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Pupils with Physical Disabilities

Muscular Dystrophy

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Muscular Dystrophy

Classroom-based tips (focus on instructional methods)

1. **Inform the pupils about the presence of a colleague with muscular dystrophy** (e.g. through project, discussion, parental participation, storytelling, involvement of the pupil himself/herself, depending on the age of the class), taking care not to stigmatise the pupil or make her/him feel uncomfortable.

2. **Speak clearly and concisely, but avoid speaking artificially slowly, exaggerating your lips, or shouting, as this affects the natural rhythm of speech.** Repeat the information, so as to make sure that the respective pupil understands the information as pupils with muscular dystrophy often experience learning problems, mainly connected with the amount of information they can process.

3. **Make use of natural gestures and facial expression as a clue to meaning.**

4. **Be aware and watch for changes in symptoms and/or for signs of abnormal fatigue throughout the day.**

5. **Take notice and address the specific emotional or behavioural problems these pupils may experience as a result of their condition**, and always encourage them to express their feelings.

6. **Provide activities promoting acceptance and support** in order to avoid marginalisation. Encourage discussions on various types of disabilities, use activities based on visual skills and creativity, which, in the case of pupils with MD, are often excellent.

7. **Ensure that each pupil has a role in class activities**.

8. **Use various teaching methods in order to offer equal chances to those pupils with MD.**

9. **Make use of visual learning materials and aids,** such as handouts, key vocabulary, diagrams, written instructions, and virtual learning environments, such as Blackboard.

10. **Divide the information/concepts into smaller chunks** to help pupils to understand what is being taught. Give one instruction at a time.

11. **Explain the lessons carefully and use dynamic activities that stimulate the creativity of pupils with muscular dystrophy;** this encourage them to keep their interest and stay actively involved in the various types of learning activities.

12. **Provide a specific set of teaching materials in digital form**, so that pupils with muscular dystrophy do not have to carry heavy books in and out of school and the classroom.

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13. **Provide copies of teachers' notes or recorded lectures,** as well as digital notes for pupils using technology.

14. **Be understanding with such issues as lateness, absences, shortened school days, fatigue, change in mood, and missed homework due to physical therapy sessions.**

15. **Provide options for tutoring or extra time to make up assignments and complete the tasks.**

16. **Provide opportunity for frequent bathroom breaks or visits to the school nurse for medication as required.**

17. **Encourage pupils to participate in all classroom activities at their own pace and comfort level.**

18. **Take into consideration the pupil's physical needs when designing class schedule,** for example, classrooms should be close to minimise the time spent and distance between classes during the course of the day.

19. **Differentiate testing and assessment by providing options according to individual needs of a pupil.** These could be extra time or untimed tests, one-on-one evaluation, alternate response mode, and use of a laptop and/or other assistive technology.

20. **Provide opportunities for the use of alternative communication means in all classroom activities,** if available, for pupils that do not have verbal communication abilities.

21. **Make arrangements for sitting and positioning in classroom** to facilitate safely moving around and participating in activities. Consult physiotherapist for specific seating needs.

22. **If pupils use wheelchairs, where possible place yourself at their eye level when talking to them.**

23. **The board in the classroom may have to be lowered if the pupil is in a wheelchair.**

24. **Allow pupils to leave classes early to give them adequate time to get to their next class.**

25. **Provide options for adapted physical activities** (consult physiotherapist). Being physically active is important for pupils with muscular dystrophy. Differentiate goals accordingly, for example by placing emphasis on recreation, and not on competition or strength-building.

School-based practical tips (focus on instructional methods)

Community

Find and have available contact details of local/national associations for MD.

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Curricular Adaptations

1. Devise individualised learning plans for pupils with MD in collaboration with other professionals and family members.

2. **Make the physical education class and sports activities in school accessible by adjustment of playing areas** (dimension, surface); equipment modification, for example using lighter balls, or balls with sounds, or modification of net height, for playing table tennis. (Cristea, Ștef, Dragoș, *Adapted Motrical Activities - Theoretical and Methodical Aspects,* http://www.fefsoradea.ro/PDF/curs/Dragos/Activitati%20motrice%20adaptate_curs.pdf

Educational Visits / Field Trips / Camps / School Exchanges / Trips Abroad

When organising field trips and school events, make arrangements by considering the following, based on individual pupil's needs: How far will this pupil with muscular dystrophy have to walk? Is there a wheelchair lift on the bus? Is there enough space in the bus for a wheelchair? Is the field trip destination accessible for wheelchairs? Have the teachers accompanying the group of pupils been informed of this pupil's needs?

Parents / Parents' Associations

1. **Arrange meetings between the parents and the staff**, including other professionals working with the pupils, such as the physiotherapist, so as to learn as much as possible about the diagnosis, their observations about the pupil's current level of ability, and possible needs during the course of the school year.

2. **Facilitate family support and confidence in parenting a child with MD.**

Safety

1. **When organising field trips and school events, make arrangements by considering the following, based on individual pupil's needs:** How far will this pupil with muscular dystrophy have to walk? Is there a wheelchair lift on the bus? Is there enough space in the bus for a wheelchair? Is the field trip destination accessible for wheelchairs? Have the teachers accompanying the group of pupils been informed of this pupil's needs?

2. **Make sure that, in case of emergency, the evacuation plan allows disabled pupils to safely get out of the building.**

3. **Ensure emergency precautions are in place and staff are properly trained if pupils' breathing or heart rate are affected.**

4. **Make the physical education class and sports activities in school accessible by adjustment of playing areas** (dimension, surface); equipment modification, for example using lighter balls, or balls with sounds, or modification of net height, for playing table tennis. (Cristea, Ștef, Dragoș, *Adapted Motrical Activities - Theoretical and Methodical Aspects,* http://www.fefsoradea.ro/PDF/curs/Dragos/Activitati%20motrice%20adaptate_curs.pdf

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School Purchases

1. Equip the building of the school institution with accessibility and safety adaptations **such as elevator, ramps, and special desks.**

2. **Allow pupils with muscular dystrophy to use assistive technological devices that help them perform tasks and improve performance,** for example a keyboard for writing. A favourable classroom accommodation, such as supportive seating, note-taking by means of recording the lesson, adjusting the height of the bench so as to match the height of the wheelchair, or lowering the blackboard, and the use of the adaptive equipment mentioned above, may improve the pupil's physical abilities.

Pupil Support

1. **Provide pupils extra support where possible,** including financial, individual teaching support such as by scheduling extra instruction time, and providing a supportive relationship.

2. **Ensure that further provision is provided to pupils who may need support during class,** such as the presence of a teaching assistant.

3. **Consider that MD is a progressive condition and be prepared for continuous adaptations and changes in all the above.**

4. **Allow time for mobility for pupils who need to change rooms for classes in order to move safely and on time to their next class.** If needed, a classmate, friend or helper may carry books and other materials between classes.

5. Find and have available contact details of local/national associations for MD.

Teacher Professional Development

Provide training for teachers who have pupils with muscular dystrophy in their classrooms.

Technology

Allow pupils with muscular dystrophy to use assistive technological devices that help them perform tasks and improve performance, for example a keyboard for writing. A favourable classroom accommodation, such as supportive seating, note-taking by means of recording the lesson, adjusting the height of the bench so as to match the height of the wheelchair, or lowering the blackboard, and the use of the adaptive equipment mentioned above, may improve the pupil's physical abilities.

Timetabling

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Supportive Literature

Definition: Muscular dystrophy, usually abbreviated as **MD**, can be defined as a collective group of inherited non-inflammatory but progressive disorders that affect muscle function (Alan E. H. Emery, Muscular Dystrophy, Oxford University Press, 2008, 3). The word comes from two Greek words, i.e. *dys*, "meaning abnormal or faulty, and *trophe*, meaning food or nourishment" (Emery, 6), thus suggesting that "the nourishment of the muscle was defective" (Emery, 6).

Affecting the muscles with definite fibre degeneration, but without evidence of morphologic aberrations, the general denomination reunites more than 30 inherited diseases, all of which cause muscle weakness and muscle loss. In point of time, certain forms of MD appear in infancy or childhood, whilst others may not appear until middle age or later.

The **different types** may vary in whom they affect, which muscles they affect, and what the symptoms are. In this context, one may note that there are nine major forms of muscular dystrophy:

- **Myotonic** - the most common form of muscular dystrophy in adults, whose name refers to a symptom, *myotonia* = prolonged spasm or stiffening of muscles after use. In Emery's opinion, myotonic muscular dystrophy means "the delayed relaxation of muscle that occurs after voluntary contraction" (Emery, 38)
- **Duchenne** - the most common form of muscular dystrophy in children, usually affecting males. The muscles decrease in size and grow weaker over time, yet may appear larger. Disease progression varies, but many people with Duchenne need a wheelchair by the age of 12.
- **Becker** – once considered to be rare (Emery, 31), this form of MD is similar to Duchenne muscular dystrophy, but the disease is much milder: symptoms appear later and progress more slowly.
- **Limb-girdle** – in this type of muscular dystrophy, weakness predominantly affects "the limb girdle muscles, that is, the muscles around the hips and the shoulders" (Emery, 33).
- **Facioscapulohumeral** –"the third most common inherited neuromuscular condition, after Duchenne and myotonic muscular dystrophies" (Cooper, Upadhhyaya, 1). It is characterised by progressive muscle weakness and involves atrophy of the muscles "of the face, upper arm and shoulder girdle" (Cooper, Upadhhyaya, 1).
- **Congenital** – congenital means "present at birth" (Emery, 37). The congenital muscular dystrophies "are a group of dystrophies in which weakness and other problems are evident in the new-born period, or certainly within the first month or so" (Emery, 37)
- **Oculopharyngeal** – a type of muscular dystrophy that affects the eye and throat.
- **Distal** – involves weakness and wasting of the distal muscles (those farthest from the centre) of the forearms, hands, lower legs, and feet.
- **Emery-Dreifuss** - causes muscle weakness and wasting in the shoulders, upper arms, and lower legs. (*Understanding Muscular Dystrophy -- the Basics*, available online)

All forms of MD grow worse as the person's muscles get weaker, most people with MD eventually losing the ability to walk.

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Muscular dystrophy has no cure, but can be kept under treatment and thus symptoms may be ameliorated and complications may be prevented. The treating possibilities include physical and speech therapy, orthopaedic devices, surgery, and medications.

Websites and EU Reports

EU Accessibility Act - http://www.europarl.europa.eu/RegData/etudes/IDAN/2016/571382/IPOL_IDA(2016)571382_EN.pdf
Muscular Dystrophy – Kids Health, http://kidshealth.org/en/teens/muscular-dystrophy.html?WT.ac=ctg
Muscular Dystrophy Association https://www.mda.org/disease
Muscular Dystrophy UK http://www.musculardystrophyuk.org/
Medical News Today, http://www.medicalnewstoday.com/articles/187618.php
Muscular dystrophy - Better Health Channel https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/muscular-dystrophy
Muscular Dystrophy - NHS Choices - http://www.nhs.uk/conditions/muscular-dystrophy/Pages/Introduction.aspx
Duchenne and Becker muscular dystrophy - https://ghr.nlm.nih.gov/condition/duchenne-and-becker-muscular-dystrophy
Facts | Muscular Dystrophy | NCBDDD | CDC- https://www.cdc.gov/ncbddd/musculardystrophy/facts.html
Association of people suffering from muscular dystrophy of Romania - https://asociatiadistroficilormuscular.wordpress.com/

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Cooper, David Upadhhyaya, Meena (2004). Facioscapulohumeral Muscular Dystrophy (FSHD): Clinical Medicine and Molecular Cell Biology, Garland Science

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Johanson, Paula (2008). Muscular Dystrophy, The Rosen Publishing Group

Understanding Muscular Dystrophy - the Basics, available online at http://www.webmd.com/children/understanding-muscular-dystrophy-basics#1

Journal of the American Heart Association http://jaha.ahajournals.org/keyword/duchenne-muscular-dystrophy-cardiomyopathy

Journal of Child Neurology, http://jcn.sagepub.com/

Assistive Technology (http://www.resna.org/professional-development/assistive-technology-journal/assistive-technology-journal)

Journal of Enabling Technology (http://www.emeraldinsight.com/journal/jet)

Technology & Disability (http://www.iospress.nl/journal/technology-and-disability/)

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