

Useful Contacts

Physiotherapist

Name _____

Telephone number _____

Occupational Therapist

Name _____

Telephone number _____

Advisory Teacher

Name _____

Telephone number _____

Speech & Language Therapist

Name _____

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Other

Name _____

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Advisory Teaching Service

BASES

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Understanding and responding
to pupils with

Neuromuscular Conditions

Information and advice for schools



Advisory Teaching Service

C&L / SEMH / PD Team



Background to Neuromuscular Conditions

Muscle function

- The main framework of the body (skeleton) is covered by muscles
- The two principal functions of muscle are to produce movement and to maintain posture
- These functions are achieved by adjusting the length and tension of muscle, i.e. by muscles contracting & relaxing
- Sensory receptors in the muscles monitor the tension and length of the muscles and provide the nervous system with information about the position of the body parts

What causes a neuromuscular condition?

- There are a significant number of neuromuscular conditions with more being classified every year
- The conditions affect about 1 in every thousand people
- They can be inherited or occur without any genetic link
- The conditions lead to muscle wasting or nerve deterioration that results in a loss of muscle strength
- They range both in severity and the muscle groups affected; each child will be effected differently
- The majority are progressive and can cause shortened life expectancy
- Despite various major research projects there is currently no cure but there are a variety of ways of managing the implications, e.g. medication, physiotherapy

Useful websites

www.muscular-dystrophy.org

www.actionduchenne.org

In an educational setting

What are the challenges?

- Fully and safely accessing some aspects of the school curriculum, e.g. practical activities and PE
- Accessing different areas of the school and site
- Providing equal access to school trips
- Providing appropriate and sensitive support for self-care activities
- Ensuring students can sit correctly, comfortably and safely
- Enabling self-image and self-esteem, particularly in the context of an rare and progressive condition

How to help?

- ✓ Consider the **whole** student, i.e. social, personal, emotional and cognitive as well as physical needs
- ✓ Develop a personalised curriculum to ensure all needs can be met
- ✓ Refer to advice and guidance from other agencies as appropriate, e.g. occupational therapy
- ✓ Use generalised and specific tools and equipment, e.g. to record work
- ✓ Ensure safety of the student and staff, e.g. by developing appropriate protocols and risk assessments for manual handling and fire evacuation
- ✓ Decide priorities to set short, medium and long-term goals
- ✓ Work closely with the student's family, especially at times of transition and change
- ✓ Ensure all staff are aware of the student's needs
- ✓ Allow for extra time as appropriate, e.g. to move between different areas of the school
- ✓ Allow for fatigue and other associated difficulties
- ✓ Provide positive role models to the student and their peers