



PHYSICAL THERAPY FOR CHILDREN WITH MPS AND RELATED DISEASES INFORMATION FOR PARENTS

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PURPOSE

Children diagnosed with MPS and related diseases have a wide range of medical complications, skeletal limitations and cognitive changes that impact fine and gross motor functions. This fact sheet is intended to be a general guide regarding securing and implementing physical therapy services that can be individualized to each patient according to the specific need.

Children diagnosed with MPS and related disease should be referred for a comprehensive physical therapy evaluation as soon as possible post diagnosis. A referral to a physical therapist can be facilitated by a primary care physician and/or an eligible program assisting individuals with disabilities (e.g., Regional Center, California Children Services, etc.) A comprehensive record should be compiled by the parent or guardian which includes neurological evaluations, developmental assessments, skeletal films and orthopaedic reports with specific attention to any contraindications for physical therapy.

WHAT TO EXPECT?

A comprehensive PT evaluation can take from 2 to 4 hours and should include a review of medical and developmental history with a focus on presently observed functional impairment (problem areas). Observations of sitting, standing, bending, walking, jumping, climbing and other gross motor movements will be made. Measurements will be taken to determine flexibility and range of motion of fingers, arms and legs. Upon completion of the assessment with an integration of results from other professionals the physical therapist will meet with you to explain the observed results and develop a working treatment plan.

TREATMENT

Physical therapists utilize a variety of different techniques depending on the age, ability and need of patient. The younger patient may be encouraged to reach, jump, lift, climb in the context of a play environment to stretch muscles for the purpose of maintaining flexibility and range of motion. Parents and caregivers may be trained in how to incorporate similar kinds of activities in the home and school environments.

Exercises and treatment goals should be reviewed and updated frequently as the child gains or loses skills. Physical therapist may also recommend nighttime or rest time splints for stretching and or daytime orthotics or braces to improve leg alignment. Children who have more involved needs may be assessed for adaptive equipment such as wheelchairs, special car seats, bath chairs, hand splint,

adaptive eating utensils, etc. In many cases physical therapists will collaborate with other professionals such as occupational therapist, speech therapist and adaptive equipment providers in order to meet the full range of needs for a given child. The frequency of physical therapy services will depend on the results of the therapists evaluation, the child and medical course.

As a general guide, children who are working on maintaining skills or improving functional abilities may receive physical therapy 1-2 times per week along with a home exercise program. Children who have received a HSCT or are receiving ERT may benefit from more intensive therapy, such as 2-3 times per week, capitalize on their potential for skeletal changes and improving movement patterns. Alternative and creative ways of building physical activity involving gross motor skills like gymnastics improve the enjoyment for the child who requires frequent formal interventions.

The goal of physical therapy is to maximize each child's functional abilities and motor skills. Physical therapy will not cure MPS and will not stop the progression of the diseases. However, physical therapy may help a child maintain their functional abilities longer as the disorder progresses or help them gain new skills after medical interventions.

In summary, physical therapy is a vital component of the care of the child with MPS and related diseases. Physical therapist should work with families to develop goals, conduct therapeutic interventions and provide home exercise programs to maximize each child's functional abilities and independence.