Nutrition and OI

Introduction
To promote bone development and optimal health, children and adults with osteogenesis imperfecta (OI) should eat a balanced diet, which is low in fat, salt and added sugar and contains a variety of vitamins and minerals. Excessive weight gain should be avoided. Depending on the severity of OI, body size, and activity level, it may be necessary to reduce portion size, meal frequency, and total caloric intake to reach a healthy balance.

Finding a healthy balance between calorie intake and exercise can be difficult. Complicating factors for people with OI can include:
- Small body size
- Limited mobility
- Low appetite
- Dentinogenesis imperfecta (DI)

Because OI is a genetic disorder of collagen, and not a calcium or nutrient deficiency, there are no foods or supplements that will cure OI.

Nutrition Related Problems

Difficulties eating solid food have been identified as a problem for some children with OI. Swallowing studies are useful for evaluating eating problems in infants and children. Dentinogenesis imperfecta (DI), decreased muscle strength and tongue control can make it difficult to transition from a diet based on milk or formula and pureed foods into eating solid foods. A food program designed by a clinical nutritionist or an oral motor therapist may be necessary to introduce a variety of food textures into the child’s diet.

Failure to thrive is occasionally raised as a concern for infants with OI. Physicians and parents are cautioned to carefully evaluate the situation because many infants who have OI are unusually small, and do not grow at the normal rate. Some infants have difficulty eating due to respiratory problems or gastric reflux. Swallowing studies may provide information to guide treatment.

Malnutrition has been identified in some children and adults with OI. It is caused by low caloric intake, difficulties eating solid food, and a decreased appetite. Children and adults who suffer from chronic pain, or who recently have had surgery, may have very small appetites. In these situations it is important to obtain adequate nutrition and hydration.

Obesity is a serious issue for some children and adults with OI. Lack of physical activity, small body size and a diet high in fat, salt and calories can quickly cause a person to be overweight. Extra weight can impede mobility, put additional stress on weak bones, and increase the risk of other health problems such as diabetes and high blood pressure.

Weight Control
Strategies for maintaining a healthy weight include:
- Eat low-fat, high-nutrient foods,
- Control portion size,
- Exercise as much as safely possible,
- Consult with a registered dietitian or nutritionist about food choices, and how to limit portion size without missing out on important nutrients,
- Consult with a doctor or physical therapist about increasing physically activity.
Calcium and Bone Health
Calcium does not improve the basic collagen defects that cause OI. Even so, people with OI need to get adequate calcium in their diets to develop peak bone mass and prevent bone loss. In 1997, the National Academy of Sciences developed the following Recommended Dietary Intake for calcium:

- Young children (1-3) 500 mg a day
- Older children (4-8) 800 mg a day
- Preteens/adolescents (9-18) 1,300 mg a day
- Men and women (19-50) 1,000 mg a day
- Men and women (50+) 1,200 mg a day

These guidelines were developed for people of average height and weight. A person with OI may have lower calcium needs. It is recommended that people with OI, particularly if physician and/or registered dietitian about their individual calcium needs. A measurement of calcium in a 24-hour urine collection may help determine if a person with OI is getting too much or too little calcium.

Calcium supplements are also sometimes recommended for people taking certain medications such as bisphosphonates. Check with your doctor to determine if a supplement is necessary.

Low-fat and skim milk have the same amount of calcium as whole milk, but significantly fewer calories. In addition to dairy products, calcium is also found in foods such as broccoli, kale, some dried beans and nuts and soy-based products. Manufacturers are increasingly fortifying other foods.

Vitamin D and Bone Health
Vitamin D is necessary to help the body absorb calcium and make bone. Most of the vitamin D in our bodies is made from sunlight absorbed through the skin. Vitamin D is also found in fortified foods and in dietary supplements in the form called D-3. A blood test that measures 25(OH)D is the only way to tell if a person has adequate levels of Vitamin D in their system. The amount of vitamin D in food or supplements is measured in terms of International Units (IU). Children and adults who take a bone building drug often need a supplement.

Vitamin C
Vitamin C has many functions in the body, including the production of healthy connective tissues, and the healing of wounds and fractures. Vitamin C is abundant in many fruits (such as citrus fruits, strawberries, and cantaloupe) and vegetables (including tomato, bell peppers, and sweet potato). It is fairly easy to get adequate Vitamin C through the diet.

Guidelines for a Healthy Diet
The U.S. Department of Agriculture has developed a Food Guide Pyramid to help people make healthy daily food choices (www.MyPyramid.gov). The pyramid offers guidelines for the daily number of servings for each of six food groups:

- Bread, cereal, rice and pasta
- Vegetables
- Fruit
- Milk, yogurt and cheese
- Meat, poultry, fish, dry beans, eggs and nuts
- Fats, oils and sweets.

Beverage recommendations stress the need for water every day. Fruit juices should make up only one of the fruit servings per day. Sodas (carbonated beverages) should be limited because they replace milk or water and are usually high in sugar and salt. The phosphorus in sodas also decreases calcium absorption.

It is important to remember that this pyramid was developed for people of average body size and activity level. Children and adults with OI can get guidance from their physician or a dietitian regarding the appropriate number of daily servings for their body size and activity level.

The OI Foundation prepared this fact sheet with assistance from Jay Shapiro, MD and Eileen McMahon RD.

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