652 6352**.
- **NHS Choices** – **www.nhs.uk/Conditions/Muscular-dystrophy/Pages/Symptoms.aspx**.

