A child born with lymphedema has a life-long medical problem that concerns the entire family. Primary lymphedema has been classified as aplastic (defective development or congenital absence of a tissue or organ), hyperplastic (an increase in the number of cells in the tissue or organ), or hypoplastic (decrease in the number of cells). There can be widespread lymphatic abnormalities, including in-testinal lymphangiectasia and other visceral anomalies. Rarer forms may be hereditary.

A complete and expert physician assessment is necessary to identify all medical issues at hand. A thorough medical evaluation should include precise definition of the specific lymphatic disturbance and associated abnormalities, family history, and appropriate treatment of other medical illness. Consultation by a dysmorphologist (one who studies the abnormal development of tissue form) may be indicated and genetic counseling helpful.

We at HealthSouth Rehabilitation Institute of Tucson are fortunate to have the resources of two renowned lymphologists, Dr. Marlys Witte and Dr. Charles Witte. They are located at the University of Arizona Health Sciences Center and have been involved with research and diagnosis of lymphatic disorders for more than 30 years.

It is advisable to start physician-directed therapy as soon as possible after the medical work-up is complete. Traditionally, after intensive therapy, follow-through with the home maintenance program falls to the responsibility of the parents or other adult family members. The therapist following this traditional approach may thereby focus the education and training component of the treatment program on the adult, missing the most important member of the team — the child.

This pattern of parental responsibility can continue through preteen years, making it more difficult for the older child to be able to follow through on his or her own. Responsibility for the home maintenance program should be taught to the child in accordance with chronological and psycho-social guidelines. Early introduction of management of the lymphedema condition with activities of daily living, the child should be better able to continue with a maintenance program through adult years.

The development of intervention strategies for pediatric lymphedema patients and their families should be based on human development. This includes the physical development, cognitive development and the environmental or social development. The child's ability to adjust his performance in accordance to the environment, his adapting skills, also play a role in how the program should be designed.

The newborn's responses are reflexive. As learning experiences continue and the neurological development progresses, the child becomes a participant in the activities around her. Each new learning experience sets the foundation, the "building blocks," for the higher level functions that are to come. These "building blocks" are learned in a somewhat predictable order.

A child's play is his work. Therefore it is recommended that education and training for the pediatric lymphedema patient be approached in a matter-of-fact manner. Not every child masters skills at the same rate of learning. Remember that since new learning experiences set the foundation for more complex functions, the child must master the more basic tasks first to be successful with future ones.

Between the ages of seven and ten months a child will be reaching purposely and engaging in hand games such as peek-a-boo and clapping. The therapist and parent can begin to teach the child the home program protocols by doing hand-over-hand manual lymph drainage. This should be only one to two sequences at the beginning. By the age of 10 months this can be increased to three or four sequences of manual lymph drainage.

Between the ages of 12 months and 18 months the child begins to assist with dressing, taking off clothes and following two step commands. The child's home program involvement can include helping to set up the bandages for the multi-layered compression wrap, taking off bandaging, and starting to do one sequence of manual lymph drainage with minimal assist.

Between two and three years of age the child is taking more responsibility for personal self-care and can be included in more activities with the home program. This might include starting to put supplies away with verbal cuing, beginning backward chaining with application of bandages, and knowing the sequence of the home program protocols. Remember, this is the traditional "TERRIBLE TWOS" and the therapist and parent can expect resistance to participation in the home program. Again, approach in a matter-of-fact manner with no more (or less) expectations than having the child dress or put on pajamas at night.

Between three and four years of age the child should be participating in some fine motor tasks such as managing zippers, tying shoe laces and cutting a line with scissors. Backward chaining for multi-layered compression bandaging can be accomplished from the ankle. Manual lymph drainage can be done with distant supervision and occasional assist. Some children could be donning the compression garment by themselves at this age.

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Enigma of Exercise... Cont.

but it also positively impacts the lymphatic system. Prior research has shown that muscle contraction performed while the limb is bandaged increases protein reabsorption and enhances lymphatic flow (9). Therefore, at BCPTC, the women wear compression bandages during exercise to help enhance the muscle pump force on the lymphatic system and to help prevent excess filtration into the tissues of the arm during activity. Bandages are also worn during their home exercise program.

The weight training component progresses gradually, lifting very light weights (1-2 lbs.) at the onset and carefully monitoring the limb’s response. All muscle groups of the arm are used with emphasis on the muscles of the shoulder and elbow.

The number of repetitions for each exercise is also a factor for careful consideration — lymphedema can be worsened by too much weight or too many repetitions. Most women progress themselves to three sets of ten repetitions with each activity. Again, the limb must be used as a barometer of response to treatment. Some individuals may be able to do more, some less. Regardless, each individual lymphedema patient must be aware of what level of weight and repetitions is appropriate for her/his arm (yes, there are men who have developed breast cancer and lymphedema in the upper limb).

Aerobic activities can also be used to enhance lymphatic flow in the breast cancer lymphedema patient. Physiologically, with each breath we take there is a suction force on our lymphatic system which increases lymphatic uptake (1,2). Aerobic cross-training, performed with the limb bandaged, may be a way to vicariously strengthen the lymphatic system while strengthening the cardio-respiratory system. Many women who have undergone treatment for breast cancer complain of fatigue which lasts long after treatment for cancer has ended. It has been shown that the cardio-respiratory capacity of the cancer patient is greatly diminished after treatment (9). Furthermore, it has been demonstrated that women with breast cancer who perform cardio-respiratory exercise during treatment are able to combat some of the deleterious effects of cancer treatment on their cardio-respiratory system (10).

The development of an effective and safe exercise program for the individual who has had an axillary dissection requires a basic understanding of the physiology of normal lymphatics as well as the pathophysiology of breast cancer lymphedema. Post-operative flexibility exercises, weight training, and aerobic activities can be undertaken to help enhance lymphatic flow.

Regardless of whether or not lymphedema is present, following the guidelines as outlined previously allows the individual who has had an axillary dissection to return to normal activity gradually without an over-riding fear of precipitating or exacerbating the edema.

For information about Linda T. Miller’s Exercise Booklet, please write to: BCPTC, 1905 Spruce St., Philadelphia, PA 19103.

REFERENCES


Linda T. Miller is a Physical Therapist and Clinical Director of the Breast Cancer Physical Therapy Center in Philadelphia, PA. She also serves on the Medical Advisory Board of the National Lymphedema Network and presented a workshop on Rehabilitation Exercises at the second NLN conference this past September.