Amaze & Reaching Families FACT SHEET Updated Nov 2019

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** – 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 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.
- **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.

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- **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 to help maintain muscle strength and flexibility and prevent 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

- **Amaze SENDIASS** – the **Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS)** offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds, including education, health, and social care. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Contact **sendiass@amazesussex.org.uk** or phone **01273 772289**. To find out more visit our website at **amazesussex.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 with SEND who are registered on the compass. Go to: **www.compasscard.org.uk**, email Amaze at: **compass@amazesussex.co.uk** or call: **01273 772289** (Brighton & Hove) or **0300 123 9186** (West Sussex)
- **Disability Living Allowance (DLA) –** if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim DLA for them. Visit **www.gov.uk** and search for DLA. Amaze can also give you advice and support with making a claim. Call our helpline: **01273 772289** or visit our website: **amazesussex.org.uk**.
- **Seaside View Child Development Centre** – this is where many children are diagnosed and where health professionals such as paediatricians and occupational therapists work together to support and treat your child. Assessments will usually be via a health or education professional but you can contact Seaside View directly on: **01273 265780.**

Further reading and useful links

- **Action Duchenne – www.actionduchenne.org.**
- **Becker United – www.beckerunited.com.**
- **Duchenne Family Support Group – www.dfsg.org.uk**, helpline: **0800 121 4518.**
- **Local Offer** – the local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit **new.brighton-hove.gov.uk/special-educational-needs-and-disabilities**
- **Muscular Dystrophy Campaign – www.musculardystrophyuk.org, helpline: 0800 652 6352.**
- **NHS Choices – www.nhs.uk/Conditions/Muscular-dystrophy/Pages/Symptoms.aspx**