

Fact Sheet

Myotonic Dystrophy

General Overview

Myotonic dystrophy is a form of muscular dystrophy in which the muscles have difficulty relaxing. Muscle myotonia (abnormally prolonged muscle contraction, with difficulty relaxing) may develop soon after birth or begin as late as early adulthood, especially affecting the hands, wrists and tongue. In teens, it can cause a number of problems, including muscle weakness and wasting (where the muscles shrink over time), cataracts, and heart problems. A person with myotonic dystrophy has difficulty relaxing his or her grasp, especially in the cold. Myotonic dystrophy affects heart muscle, causing irregularities in the heartbeat. It also affects the muscles of the digestive system, causing constipation and other digestive problems. Myotonic dystrophy may cause cataracts, retinal degeneration, low IQ, frontal balding, skin disorders, atrophy of the testicles, and insulin resistance. It can also cause sleep apnea—a condition in which normal breathing is interrupted during sleep. Myotonic dystrophy increases the need for sleep and decreases motivation. Severe disabilities do not set in until about 20 years after symptoms begin.

EFFECTS ON DEVELOPMENTAL AREAS

Social and Emotional

- May have limited social skills due to absences from day care/ school
- May have anxiety about attending care.

Physical Development

- Muscle weakness progresses at different rates during stages of the child's development
- May require regular physical therapy to strengthen muscles
- May have scoliosis (curvature of the spine) caused by weakness in muscles
- May have difficulty in breathing
- May have some delay in the onset of walking
- May have a waddling gait and prone to falls
- May have difficulty in running, climbing and much of the gross motor activities.

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Language and Communication Development

- Communication skills effected by both physical and developmental delays due to muscle weakness of the tongue
- Limited tongue control may result in some speech delays
- Delays in speech production may prevent children from saying clear words even though they know what they want to say
- May experience frustrations in making themselves understood many children may try/use gestures in order to communicate their want or needs.

Health and Safety

- May have health issues concerning the heart.
- May have skin problems due to weakness of muscles
- May be prone to chest infections.
- May suffer from constipation and thus may be on medication to control this.
- May have problems with insulin production causing diabetes
- May have difficulty in swallowing (dysphagia)
- May sleep excessively.

Cognitive Development

- May need help to practice and consolidate new knowledge and skills
- May have specific learning difficulties such as dyslexia
- May have intellectual impairment.

Inclusion Strategies

Each child diagnosed with **Moyotonic Dystrophy** will be different and individual. It is important to gain information from the parents as to what characteristics of **Moyotonic Dystrophy** their child displays. It is important to work closely with the parents as well as any additional support specialists e.g. therapists who may be involved with the child. It is also important to gain an understanding from the parent as to what is the most important aspect of their child attending your service. What is it that parents hope to gain from using your service? The following inclusion strategies are just some examples which may be applied to support the inclusion process. This list is only the start and it is dependant on a variety of factors such as environment, length of time child is in care, child's interest, likes, dislikes, skills already achieved. Strategies developed should be age appropriate for the child. The strategies are divided into developmental areas however some strategies overlap and assist in a variety of developmental areas.

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Social and Emotional Development

- Always encourage inclusion in group activities in an active or passive role.
- Provide ample opportunity for dramatic play episodes.
- Plan for the dramatisation of favourite stories using props and felt pieces encouraging children to participate in the retelling on these stories.
- Support peer relationships support by acknowledging all in the group from which their social skill development benefits enormously.

Physical Development

- Hands can be strengthened through shovelling experiences in the sand/mud pit
- Hammering experiences help children develop accuracy in their arm movements
- Pouring activities in water play promote stability and control
- Ball skills including bouncing, catching and throwing promote stability and planning for arm and hand movements. Begin with rolling experiences and substitute a ball with a balloon (to allow for slower movements) or bean bag (may be easier to catch)
- Waving streamers or ribbons through the air promotes shoulder strength
- Obstacle courses encourage skills which enhance strength and co-ordination
- Clapping games and finger plays promote bilateral co-ordination i.e. the ability to use both hands together as does holding a book with one hand and turning pages with the other and lacing and threading experiences
- Sensory experiences including play dough, finger painting etc strengthen hands
- Stickle bricks can be used to develop pulling apart and putting together skills
- Tactile experiences can promote sensory discrimination
- Shape sorters, stacking rings, stacking cups, simple shape puzzles and activity boards all promote dexterity including the skills of grasp and release, pinch and thumb control, wrist movement and finger co-ordination.

Cognitive Development

- Provide experiences that allow for practice in memory, problem solving and gaining new knowledge e.g. memory games, books that ask "where is, how many etc" or ask child for ideas on how to problem solve e.g. "where did we put the Yesterday"
- Provide reminders of sensory information through activities e.g. listening to tape/CD on sounds and asking what the sound reminds you of.
- Practice lots of facial games to strengthen muscles e.g. bubble blowing, making funny faces, looking in the mirror, expressing feelings through the face e.g. show me your sad , happy face etc.

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Language and Communication Development

- Be alert to the child's attempts to communicate and ensure that the environment provides opportunities and time for children to practice and improve these skills
- Respect and understand the communication systems that the child uses including sign and symbol substitutions to augment verbal communication skills
- Child's communication skills may not necessarily reflect their comprehension i.e. the child's level of comprehension is often much higher than the level of expressive language
- Give clear instructions and send clear messages – one at a time
- Use consistency terms for routines e.g. do not interchange little lunch and morning tea – use one or the other
- Provide children with advance warning and prepare them for major changes to the daily routine.

References

- Umansky, W. and Hooper, S. (1998) *Young Children with Special Needs* Third Edition New Jersey, USA:Prentice-Hall
- Deiner, P.L. (1993) *Resources for Teaching Children with Diverse Abilities - Birth through Eight*. Harcourt Brace:
- Brannelly K (2000) *Ideas for inclusion and programming tips*, Book 1 Carata

Websites

<http://www.mydr.com.au/first-aid-self-care/myotonic-dystrophy>

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