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# Exercise and Activity: Key Elements in the Management of OI

Osteogenesis imperfecta (OI) is a connective tissue disorder characterized by fragile bones, weak muscles, and loose ligaments. Bone problems can include bowing of the long bones, scoliosis (curvature of the spine), a barrel chest, and joint problems. Varying degrees of short stature and decreased muscle mass and strength also may be present.

Not so long ago, parents were advised to “protect” their children with this disorder by carrying them on pillows and avoiding recreational activities. But this well-intentioned approach did not protect children from fractures (broken bones) and may have hindered their development and achievement of independent functioning.

Bone growth depends on muscle pull as well as loading (weight bearing) through standing, walking, and lifting. Immobilization may result in loss of muscle and skeletal mass. It can take as long as a year to restore this bone mass following a relatively short period of immobilization. Over the years, it has become clear that physical activity is an important part of managing OI in both children and adults.

Research indicates that physical activity is important because it promotes:

- general health through
  - cardiovascular fitness
  - mental alertness
  - weight control
  - improved sleep quality
  - improved ability to handle infection
  - reduced risk for some cancers
- maximum bone density

- optimal physical function to support independence in daily activities
- optimal psychological and social well-being by improving self-confidence and the ability to interact socially with peers.

Children and adults with OI will benefit from a regular program of physical activity to promote optimal function through muscle strengthening, aerobic exercise, and recreational pursuits. Specifics of the exercise program vary depending on the person's age, level of function, severity of OI, and needs and desires. A well-designed program can combine activities to prevent problems as well as to restore function.

Activity programs may include specific exercises recommended by rehabilitation professionals (physiatrists, physical therapists, occupational therapists, and recreation therapists) as well as sports and other recreational activities. Having fun and feeling a sense of accomplishment are legitimate goals for an exercise program. In addition, diet, weight control, and commitment to a healthy lifestyle are essential to longevity and an improved quality of life.

The optimal long-term goal for children with OI is good health and independence in all areas of function (social, educational, self-care, locomotion, and recreation), using adaptive devices as needed. Goals for adults with OI include maintaining independence, preserving bone density, and supporting cardiovascular function. To achieve these goals, it is often necessary to improve muscle strength and body alignment.

## **When to Begin**

The first year of life includes many motor skill transitions and is a critical window of opportunity for babies who are born with muscle weakness, alignment problems, and fragility. Physical therapy should begin as soon as the infant exhibits weakness or motor skill delays when compared with other infants of the same age. This might be first noticed because the baby cannot hold up his or her head independently or sit without support until later than most other children.

Treatments for such problems are often aimed at proper positioning and placing children in positions that encourage their use of certain muscle groups. Proper positioning elicits specific antigravity muscular effort, which is the basis for learning to sit and, later on, stand. Babies with large heads will face additional challenges and limitations in developing the ability to move against gravity.

An infant or child with weakness or motor skill delays should be working for brief periods daily or at least 5 days a week to improve muscle strength and motor skills. In the process, the child gains endurance and independence in self-care activities. Treatment should not be confined to "therapy hours" only. Very short

exercise efforts during the day, as short as 5 minutes, will often result in improvement more quickly than an hour-long session once or twice a week.

Depending on the child's age, the interventions can take several forms, including positioning, specific exercises, and developmental activities (such as standing in a standing device). Ideally, family members and care providers would integrate the activities naturally into the child's day. Playtime can be purposeful, but it should still be fun for both the parent and the child.

Children with OI can excel in the water, particularly if the activity is presented as an opportunity for recreation and independent exploration, rather than a demand to exercise. Water exercise can begin during infancy, with the child lying on his or back in 2 to 3 inches of warm water to promote independent kicking. Over time, the child can progress to independent activity in the water, first in a swim vest or other support, then swimming without support. Walking in the water may be possible for individuals who are unable to walk outside the pool. Water activities in childhood can be the foundation for a lifelong, enjoyable fitness activity.

Adults with OI can benefit from water activity as well. It is an excellent form of aerobic conditioning and may have some benefit with respect to strengthening. Because water activities do little to promote bone health, however, adults also should try to add walking or other weight-bearing exercise to their physical activity program.

## **Safety**

People of any age who have OI can safely exercise. Obstacles to consider when evaluating an activity include prior fracture history, degree of bending of long bones, degree of muscle weakness, joint stiffness or laxity (looseness), joint alignment, poor exercise tolerance, and lack of stamina. Inability to accomplish daily activities without specialized equipment also can affect which activities can be done safely. For example, long-term sitting in a wheelchair may be associated with hip flexion contractures and compensatory back curvatures, which often are associated with back pain, joint stiffness, osteoporosis, and obesity. A safe physical activity program would include getting out of the chair and changing body positions at least every 2 hours when possible.

People who have OI should avoid some activities. These include jumping, diving, and contact sports as well as activities that promote falls, abrupt joint compressions, or high rotary (twisting) forces on bones.

## **Steps for Developing a Successful Exercise Program at Any Age**

1. Determine the person's capabilities by asking: "What can the child or adult do?"
2. Determine the goal you want to pursue by asking: "What is the child or adult trying to achieve?"
3. Determine the constraints or limitations to achieving the goal by asking: "Is limited range of motion, strength, alignment, or joint instability preventing successful performance?" These limitations may have to be addressed before the goal can be accomplished, perhaps by modifying the exercise program.
4. Determine which equipment or treatments are available to help accomplish the goal. A wide range of devices can support improved function. Examples include bathroom safety equipment, walking aids, and devices for reaching objects in high or low places. A consultation with an occupational therapist may be necessary to help choose the best devices to accomplish a specific goal.

## **It's Never Too Late to Begin**

Adults and older children who do not exercise are encouraged to make a new commitment to a healthy lifestyle and become more physically active. They should include enjoyable exercises that will improve strength, balance, and endurance and, if possible, promote socialization. Rehabilitation specialists or exercise specialists who are familiar with OI or osteoporosis can help design an appropriate program. Enjoyment plus improved function can be found through physical activity at every age.

## **Resources**

More detailed information about implementing an exercise and physical activity program for people with OI can be found in *Therapeutic Strategies for Osteogenesis Imperfecta: A Guide for Physical and Occupational Therapists*. To receive a copy of this publication, visit the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center Web site at [www.niams.nih.gov/bone](http://www.niams.nih.gov/bone) or call 800-624-BONE (free of charge).

For more information on osteogenesis imperfecta, visit the Osteogenesis Imperfecta Foundation Web site at [www.oif.org](http://www.oif.org) or call 800-891-BONE (free of charge) or 301-947-0083.

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