

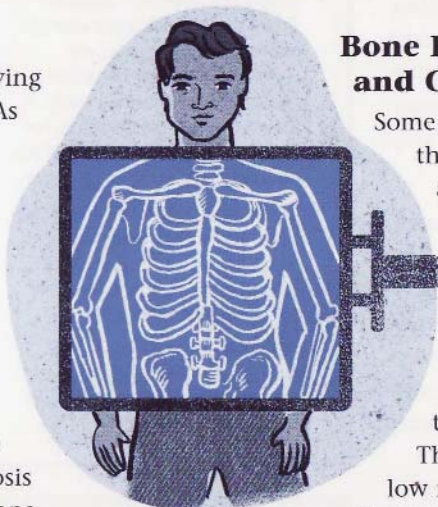
Nutrition

Bone Health and Cystic Fibrosis

People with cystic fibrosis (CF) are living longer than ever. As people age, bones get weaker and break easier. Two common bone diseases are **osteoporosis** (*os-tea-o-pour-o-sis*)*, or **osteopenia** (*os-tea-o-pea-knee-a*). People with CF are prone to osteoporosis and osteopenia. Bone health is vital for health and normal growth!

Bones have a thick outer shell and a strong inner mesh. This mesh looks like a “honeycomb.”

It contains **collagen**, **protein**, **calcium**, and other **minerals**. There are blood vessels and **bone marrow** in the other spaces of the bones. Having holes in your bones does not make them weaker! As with bricks or cement blocks, holes strengthen bones.



Bone Disease and CF

Some of the minerals that build bones are **calcium**, **phosphorus**, **magnesium**, and **fluoride**. With osteopenia, bones do not have enough of these minerals. This is often called low mineral **density**.

This makes the bones weak and brittle. With osteoporosis, the holes you normally have in your bones get too big. This is why osteoporosis means “**porous**

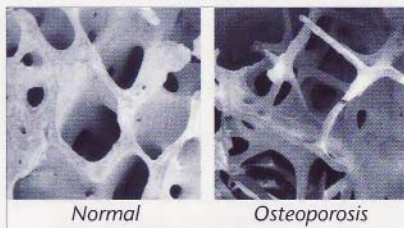


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bones.” Both osteopenia and osteoporosis make bones more fragile and prone to break or **fracture**.

Since people with CF can have low bone minerals, they are prone to osteopenia. In CF, it can happen at any age but becomes more common in the later teen and

*Words that appear in bold italic are defined at the end of this pamphlet.

adult years. Fractures hurt. If a chest bone is broken, it is hard to deep breathe and do airway clearance. This affects lung health.

Osteopenia or osteoporosis can keep people from getting lung transplants. Poor bone health can cause big problems after a transplant.

Causes of Bone Disease in CF

There are many reasons why people with CF get osteoporosis or osteopenia. It is important to remember nutrition, lung disease and bone health are all related. When people do not feel well they eat less.



Poor food digestion, called

malabsorption, causes **malnutrition**. With malabsorption, the body may not get the vitamins and minerals that are vital to bone health. These are vitamin D, a **fat-soluble vitamin**, and calcium. The right amount of pancreatic enzymes and food are necessary for a good diet, good body weight

and healthy bones. Low body weight can lead to low bone density and fractures.

Poor nutrition and lung disease can slow **puberty** too. A lot of bone is made in puberty, during the teen years. Since this is the bone you will have for the rest of your life, slowed puberty can lead to less bone being made. This sets the stage for future bone disease.

Prompt diagnosis and care for CF-related diabetes (CFRD) is vital for bone health. Diabetes treatment makes it possible for the body to use the vitamins and minerals in food for building and maintaining bones.

Bone Health DOs...

- **Regular Exercise** - *Weight-bearing* and *resistance exercise* like walking, jogging, or weight lifting are great for bone health. Exercise early in life may build more bone for life. Your CF care team can help you build an exercise program.
- **Good Nutrition** - A balanced diet, enough *calories*, the right *nutrients*, and enough pancreatic enzymes are vital for growth and health.
- **Medical Care** - Regular CF care center visits and doing therapies to stay healthy can help keep bones strong.

Bone Health DON'Ts...

- **Alcohol and Caffeine** - They lower bone density.
- **Carbonated Drinks** - Instead of sodas, drink whole milk for calcium, vitamin D, and calories.
- **Tobacco** - Smoking hurts your lungs and bones, causing osteoporosis and fractures.

Lung infections cause **inflammation**. This can also lead to bone loss. Treating illness early may lessen bone loss.

When people are sick and inactive, muscles and bones weaken. Activity helps bones get strong and stay strong.

Caffeine, alcohol, tobacco, **steroids**, and other medicines can make you prone to bone disease too. Long-term steroid use also can make bones thin and weak.

Some medicines can affect bone health.

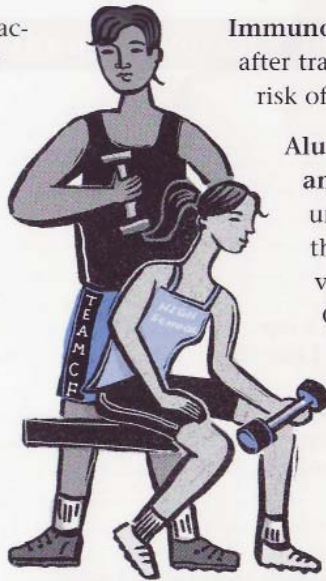
Ask your CF care team how your or your child's medicines or supplements affect bone health.

Steroids can help lungs but hurt bones. Your CF care team will monitor them and use the smallest amount.

Depo-Provera® (i.e., medroxyprogesterone acetate) is birth control medicine. It may raise your bone disease risk. It should be avoided if possible.

Megace® (i.e., megestrol acetate) is used to increase appetite. It may affect testosterone levels and raise the risk of bone

loss. If you are taking Megace®, your CF care team should monitor its use.



Immunosuppressants are used after transplants. They raise the risk of osteoporosis.

Aluminum-containing antacids can block calcium absorption. Avoid them. Some antacids provide calcium. Ask your CF care team or dietitian which antacids to take.

Herbal medicines and “**natural supplements**” can block nutrient absorption. Talk with your CF care team or dietitian before using them.

Bone Disease: Causes & Risk Factors

- Low body weight
- Low vitamin D
- Low calcium intake
- Malabsorption
- Not enough pancreatic enzymes
- Tobacco, alcohol, and caffeine use
- Moderate to severe lung illness
- Chronic infections
- Chronic bone and joint swelling
- CF-Related Diabetes
- Organ transplant
- Long-term steroid use
- Low *sexual hormones*
- Lack of exercise, especially weight-bearing

Talk with your CF care team or dietitian to learn about bone health and risk of bone disease. They can teach you how to keep bones healthy and strong.

Screening

Your CF care team will screen for osteoporosis or osteopenia by checking height and weight. They will track **pubertal development**. Some yearly lab tests screen for bone disease. If you take extra

vitamin D because of low levels, lab tests will be done more often to check vitamin D levels.

THE CALCIUM IN FOODS

Food	Calcium Content
Milk, 1 cup (whole)	290 mg
Milk, 1 cup (2%)	297 mg
Milk, 1 cup (skim)	302 mg
Milk, 1 cup (chocolate, 1%)	287 mg
Buttermilk, 1 cup	285 mg
Instant dry milk, 1/3 cup	280 mg
Soft serve ice cream, 1 cup	236 mg
Ice cream (Häagen-Dazs®), 1 cup	176 mg
Whole milk yogurt (plain), 1 cup	275 mg
Low fat yogurt (plain), 1 cup	415 mg
Low fat yogurt (fruit), 1 cup	350 mg
Non-fat yogurt (plain), 1 cup	490 mg
Non-fat frozen yogurt (chocolate), 1 cup	330 mg
Cheese (American), 1 oz	130 mg
Cheese (Swiss), 1 oz	270 mg
Cheese (Parmesan), 1 oz	330 mg
Cheese (Cheddar, Monterey Jack, Mozzarella), 1 oz	200 mg
Cottage cheese, 2%, 1 cup	155 mg
Ricotta cheese, part-skim, 1 cup	670 mg
Cheese pizza, 1 slice	220 mg
Almonds, 1/2 cup	190 mg
Roasted soybeans, 1/2 cup	120 mg
Pistachio nuts, 1/2 cup	90 mg
Hazelnuts, 1/2 cup	127 mg
Instant oatmeal (calcium fortified), 1 packet	150-500 mg
Bread, (calcium fortified), 1 slice	100-300 mg
Waffle (frozen)	80 mg
Grapefruit juice (calcium fortified), 1 cup	315 mg
Orange juice (calcium fortified), 1 cup	300 mg
Broccoli, 1 cup	90 mg
Squash (acorn), 1 cup	90 mg
Spinach, 1 cup	240 mg
Collards, frozen, boiled, 1 cup	350 mg
Tofu (with calcium), 1/2 cup	260 mg
Beans (baked, great northern, navy, yellow), 1 cup	120 mg
Refried beans, 1 cup	188 mg
Canned salmon (with bones), 3 oz	180 mg
Canned sardines in oil (with bones), 3 oz	370 mg

For Extra Calcium...

- Add 2-4 tablespoons of powdered dry milk to recipes, milk, puddings, etc. - adds 52 mg calcium per tablespoon
- Buy calcium-fortified cereals, breads, and drinks

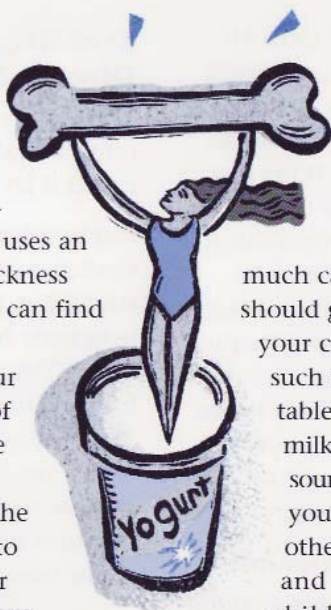
You may have a *dual-energy x-ray absorptiometry* or *DEXA* scan. This checks *bone mass* or density and can diagnose osteoporosis. It is painless. It uses an x-ray to check bone thickness throughout the body. It can find weak bones before they break. It can predict your or your child's chance of future breaks. All people with CF should have a DEXA scan by age 18. The scan is done every one to five years. If you or your child are prone to, or have, osteoporosis, the DEXA scan will be more often.

Nutrition

Nutrition is vital for bone health. Low weight and poor nutrition cause weak bones. It is important to gain and keep your ideal body weight and eat healthy. Calcium, *zinc*, magnesium, proteins, and vitamins D, K, and A are needed to build and keep strong bones.

Calcium

Calcium plays a big part in forming and keeping bones strong. The most calcium is needed for children and teens because bones grow



Bone Health Nutrients

- Calcium
- Vitamin D
- Vitamin K
- Vitamin A
- Zinc
- Magnesium
- Proteins
- Phosphorus
- Fluoride

fast in those years. People with CF, age 9 years and up, should get 1300-1500 mg of calcium a day. Your CF team can tell you how much calcium younger kids should get. It is best to get your calcium from foods such as those listed in the table on page 4. Milk and milk products are great sources of calcium. Ask your CF dietitian about other high-calcium foods and whether you or your child should take more calcium in a pill.

Calcium can decrease how well some medicines work if taken together. Ask your CF care team which medicines can be taken with calcium.

Vitamin D

Vitamin D helps the body absorb calcium so it can make bone. Fortified milk and cereals, egg yolks, and fatty fish are big sources of vitamin D. People with CF don't easily absorb vitamin D from foods. They must take vitamins like Vitamax™, ADEK®, or SourceCF® Softgels. These vitamins have *water-soluble vitamin*

D, which is easier to absorb. All people with CF over age 1 should take at least 800 IU per day of vitamin D. Those under age 1 should have 400 IU of vitamin D per day. Vitamin D levels in the blood should be checked yearly. With low levels, more vitamin D may be needed. Your body makes vitamin D from being in the sun. Being in the sun for 5-10 minutes, 2-3 times a week, can raise vitamin D levels. Remember, you need vitamin D from sun, not skin cancer! Be careful not to get sunburn.

Other Vitamins & Minerals

Vitamin K is a fat-soluble vitamin needed for bone density.

Low zinc levels can cause poor growth and slow puberty.

Low magnesium blocks the body's use of calcium.

Proteins, also known as *amino acids*, are the building blocks for all body tissues, even bones.

Treating Bone Disease in CF

The CF care team may prescribe calcium and vitamin D supplements if levels are low.

Bisphosphonates – In osteoporosis, medicines called bisphosphonates strengthen bones. These medicines help bone building cells work better. They can stop osteoporosis from getting worse or reverse it. They are not often given to kids under age 7 years. They should only be used in those with known fractures from weak bones or organ transplants.

A life of good nutrition and exercise leads to healthy, strong bones. As people with CF age, bone health can raise the quality of life. To learn more, talk with your CF care team.

Glossary

Amino acids: The building blocks of proteins that help keep the body healthy.

Bone marrow: The hollow center of bones where blood cells are made.

Bone mass: The amount of bone in the body.

Calcium: A mineral that helps build, repair and keep bones and teeth strong; also needed for muscles to work.

Calories: A unit of fuel or energy found in food.

Collagen: A strong protein found in bones, tissues, and skin.

Density: Thickness of a bone.

Dual-energy x-ray absorptiometry (DEXA): An x-ray test that checks bone thickness or density to diagnose bone disease.

Fat-soluble vitamins: Vitamins A, D, E, & K need fat for the body to absorb them from the gut; most people with CF cannot absorb fat, so they have to take special water-soluble vitamin forms.

Fluoride: One of the materials used to build bone.

Fracture: When a bone is broken or cracked.

Inflammation: The swelling of body tissue due to irritation or injury. Inflammation occurs with an infection.

Magnesium: A mineral that helps muscles and nerves work, keeps the heart beat steady, helps keep the immune system healthy, and keeps bones strong.

Malabsorption: Poor uptake of nutrients from food for use by the body. In CF, mucus may plug ducts of digestive organs and block the secretion of enzymes and hormones. This makes many nutrients unavailable for use in body maintenance and growth. This causes failure to thrive, a common CF symptom.

Malnutrition: Caused by lack of nutrients for the body to grow and remain strong.

Mineral: Material the body needs to work and stay healthy; usually a part of a multivitamin; see calcium, phosphorous, magnesium & zinc.

Nutrients: The vital items in food that are needed to grow, reproduce, and stay healthy; vitamins and minerals are nutrients.

Osteopenia: When bones have fewer minerals and are weak.

Osteoporosis: When bones are less thick or dense and are weak.

Phosphorus: A mineral that helps build healthy bones and teeth and gives the body energy.

Porous: Having holes or openings.

Protein: Found in every cell of the body; used to grow and to build and repair bone, muscles, skin and other parts of the body.

Pubertal development: The changes and growth in puberty.

Puberty: The time when the body matures and becomes able to reproduce.

Resistance exercise: Exercise that includes pulling and pushing like push-ups or lifting weights.

Sexual hormones: Testosterone, made by the testes, and estrogen, made by the ovaries.

Steroids: A type of drug that can decrease inflammation. Some steroids are used to increase the size and strength of muscles.

Water-soluble vitamin: Vitamins that are more easily absorbed by the body than fat-soluble vitamins.

Weight-bearing exercise: Exercise that works against gravity like lifting weights, walking, hiking, jogging, climbing stairs, tennis, or dancing.

Zinc: A mineral helps the body heal wounds, taste, smell, and make DNA.

Resources

This pamphlet is based on "Consensus Conference Report: Guide to Bone Health and Disease in Cystic Fibrosis" by Robert Aris, M.D.; Peter Merkel, M.D.; and others in the CF Foundation's Consensus Conference on bone health. The report is in the *Journal of Clinical Endocrinology and Metabolism* and available through the National Library of Medicine at <http://tinyurl.com/rvb7c>

To learn more about nutrition and bone health, contact:

The CF Foundation: www.cff.org,
(800) FIGHT CF, or info@cff.org

The Centers for Disease Control and Prevention: <http://tinyurl.com/gmcqc>

Medline Plus, in the National Institutes of Health: <http://tinyurl.com/g3fe8>

"Powerful Girls have Powerful Bones":
<http://tinyurl.com/g66n5>

"Milk Matters" from the National Institute of Child Health and Human Development in the National Institutes of Health:
<http://tinyurl.com/jrzj5>

The International Osteoporosis Foundation, www.osteofound.org

USDA - Calcium content in food:
<http://tinyurl.com/gk8cw>

Nutrition fact sheets and additional information on vitamins A, D, E and K are available at:
<http://tinyurl.com/jb4vn>

Adult-specific nutrition information is available at: <http://tinyurl.com/kqzl4>

Also, check out the CF Foundation's Web Cast archives for nutrition-related topics:
<http://tinyurl.com/jtoyf>

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