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Nutrition

Bone Health and Cystic Fibrosis



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People with cystic fibrosis (CF) are living longer than ever. As people age, bones get weaker and break easier. This pamphlet talks about bone disease in CF and different ways that it can be prevented with nutrition and exercise.

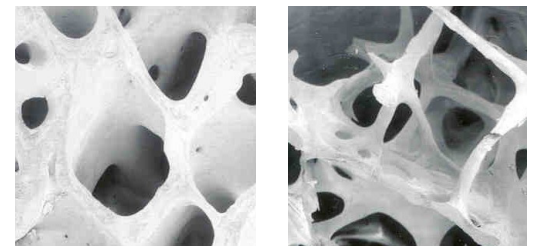
Bone Disease and CF

Two common bone diseases are **osteoporosis*** (oste-a-o-pour-o-sis) and **osteopenia** (oste-a-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.

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** bones.” Both osteopenia and



Normal

Osteoporosis

Image Copyright 2001, David W. Dempster, PhD.

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 adult years. Fractures hurt. A broken chest bone makes it hard to breathe deep and do airway clearance. Broken bones affect lung health.

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

*Brief definitions of the words that appear in bold can be found on page 4.

Bone Disease: Causes and Risk Factors

- Low body weight
- Low vitamin D
- Low calcium intake
- Malabsorption
- Not enough pancreatic enzymes
- Lack of exercise, especially weight-bearing exercise
- 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**

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 it needs. Vitamin D, a **fat-soluble vitamin**, and calcium are vital to bone health. 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 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.

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 and some medicines can make you prone to bone disease too.

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. Long-term steroid use can make bones thin and weak. Your CF care team should monitor them.
- 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.
- Medicines that suppress the immune system that are used after transplants 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 the absorption of **nutrients**. Talk with your CF care team or dietitian before using them.

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

 <p>Bone Health DO's...</p>	<p>REGULAR EXERCISE – Weight-bearing exercise 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.</p> <p>GOOD NUTRITION – A balanced diet, enough calories, the right nutrients and enough pancreatic enzymes are vital for growth and health.</p>
 <p>Bone Health DON'Ts...</p>	<p>ALCOHOL AND CAFFEINE – They lower bone density.</p> <p>CARBONATED DRINKS – Instead of sodas, drink whole milk for calcium, vitamin D and calories.</p> <p>TOBACCO – Smoking hurts your lungs and bones, causing osteoporosis and leading to fractures.</p>

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.

You may have a **dual-energy X-ray absorptiometry (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 the chance of future breaks for you or your child. 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 done 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 child's weight up 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 bones and keeping them strong. Children and teens need the most calcium because bones grow 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 5. Milk and milk products are great sources of calcium. Ask your CF dietitian about other foods high in calcium 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 our bodies absorb calcium to make bone. Fortified milk and cereals, egg yolks and fatty fish are good sources of vitamin D.

People with CF don't easily absorb vitamin D from foods. They should take vitamins made just for people with CF like Vitamax™, AquADEK® or SourceCF®. These vitamins have **water-soluble vitamin D**, which is easier to absorb.

Vitamin D levels in the blood should be checked once a year and after taking extra vitamin D as prescribed. If the amount of vitamin D in your blood is low, you may need to take more.

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. Be careful not to stay out in the sun too long to avoid sunburn.

OTHER VITAMINS AND 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/or vitamin D supplements if your 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.

Take Vitamin D Every Day!

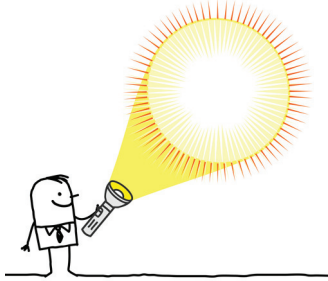
- 11 years and older, take 800-2000 IU.
- 1-10 years, take 800-1000 IU.
- 12 months and younger, take 400-500 IU.
- Make sure the form of Vitamin D is cholecalciferol or Vitamin D3.



Bone Health Nutrients

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

Words Defined



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

Bisphosphonates: Medicines that help bone-building cells work better and help strengthen bones.

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 see if there is bone disease.

Fat-soluble vitamin: Vitamins A, D, E and 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 and keep teeth strong.

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: When the body does not absorb nutrients from food. In CF, mucus may plug ducts of digestive organs and block the secretion of enzymes. This makes many nutrients unavailable for the body to grow and stay healthy.

Malnutrition: When the body is not getting enough nutrients to grow and remain strong.

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

Nutrients: The vital items in food that are needed for the body to grow and stay healthy; vitamins, minerals, proteins, fats and carbohydrates are nutrients.

Osteopenia (oste-a-o-pea-knee-a): When bones have fewer minerals and are weak.

Osteoporosis (oste-a-o-pour-o-sis): 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 walking, hiking, jogging, climbing stairs, tennis or dancing.

Zinc: A mineral that helps the body build and keep bones strong and heal wounds.

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. — it adds 52 mg calcium per tablespoon.
- Buy calcium-fortified cereals, breads and drinks.

Learn More: CF Foundation 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., et al. and “An Update on the Screening, Diagnosis, Management and Treatment of Vitamin D Deficiency in Individuals with Cystic Fibrosis: Evidence-Based Recommendations from the Cystic Fibrosis Foundation” by Vin Tangpricha, M.D., Ph.D., et al. These reports were published in the *Journal of Clinical Endocrinology and Metabolism*.

You can find more information on the CF Foundation’s website at:

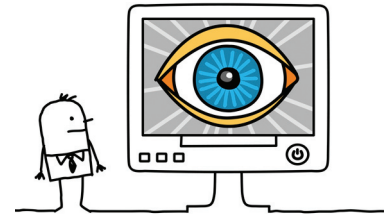
www.cff.org/treatments/CFCareGuidelines/Nutrition.

Nutrition fact sheets and additional information on vitamins A, D, E and K are available at:

www.cff.org/LivingWithCF/StayingHealthy/Diet/Vitamins.

And check out the CF Foundation’s Webcast Archives for nutrition-related topics:

www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/Nutrition.



For more information, visit:

Centers for Disease Control and Prevention (CDC):

www.cdc.gov/nutrition/everyone/basics/vitamins/calcium.html

National Institutes of Health:

- Bone Diseases:
www.nlm.nih.gov/medlineplus/bonediseases.html
- “Milk Matters”:
www.nichd.nih.gov/milk/milk.cfm

“Best Bones Forever!”:

www.bestbonesforever.gov

The International Osteoporosis Foundation:

www.osteofound.org

U.S. Department of Agriculture:

Calcium content in food:

www.ars.usda.gov/Services/docs.htm?docid=17477



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