ACTIVE LIVING ALLIANCE
FOR CANADIANS WITH A DISABILITY

Helping Canadians with Disability/Chronic Disease Get Physically Active:
Tip Sheets for Intermediaries

For Canadians with a disability, regular physical activity may be even more important than it is for the rest of the population. For a person with a disability, an active lifestyle can open doors to increased health, social inclusion and self-empowerment - doors which might otherwise remain closed. Access to physical activity can eliminate the likelihood of acquiring secondary health conditions like diabetes, high blood pressure or heart disease. Being active builds resiliency and can provide an all-important outlet for a person with a disability.

These tip sheets are designed to provide general information in support of Canada's Physical Activity Guidelines, developed by the Canadian Society for Exercise Physiology.

MUSCULAR DYSTROPHY

General Information

Facts and Figures

- Muscular Dystrophy (MD) refers to a group of muscle disorders where muscles weaken and shrink over time;
- There are a variety of forms of MD, distinguished by factors including age, type of muscle weakness, speed of symptom progression, involvement of other tissues, and the pattern of inheritance;
- All forms of MD are inherited and are associated with a specific gene mutation;
- MD is relatively rare, effecting less than 1 out of 50,000 individuals.

What is Muscular Dystrophy?

Muscular Dystrophy (MD) is a neuromuscular, genetic disorder which causes progressive weakness and wasting of the voluntary muscles that control body movement, notably the arm, leg, face, heart muscles, or spine.

MD affects people of either gender. Some types of MD are first evident in infancy or early childhood, while other types may not appear until late in life.

There are various types of MD which are categorized depending on the primary muscle groups affected, the rate of onset, and the speed of progression of the disorder. The most common type is called Myotonic Muscular Dystrophy.

The cause of MD is not well understood, but is attributed to one of a number of distinct developmental errors in the genes that control muscle function.

There is currently no cure for MD.

Impact of MD
As muscles progressively weaken and atrophy, the body replaces them with fatty and connective tissues. Due to the nature of the disorder:

- Obesity can be very common among people with MD;
- Intellectual disabilities are not uncommon;
- Abnormal functioning of the heart and lungs may occur;
- Deformity of the spine (i.e. scoliosis) is possible;
- Joints may become stiff and lose range of motion, and may develop into contractures (stiffness or restriction in joints, muscles, skin, tendons or ligaments);
- People may experience problems with mobility and coordination, muscle weakness, and frequent falls.

Working with a person who has Muscular Dystrophy
Tips for Getting Active
For a person who has MD, regular and moderate active forms of exercise do no harm, and conversely may have a beneficial psychological effect. This type of exercise is highly recommended for people with MD, in order to preserve their muscle strength. Activities of a recreational nature may be preferred and are more likely to be maintained by the individual.

People with MD fatigue very easily, thus it is important that physical activity leaders are aware of individual limitations. Excessive fatigue can have detrimental effects by actually worsening muscle weakness and atrophy.

When working with a person who has MD, consider the following:

- Make sure you ask and are aware of the type of MD that the person has, and which specific limitations and symptoms are present as a result;
- People with MD usually have a multi-disciplinary team of health care professionals who support them. This will most likely include an occupational therapist and a physiotherapist. Seek permission from the participant to ask these professionals for advice on specific implications and suggestions for physical activity programs.

Teaching and Communication Technique

- Many people with MD have difficulty maintaining posture due to muscle weakness. Enable the participant to play in a supported position (i.e. in a chair);
- Adapt the specific skill or activity so that the participant is not required to move against gravity (i.e. underhand ball toss or roll as opposed to overhand throwing);
- Provide plenty of rest and water breaks (i.e. use interval activities or continuous substitution of participants). Minimize the intensity and length of the activity. Never let the participant get to the point of fatigue;
- Shorten the distance of the play area;
- Avoid activities that are too strenuous on joints. People with MD have extremely low muscle tone, causing certain joints in the body to dislocate

more easily than in others (i.e., especially the shoulder joint). Equipment that does not weigh as much and is easy to grab will help avoid this (i.e. bean bags, ribbons);
- Activities in the water are extremely beneficial for people with MD. Many people with mobility impairments are much more mobile and independent in the water than on land. You can perform strength and endurance activities in the water without causing stress on the joints. Also water tends to have a calming and relaxing effect. Use a variety of floatation devices, like flutter boards and pool noodles, as support to enable the participant to be as independent as possible during activity.

Physical Activity Tips and Modifications

The following are some suggestions for specific activity modifications:

- Have a teammate act as a runner in a game of baseball, if needed;
- Substitute skills; for example throw rather than kick;
- Change the scoring system; for example, award points if the person with MD touches the ball in a game of soccer, rather than requiring them to score;
- Use lighter equipment;
- Lower the nets or move the targets closer;
- Strike a soccer ball with a stick to substitute for kicking;
- Use slower moving objects such as larger lightweight balls, balloons, or deflated balls;
- Have everyone use one hand;
- Have everyone use scooter boards;
- Have an equal number of participants using wheelchairs per side;
- Roll the ball for easier tracking.

Resources:
Muscular Dystrophy Canada - http://muscle.ca/index.html

National Consortium for Physical Education and Recreation for Individuals with Disabilities (1995). Adapted Physical Education National Standards. Champaign, IL: Human Kinetics.

Steadward, R.D., Wheeler, G.D., and Watkinson, E.J. (2003). Adapted Physical Activity. Edmonton, AB: University of Alberta Press.

Healthline: Contracture Deformity: Symptoms, Causes and Prevention - www.healthline.com/health/contracture-deformity

Muscular Dystrophy - Causes, Symptoms, Treatment, Diagnosis - http://bodyandhealth.canada.com/channel_condition_info_details.asp?channel_id=9&disease_id=91&relation_id=10860

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