

## Physical Therapy for Patients with Multiple Hereditary Exostoses

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### INTRODUCTION:

#### *What is Physical Therapy?*

Physical therapy is a profession that specializes in the diagnosis and management of movement dysfunction with the goal of restoring, enhancing, maintaining and promoting not only optimal physical function but optimal wellness, fitness and quality of life as it relates to movement and health. (1)

Physical Therapy can only be performed by a licensed Physical Therapist. Physical Therapists possess specialized training at the post-graduate level and have a license to practice Physical Therapy. Many people who have suffered an injury, disease or disability can benefit from Physical Therapy intervention. People who want to prevent illness and disability can benefit from Physical Therapy as well. (1)

#### *What does a Physical Therapist do?*

A Physical Therapist performs an examination of many systems in the body. These are the cardiovascular system, the neuromuscular system, the musculoskeletal and the integumentary system. The physical therapist looks specifically at how much a joint can move (range of motion) and how strong the muscles of the body are, including the heart. They look at what activities are hindered by pain or loss of motion or strength. Physical Therapists also examine balance, coordination and walking abilities.

After a complete assessment of the information and an interview with the patient, the Physical Therapist develops a plan of care to address any issues that are present. Based on a patient's personal goals, the Physical Therapist will develop a plan of care with specific interventions to help the patient to achieve those goals. Physical Therapists strive to provide patient and family centered care, which recognizes the importance of the patient and their family in the decision making process.

Physical Therapy interventions can include stretching, strengthening, postural and aerobic exercises, functional activities and activities of daily living training. Physical Therapists also educate patients on the importance of wellness and injury prevention.

Physical Therapists work as a team with other health care professionals including physicians, nurses, social workers, occupational therapists, speech therapists, recreational therapists, psychologists, and nutritionists.

## PHYSICAL THERAPY FOR PATIENTS WITH MHE

### *How can Physical Therapy help patients with MHE?*

For patients with Multiple Hereditary Exostoses, Physical Therapy is very important. The physical therapist works together with the orthopedic surgeon to determine the best course of treatment for exostoses.

### *Pre-surgery:*

As described throughout this book, exostoses can be present in any bone of the body. Depending on the location and amount of pain and disability, the orthopedic surgeon may or may not recommend surgery. Prior to surgery, the focus of Physical Therapy is to prevent or slow the loss of range of motion and function that can be caused by exostoses. Conservative treatment of exostoses may include physical modalities for pain relief. Although there is no evidence that exostoses growth can be prevented or slowed with Physical Therapy, the disability associated with the exostoses can sometimes be managed effectively with therapeutic interventions. Flexibility and strengthening exercises have been shown to decrease progressive disability in patients with other musculoskeletal disorders like fibromyalgia and rheumatoid arthritis (1, 2, 3).

Another focus of physical therapy, before and after surgery is required, may be to accommodate some of the deformities that occur as a result of the exostoses. These could include shoe lifts to make lengths of the legs equal, splints to protect joints and cushions to make certain positions more comfortable. Equipment can also be provided to make activities of daily living easier and less painful. These include long handled utensils, brushes, reachers and grippers. Problems with mobility can be addressed with walking aides like canes and crutches.

Additionally, it has been shown that cardiovascular exercise can decrease pain and improve overall well being in patients with musculoskeletal impairments (4, 5, 6).

A supervised exercise program that includes aerobic exercise and strength training may also help to decrease the pain and stiffness associated with MHE. While there are many benefits to exercise, anything that causes increased pain in the area of exostoses should be discontinued and reported to the medical professional.

When the decision to have surgery is made, the patient's individual needs after surgery should be anticipated. Often, patients can be seen for a pre-operative Physical Therapy visit. During this visit, patients can learn how to use some of the equipment that they may need to use after the surgery. Practicing these new skills, like walking with crutches, or moving around with a cast or fixator, can make the patient less apprehensive about the rehabilitation process that will take place after the surgery.

This pre-surgery visit is also beneficial to problem solving obstacles to post-surgery rehabilitation. For example, many patients with painful exostoses under their arms, may not be able to use traditional axillary crutches to maintain decreased weight bearing on their legs after surgery. In this case, forearm crutches or a walker may be more appropriate for the patient. Additionally, a patient who does not demonstrate sufficient endurance may need a wheelchair to use for going outside of the house after surgery.

Similarly, the patient who may have decreased weight-bearing abilities after surgery will need to practice new approaches to everyday activities. These might include going up and down stairs, getting into and out of a car, using the toilet, bathing and going to school or work. The patient and the therapist can simulate these activities and problem solve together, before the surgery, so that they are prepared with successful strategies after the surgery is performed.

### ***Post-surgery:***

If it is determined that surgery is indicated to remove painful exostoses and increase a patient's function, physical therapy is important following surgery. Depending on the surgery, there may be a period of rehabilitation and the potential for a temporary decrease in function due to pain and muscle weakness. The focus of Physical Therapy after surgery is to minimize the pain and maximize the patient's movement potential around the area that the exostoses were removed.

Some patients with MHE may only require a brief hospital stay after removal of exostoses; others may require a rehab stay where more frequent and intense therapy is required. This depends on the location of the surgery, the extent of the surgery, the amount of function that is lost by the exostoses and the patient's prior level of functioning. During rehabilitation, therapy occurs daily and includes specifically stretching and strengthening of the muscles around the area of surgery. If pain and function were limited prior to the surgery, there may be some soft tissue limitations that are present after the surgery that will require special attention.

Based on the evaluation and orthopedic recommendations, weight bearing will be monitored and progressed as directed. In procedures, which include limb lengthening, physical therapy will also address the joints that surround the fixator to prevent further contractures.

Once surgery incisions are healed, a heated pool may be a good environment for therapy. The water's property of buoyancy can decrease the pain that may occur with weight bearing. Aquatic therapy can also provide an environment where muscles can be strengthened in a fun way with swimming.

Once the patient's goals are achieved and intense physical therapy is not required, transition planning will occur and recommendations for the home, work or school and community will be provided. The development of a home exercise program will maintain the gains that have been achieved through surgery and therapy and prevent secondary complications that are due to pain and immobility.

### ***Is Physical Therapy painful?***

Some activities that are performed in Physical Therapy can be uncomfortable because it is hard work. There are things that a therapist can do for their patient to make therapy and exercise more comfortable. Some examples of this are relaxation techniques such as deep breathing and imagery. There are also modalities like heat and ice, which can ease the discomfort caused by exostoses or surgery. Music therapy has been shown to be effective at decreasing pain in patients with other types of chronic pain (7).

***Are there other diagnoses that are associated with MHE and/ or MHE surgery?***

There are some neurological disorders that can be associated with MHE. These include peripheral neuropathy and Complex Regional Pain Syndrome. (9,10,11) Secondary complications from these can also be addressed with Physical Therapy.

In peripheral neuropathy, the nerves that control the muscles are damaged due to being compressed by exostoses. This leads to a loss of nerve conduction to the muscle and resulting weakness in that muscle. It can affect the motor part of the nerve or the sensory part of the nerve. Impairment can range from slight to complete. Because the nerves are not central to the nervous system, they can regenerate once the compression is relieved surgically. This is, however, a slow process. Physical Therapy can address this with strengthening exercises and bracing, while the nerves to the muscles are healing. (9,10)

Complex Regional Pain Syndrome, type I, (also known as reflex neurovascular or sympathetic dystrophy or reflex sympathetic dystrophy (“RSD”)) is a common condition characterized by extreme limb pain associated with autonomic dysfunction. This condition is associated with mild trauma to an extremity, as in the case of a painful exostoses or surgical removal of exostoses.

In this situation, there can be temperature, hypersensitivity, and trophic changes to the effected extremity. Treatment of this disorder in adults ranges from medications, surgical sympathetic nervous system blocks and psychotherapy. In children, studies show the symptoms of this condition can be controlled with physical and occupational therapy.

Treatment for this includes de-sensitization techniques where various textures are applied to the affected area for prolonged periods of time. This usually begins with very light touching with cotton and progresses to different textures, such as cloth and brushes. Weight bearing activities are also essential to retraining the sensory system. Progressing weight bearing to the patient’s tolerance is an important part of treatment. If the patient’s surgical procedure initially prohibits weight bearing, other activities will have to be improvised in the interim. Exercise is also an integral part of treatment for complex regional pain syndrome and has been shown to be an effective treatment for this chronic pain disorder without the use of medications. (11)

***Is it safe for patients with MHE to participate in sports and recreation?***

Fitness and well-being is important for everyone, including the patient with MHE. Every opportunity for continuing exercise in a supervised manner should be encouraged. It may be advisable for schools to provide parents with a detailed physical education curriculum that can be reviewed by the child’s orthopedist. Sports and physical education can often be safe to participate in with a doctor’s approval as long as the patient is being monitored by the orthopedic surgeon and physical therapist. Non-contact sports like swimming, cycling, dancing, tai chi, yoga and "Pilates" can be safe and fun forms of exercise for some patients with MHE. However, it is important to remember that MHE affects patients differently and specific sports and activities may not be appropriate choices for people whose mobility is blocked by pelvic, hip and leg exostoses. In addition, if a child with MHE experiences pain while participating in sports or PE activities, the child should not be pushed to continue that activity and medical advice should be sought.

Some people with MHE tire very easily when doing physical activity. In addition to blocking certain movements, exostoses put significant pressure on vital structures, causing fatigue. Some children are unable to participate in their school's physical education class. In these cases, there are federal laws under the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA), which entitle these patients to adaptations and accommodations and prohibit discrimination based on physical disability. Physical Therapists can work with schools to adapt physical education classes or provide alternative activities in order to meet the curriculum's health and physical education requirement. Some families have reported that certain school districts have tried to impose an alternative PE curriculum consisting of a series of written reports on PE-related topics every week. When working with patients suffering from chronic fatigue it is important to remember that this type of extra work, particularly when the child is affected by hand and wrist exostoses, exacerbates fatigue and worsens, rather than remedies, the situation. In some cases where fatigue is severe and participating in PE or complying with standard alternatives are not an option, physical therapy exercises (whether performed at a physical therapy center or as part of a home program), can be used to meet State physical therapy requirements.

Physical Fitness is an individualized concept. There are many types of activities that can be beneficial even if a person with MHE cannot participate in competitive or recreational sports due to fatigue or mobility impairments. Options for fitness include adapted wheelchair sports, seated aerobics and dance, and water aerobics. Physical Therapists can work with patients to determine their optimal activity level and options for fitness and well-being. It is important to remember that the main goal is to have the child function as much as possible in a normal school setting, and that for some students walking to and from classes, sitting through classes, and keeping up with their studies constitutes physical activity.

## **CONCLUSION:**

An overview of Physical Therapy has been provided; however, each patient is individual and not all Physical Therapy interventions are indicated for all patients. All Physical Therapy should be patient and family centered in its approach. This is very important with MHE, due to the hereditary nature. Exercise and fitness can be a family event and something that they can share to benefit each other.

## **References:**

- (1) **Guide to Physical Therapy Practice.** 2<sup>nd</sup> edition. **Physical Therapy:** 2001; 81:9 744.
- (2) Anthony KK, Schanberg LE. **Juvenile Primary Fibromyalgia Syndrome.** *Curr Rheumatol Report.*2001 Apr;3(2):165-71.
- (3) Klepper SE **Effects Of An Eight-Week Physical Conditioning Program On Disease Signs And Symptoms In Children With Chronic Arthritis.** *Arthritis Care Res.* 1999 Feb;12 (1): 52-62.
- (4) Han A, Robinson V, Judd M, Taixiang W, Wells G, Tugwell P. **Tai Chi For Treating Rheumatoid Arthritis.** *Cochrane Database Syst rev.* 2004; (3): CD004849H

- (5) Frost, JA Klaber Moffett, JS Mose, JCT Fairbank, **Randomised Controlled Trial For Evaluation Of Fitness Programme For Chronic Low Back Pain.** BMJ 1995; 310: 151-154 (21 January)
- (6) Varju C, Kutas R, Petho E, Czirjak L. **Role Of Physiotherapy In The Rehabilitation Of Patients With Idiopathic Inflammatory Myopathies.** Orv Hetil. 2004 Jan 4; 145 (1) 25-30.
- (7) Stanton-Hicks M, Baron R, Boas R, Gordh T, Harden N, Hendler N, Koltzenburg M, Raj P, Wilder R. **Complex Regional Pain Syndromes: Guidelines For Therapy.** Clin J Pain. 1998 Jun; 14 (2): 155-66.
- (8) Standley JM, Hanser SB. **Music Therapy Research and Applications in Pediatric Oncology Treatment.** J Pediatric Oncol Nurs. 1995 Jan; 12 (1):3-8.
- (9) Paik NJ, Han TR, Lim SJ. **Multiple peripheral nerve compressions related to malignantly transformed hereditary multiple exostoses.** Muscle Nerve. 2000 Aug;23(8):1290-4.
- (10) Levin KH, Wilbourn AJ, Jones HR Jr. **Childhood peroneal neuropathy from bone tumors.** Pediatr Neurol. 1991 Jul-Aug;7(4):308-9.
- (11) Sherry D, Wallace C, Kelley C, Kidder M and Sapp. **Short and Long term Outcomes of Children with Complex Regional Pain Syndrome type I Treated with Exercise Therapy.** J Clinical Pain. 1999 15 (3): 218-223.

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