

# 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** – some types of MD can cause problems with heart muscles and those used for breathing. Treatment may involve monitoring, medication and/or the fitting of a pacemaker.
- **Corrective Surgery** – surgery may be performed to correct problems such as scoliosis and to treat droopy eyelids, tight joints or weak shoulder muscles.



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- **Medication** – in people with Duchenne MD, steroids may be used to improve muscle strength and slow down the process of muscle weakness. A newer medication, Ataluren, is sometimes prescribed to children with Duchenne MD aged 5 or over who can still walk.
- **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.
- **Physiotherapy** – low impact exercise and physiotherapy can help to maintain muscle strength and flexibility and prevent stiff joints. Various splints may be helpful.

### Ask About

- **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. Information can be found via the local offer website: <https://westsussex.local-offer.org/services/265-child-disability-teams-lifelong-services-social-care> or families should call the Integrated Front Door (IFD) for West Sussex Children Services on **01403 229900** or complete the online referral: [www.westsussex.gov.uk/Raiseaconcernaboutachild](http://www.westsussex.gov.uk/Raiseaconcernaboutachild).
- **Muscular Dystrophy UK** – [www.musculardystrophyuk.org](http://www.musculardystrophyuk.org), helpline: **0800 652 6352**. They also have a facebook group for South East families: [www.facebook.com/groups/MDUKSouthEast/about](https://www.facebook.com/groups/MDUKSouthEast/about).
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Chichester: **01243 536182**; Crawley and East Grinstead: **01293 572480**; Horsham: **01243 536182**; Mid-Sussex: **01444 243150**; Worthing: **01903 242558**.
- **Sensory Toys** – available to borrow from a number of children and family centres. See: [www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries](http://www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries).
- **Short Breaks for Disabled Children** – commissions holiday clubs, after school clubs, buddy schemes and short breaks at home or in the community. Tel: **0330 222 2562** or email: [SENDCommissioningTeam@westsussex.gov.uk](mailto:SENDCommissioningTeam@westsussex.gov.uk).
- **South East Coast Muscle Group** - for meeting up with other families, please contact Joel Rackham on **020 7803 2886** or email [j.rackham@musculardystrophyuk.org](mailto:j.rackham@musculardystrophyuk.org).
- **West Sussex Children Services** – support from health and social care. If your child is under 18, call the Integrated Front Door (IFD) for West Sussex Children Services, tel: **01403 229888** or email: [WSChildrenservices@westsussex.gov.uk](mailto:WSChildrenservices@westsussex.gov.uk). For over 18s call the Adults' CarePoint: **01243 642121**, or email: [socialcare@westsussex.gov.uk](mailto:socialcare@westsussex.gov.uk).
- **Other resources** – the Ashdown club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, Horsham: **01403 218888**.

### Further reading and useful links

- **Making Sense of it All: From Birth to Adulthood** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: [www.reachingfamilies.org.uk/guides.html](http://www.reachingfamilies.org.uk/guides.html).
- **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/disability-living-allowance-children](http://www.gov.uk/disability-living-allowance-children).
- **Action Duchenne** – for information and support go to: [www.actionduchenne.org](http://www.actionduchenne.org).
- **Duchenne Family Support Group** – [www.dfsg.org.uk](http://www.dfsg.org.uk), email: [info@dfsg.org.uk](mailto:info@dfsg.org.uk) or call the helpline: **0800 121 4518**.
- **West Sussex Local Offer** – go to [westsussex.local-offer.org](http://westsussex.local-offer.org) and search for 'Muscular dystrophy'.

