Why is Exercise Important?

Not so long ago, parents were advised to “protect” their children who have OI by transporting them on pillows and avoiding recreational activities. However, this well-intentioned approach did not protect children from fractures, and may have hindered development and achievement of independent functioning.

Why is the “conventional wisdom” changing?
Bone growth depends on muscle pull, as well as “loading” or weight-bearing through standing, walking and lifting. Research has proven that immobilization may result in a loss of muscle and skeletal mass. It may take as long as a year to restore 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. Diet, weight control and a commitment to a healthy lifestyle are also essential to longevity and an improved quality of life.

How does physical activity help?
Research indicates that physical activity is important for the following reasons:

• Promotion of improved general health through
  • cardiovascular fitness
  • mental alertness
  • weight control
  • improved sleep quality
  • improved ability to handle infection
  • reduced risk of cancer
• Promotion of maximum bone density
• Promotion of optimal physical function to support independence in daily activities
• Promotion of optimal psychological and social well-being by improving self-confidence and the ability to interact socially with peers.

What should my fitness goals be?
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 include maintaining independence, preserving bone density and supporting cardiovascular function. To achieve these goals, it is often necessary to improve muscle fitness and body alignment.

Specifics of the exercise program vary depending on the individual’s age, level of function, severity of OI, and needs and desires. Activity programs may include exercises recommended by rehabilitation professionals as well as sports and other recreational activities.

When should I begin a fitness program?
The first year of life includes many motor skill transitions and is a critical window of opportunity for babies who are born with weakness, alignment abnormalities and fragility. Physical therapy should begin as soon as it is evident that the infant has weakness or motor skill delay when compared to same-age children. Children with OI can excel in the aquatic environment, particularly if it is presented as an opportu-

Information contained in this Q&A is excerpted from the fact sheet “Exercise and Activity: Key Elements in the Management of OI”.

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Exercising

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nity for recreation and independent exploration, rather than as a situation where an adult places demands on a child to exercise.

Adults with OI can benefit from aquatic activity, as well. It is an excellent form of aerobic conditioning, and may impart some benefit with respect to strengthening. For promotion of skeletal health adults should also try to add walking or other exercises that will increase bone-loading. Adults and older children who do not have the exercise habit should be encouraged to make a new commitment to a healthy lifestyle and become more physically active. Their 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.

Isn’t exercise dangerous for people with OI?
Exercise can be done safely by people of any age who have OI. Obstacles to performance to consider when evaluating an activity include prior fracture history, degree of bending in long bones, degree of muscle weakness, joint stiffness or laxity, joint alignment, poor exercise tolerance and stamina. For instance, long-term sitting in a wheelchair may be associated with back pain and joint stiffness. A safe exercise activity could be as simple as getting out of the chair and changing body positions at least once every two hours.

People with OI should avoid some activities, including jumping, diving, contact sports and activities that might promote falls, abrupt joint compressions or high twisting forces on bones.

Where do I start?
ALWAYS begin by discussing your goals with a qualified medical professional familiar with your or your child’s medical history. One strategy for developing a successful exercise program at any age is:

- Determine the person’s capabilities.
  - Ask “What can the child/adult do?”
- Determine the objective you want to pursue.
  - Ask “What is the child/adult trying to achieve?”
- Determine the constraints or limitations to achieving the goal or objective.
  - Ask “Is limited range of motion, strength, alignment or joint instability preventing successful performance?” These issues may need to be addressed before the goal can be accomplished, or incorporated into a program that maximizes reduction of the limitations.
- Determine which compensations or aids are available to help accomplish the goal.
  - A very wide variety of devices exist to support improved function. Examples include bathroom safety equipment, ambulation aids, reachers, and floatation devices. A consultation with an occupational therapist might be necessary to help choose the best devices to accomplish a specific goal.

Where can I find more information?
The OI Foundation has a variety of materials and fact sheets related to exercise and physical activity, including the fact sheet this article is based on, the booklet Therapeutic Strategies and the Growing Up with OI book set. These resources can be requested through Info On Demand (see sidebar). The Foundation will publish Children with OI: Strategies to Enhance Performance, a 270-page book dedicated to this subject, in the fall of 2005. To be notified by email when the book is available, register on www.oif.org by clicking on the Get Connected button. [OI]

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The OI Foundation information and resource staff responds to more than 500 inquiries each month from the OI Community. Every question, whether it’s received by mail, phone or email, gets an individual response with medically verified information. There is simply no better place to go to have your questions about OI answered.

Each quarter, we select one question relevant to the entire OI community and print a full response in Breakthrough as our Q&A.

Each month, we select either the most frequently asked question, or a question on a topic that is “timely” or “seasonal,” and answer it in our monthly email newsletter. (Register online at www.oif.org to receive the email newsletter.)

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