

MUSCULAR DYSTROPHY

This fact sheet has been written by parent carers for parent carers.
Clinical information has been approved by West Sussex practitioners.



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



MUSCULAR DYSTROPHY



- **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

- **Brooklands Park, Worthing** – accessible playground with equipment opened by RADAR key and bike track for children with physical disabilities. There is also a Changing Places facility opposite the Dome Cinema on Worthing seafront.
- **Child Disability Service** – a social work service for children and young people with severe and/or complex disabilities, it works with families and other agencies to ensure they get the right support. Call: **01403 229888** or email: cdt@westsussex.gcsx.gov.uk. Please note that some children may be referred on to the MASH (see contact details below).
- **Compass Card West Sussex** – a free leisure discount card for 0 to 25 year olds with SEND, which is run by Amaze. Find out more at: www.amazebrighton.org.uk or by calling: **0300 123 9186**.
- **Horsham Park** – accessible swing opened by RADAR key and Changing Places facility located within the Pavilions.
- **Independent Support** – Amaze's Independent Supporters provide advice and support to parent carers and young people applying for or transferring to an EHC Plan in Sussex. For Sussex Independent Support, call: **0300 123 7782**.
- **MASH** – support from health and social care. If your child is under 18, call the MASH, tel: **01403 229888**, email: MASH@westsussex.gcsx.gov.uk. For over 18s call the Adult Social CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Chichester: **01243 536182**, Crawley: **01293 572480**, Horsham and Mid-Sussex: **01444 243150**, Worthing: **01903 242558**.
- **Other resources** – the Ashdown Club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, Crawley: **01293 531963**, Horsham: **01403 218888**.

Further reading and useful links

- **Making Sense of it All** – our handy parent/carer guide contains information and advice on benefits, support for your child at school, getting help from social services and accessing social & leisure activities – www.reachingfamilies.org.uk.
- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. For further information visit www.gov.uk/dla-disability-living-allowance-benefit/overview.
- **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.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org> and search for 'Muscular dystrophy'.

