

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

### Introduction

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

Not so long ago, parents were advised to “protect” children who have OI by carrying them on pillows and avoiding recreational activities. This well-intentioned approach did not protect children from fractures (broken bones), and may have hindered development and achievement of independent functioning. Bone growth depends on muscle pull as well as loading or weight bearing through standing, walking and lifting. Immobilization may result in loss of muscle and skeletal mass. It may take as long as a year to restore 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 gaining 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 it is evident that the infant has 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 possibly not sit without support until later than most other children.

Treatments for such problems are often aimed at proper positioning, and placing children in a position to encourage their use of certain muscle groups. Proper positioning elicits specific antigravity muscular effort, which is the basis for learning to sit and stand later on. 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 five days a week to improve muscle strength and motor skills such as coordination and balance. 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 five 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 will take several forms including positioning, specific exercises, and developmental activities such as standing in a standing device. Ideally, the activities are integrated naturally into the child’s day by family members and care providers. Playtime can be purposeful, but it should still be fun for parent and child.

Children with OI can excel in the water, particularly if it is presented as an opportunity for recreation and independent exploration, rather than a situation where an adult places demands on the child to exercise. Water exercise can begin during infancy with backlying 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. Waterwalking may be possible for individuals who are not able 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 should also 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, degrees of bending of long bones, degree of muscle weakness, joint stiffness or laxity (looseness), joint alignment, poor exercise tolerance, and stamina. Inability to accomplish daily activities without specialized equipment can also affect which activities can be done safely. For instance, long-term sitting in a wheelchair may be associated with hip flexion contractures and compensatory back curvatures, often 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 objective 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 program itself.
4. Determine which equipment or treatments are available to help accomplish the goal. A wide range of devices exist to 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 have the exercise habit are encouraged to make a new commitment to a healthy lifestyle and become more physically active. Each person’s program should include exercises that will improve strength, balance, and endurance; be enjoyable; and promote socialization, if possible. 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.

*The OI Foundation acknowledges the assistance of  
Lynn Gerber, M.D. and Holly Cintas, PT, Ph.D.  
in the preparation of this publication.*

The National Institutes of Health  
Osteoporosis and Related Bone Diseases ~ National Resource Center  
assisted in the preparation of this publication.  
Revised August 2005