Physiotherapy Guidelines for Huntington's Disease

Background: Guidelines for physiotherapy in Huntington's disease have recently been published (<u>https://n.neurology.org/content/94/5/217</u>). These guidelines are based on the best available research and give recommendations for treatments physiotherapists should use to help people with Huntington's disease manage their problems with movement and daily activities.

Physiotherapists use a variety of treatments to help people with Huntington's disease perform daily activities with the least amount of help from others. These treatments include education about staying active and how to safely exercise, teaching people to walk and balance better, showing people ways to prevent falls, and advising people about walking devices like canes/sticks and walkers and other equipment. Physiotherapy and exercise are one part of the total care of a person with Huntington's disease, which may include treatment by other health professionals such as neurologists, psychiatrists, speech therapists, occupational therapists, counselors, and social workers.

Role of the Physiotherapist: The physiotherapist will examine people's walking ability, posture, balance, muscle strength, and their ability to take care of themselves and their homes. Physiotherapists conduct examinations to help understand why functional problems occur and to determine the best physiotherapy treatments to meet peoples' unique needs.

When to Contact a Physiotherapist: We suggest that people with Huntington's disease see a physiotherapist soon after they are diagnosed. This will allow the therapist to perform an evaluation and decide which physiotherapy treatments best meet their current needs. Starting an exercise program soon after diagnosis will help people to move and balance better, and to be able to do their daily activities without help from others for as long as possible. The physiotherapist can also help answer questions about how often to exercise as well as the type and amount of exercises. We recommend that people with Huntington's disease see a physiotherapist every 6 months. However, if people with Huntington's disease have trouble walking, getting in and out of chairs or bed, or have stumbles or falls, they may need to see a physiotherapist more frequently to reduce these problems.

Recommendations for Exercise and Physical Activity for people with Huntington's Disease: <u>General Exercise Guidelines:</u>

- a) Try to exercise at least three times a week for 20-30 minutes at a moderate intensity. Moderate intensity means that exercise should feel somewhat hard but not so hard that you cannot have a short conversation with someone. Your therapist can help you to determine the best specific exercises for you.
- b) Try to include exercise as part of your daily routine. Think about moving more and sitting less. Choose a time of day when you feel it is best to exercise. Choose the type of exercise that you like and that fits your physical abilities. Try to include several exercises in your routine. If possible, exercise with others as this may help to motivate you to keep exercising.

Specific Guidelines for Exercise:

- a) Doing moderate intensity aerobic exercise can improve your endurance and ability to move. Aerobic exercises include riding a stationary bicycle or an elliptical machine, going on a brisk walk or run, and walking or running on a treadmill.
- b) Strengthening and resistance exercises or circuit training (i.e., doing different exercises for a few minutes each) added to your exercise routine may help improve your ability to move.
 - Strengthening and resistance exercises may include exercise with resistance bands or weights, and doing exercises such as squats, lunges and step-ups as suggested by a physiotherapist.
- c) Regular walking (with physiotherapist help or done on own) may improve your ability to move.
- d) Practicing transfers (getting in and out of bed or in and out of a chair) may improve your ability get around.
- e) Breathing exercises may improve breathing function and coughing.

Guidelines for Mobility and Positioning Devices:

- a) For people who require help for walking, the physiotherapist may suggest the use of a walker with four wheels (rollator walker) to make walking safer and to reduce the need for help from others.
- b) For people who don't have good posture while sitting, a physiotherapist may suggest the use of special chairs to keep them in a good sitting posture.
- c) For people who don't have a good position in bed or while lying down, the use of positioning devices may be helpful.
 - Examples of positioning devices are wedge cushions, bolsters, pillows and bed railings for positioning in bed.
- d) For people who have muscle stiffness, stretching exercises may help to keep the joints moving through their full range of movement.

Guidelines for Late Stage Care:

- a) We suggest that each family keep in regular contact with their healthcare team to develop the best plan for care to meet the needs of people in the late stage of the disease.
- b) Doing activities that are enjoyable and involve family and friends may help to improve the mood, movement and well-being of people with Huntington's disease.
- c) Modifications to the home or surroundings and keeping good sitting posture are suggested to help people with Huntington's disease do their daily activities.

Clinical recommendations to guide physical therapy practice for Huntington disease. Lori Quinn, Deb Kegelmeyer, Anne Kloos, Ashwini K. Rao, Monica Busse, Nora E. Fritz Neurology Feb 2020, 94 (5) 217-228; DOI: 10.1212/WNL.00000000008887