Reaching Families FACT SHEET Updated October 2023

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.
- **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

- **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**.
- **Muscular Dystrophy UK** – **www.musculardystrophyuk.org**, Helpline: **0800 652 6352**. For the South East Coast Muscle Group & meeting up with other families, please email: **musclegroup@musculardystrophyuk.org**. They also have a Facebook group for Southeast families: **www.facebook.com/groups/MDUKSouthEast/about**.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Crawley and East Grinstead: **01293 572480**, Chichester and Horsham: **01243 536182**, Mid Sussex: **01444 243150**, Worthing: **01903 242558**.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. We also offer benefits advice, peer support, a Facebook group & handbook *(see below)* for parent carers of children & young people with SEND in West Sussex: See: **www.reachingfamilies.org.uk**.
- **Sensory Toys** – sensory toys are available for loan through local family hubs and libraries. Go to: **www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries.**
- **West Sussex Children's Services** – support from health and social care. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: **WSChildrenservices@westsussex.gov.uk**. The IFD is also an entry point for the Children with Disabilities (social care) service for children & young people with severe and/or complex disabilities. Eligibility criteria apply – See: **https://westsussex.local-offer.org/services/265**. For over 18s call the Adults' CarePoint: **01243 642121**, or email: **socialcare@westsussex.gov.uk**.

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**.
- **Action Duchenne** – for information and support go to: **www.actionduchenne.org**.
- **Duchenne Family Support Group** – **www.dfsg.org.uk**, email: **info@dfsg.org.uk** or call the helpline: **0800 121 4518**.
- **NHS Health A-Z** has information on this condition at: **www.nhs.uk/conditions/muscular-dystrophy**.
- **West Sussex Local Offer** – go to **https://westsussex.local-offer.org** for local services, support and details of Short Breaks providers for children & young people aged 0 - 25 years with SEND.