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The Osteogenesis Imperfecta Foundation, Inc. is the only voluntary national health organization dedicated to helping people cope with the problems associated with osteogenesis imperfecta. The Foundation's mission is to improve the quality of life for people affected by OI through research to find treatments and a cure, education, awareness, and mutual support.

# 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

**Constipation** is a problem for some people with OI. Pelvic asymmetry, seen in people with more severe OI, is associated with a tendency to have constipation. A high-fiber diet, drinking plenty of water and other fluids and physical activity may help remedy this problem. A physician should monitor chronic constipation. In some cases, it can result in serious complications. For more detailed information see the OI Foundation fact sheet "OI Issues: Constipation".

**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. Body mass index (BMI)--the ratio of weight to height—is frequently used to determine if a person is at a healthy weight. A BMI of 25 is considered overweight. People with OI who are shorter than average or who have rods tend to have a BMI in the 26-27 range, a score that would indicate overweight in others. For more information or to calculate your BMI visit the Center for Disease Control web site, [www.cdc.gov](http://www.cdc.gov).

### **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. Bone loss from any cause (calcium related, inactivity related, age related) makes OI bones even more fragile. 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

they are much smaller than average, or have a family history of kidney stones talk to a 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.

If you are unable to get the appropriate amount of calcium for your body size and age through your diet, a calcium supplement may be needed. 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, such as cereal and bread, with calcium. Most brands of calcium fortified orange juice have the same amount of calcium as milk.

## **Vitamin D and Bone Health**

Vitamin D is necessary to help the body absorb calcium and make bone. New research suggests that it may play a role in the immune system, and that low levels may contribute to chronic pain. Most of the vitamin D in our bodies is made from sunlight absorbed through the skin. Vitamin D is also found in many 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. Researchers recently began recommending that blood levels of vitamin D for children and adults on this test should be increased from a previous recommended level of 20 ng/ml to between 32 and 70 ng/ml. Studies suggest that many people have low vitamin D levels, especially in the winter.

The amount of vitamin D in food or supplements is measured in terms of International Units (IU). The latest research supports the following guidelines for vitamin D for people with OI. See **Note: Vitamin D Research** in the Resources section for more information.

### **Suggested Vitamin D-3 Intake for People with OI:**

<b>Weight</b>	<b>IU per day</b>
50 lbs. (20 kg)	600-800
90 lbs. (40 kg)	1100-1600
110 lbs. (50 kg)	1200-2000
150 lbs (70 kg) and above	2000-2800

## **Other Nutrients**

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. There is some evidence that Vitamin C tablets can increase the risk of kidney stones in people who already have high levels of calcium in the urine. Because

high urine calcium affects some people with OI, check with a physician before taking Vitamin C supplements.

## **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](http://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.

## **Resources**

There are many web sites with nutrition information and recipes to help people make healthy food choices. A sample is listed below.

**American Dietetic Association** [www.eatright.org](http://www.eatright.org)

This site includes hundreds of daily nutrition tips, nutrition fact sheets, and information on finding a registered dietitian in your area.

**Five-a-Day Site** [www.dcpic.nci.nih.gov/5aday/](http://www.dcpic.nci.nih.gov/5aday/)

This site promotes the National Cancer Institute's "Five a Day" program to encourage Americans to eat more fruits and vegetables. It includes recipes.

**Food and Nutrition Information Center**

[www.nal.usda.gov/fnic/index.html](http://www.nal.usda.gov/fnic/index.html)

The U.S. Department of Agriculture, which publishes the Food Guide Pyramid, offers this resource to explain the Pyramid and other nutrition guidelines. It includes links to the National Academy of Sciences, which publishes the Recommended Daily Allowance (RDA) of calories, vitamins, and minerals.

Other government web sites that feature useful nutrition information include:

[www.healthierus.gov/nutrition.html](http://www.healthierus.gov/nutrition.html)

[www.smallstep.gov](http://www.smallstep.gov).

**National Osteoporosis Foundation** [www.nof.org](http://www.nof.org)

The National Osteoporosis Foundation's web site includes detailed information on calcium and its relationship to bone health.

**NOTE: Vitamin D recommendations** are based on unpublished research conducted by Jay Shapiro, M.D. of the Kennedy Krieger Institute, Baltimore, MD. The full text of his proposal can be found on [www.osteogenesisimperfecta.org](http://www.osteogenesisimperfecta.org) under the heading "OI News." These suggestions are particularly useful to people with OI, because they are based on weight rather than age. The OI Foundation encourages people to read Dr. Shapiro's article, share it with their doctor and discuss whether they should have the blood test and/or take vitamin D supplements.

For more information about osteogenesis imperfecta contact:



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