Nutrition

Cystic Fibrosis: Changes Through Life

Good nutrition is crucial for people with cystic fibrosis (CF). For all ages, there appears to be a connection between good lung function and a higher body weight. A balanced, high-calorie diet with salt, fat, and protein gives the body what it needs to grow normally and live well. Normal gains in weight and height help build strong lungs and preserve lung function. Good nutrition also helps to build and keep a strong immune system to fight infections. Less infections and stronger lungs mean a longer, healthier life.

Getting Off To A Good Start

Good nutrition starts with teaching infants and children good eating skills.

Children learn by watching others. Parents should give the right types of foods. Parents should also eat meals and snacks with their children so they can "see" how to eat a balanced diet and enjoy meal times.

Children should be allowed to decide how much food to eat. This teaches them how to listen to the body's cues about hunger and fullness. Do not force feed a child.

Mealtime is a time to relax and enjoy being together. Turn the television and telephone ringer off and make it "free time" to eat and enjoy!

Malabsorption And Pancreatic Enzyme Replacement

Most people with CF have a pancreas that does not work as well as it should. This is called pancreatic insufficiency. Pancreatic insufficiency causes maldigestion and malabsorption of food (especially fat). Pancreatic enzymes taken before each meal and snack help prevent maldigestion and

malabsorption. Infants should take enzymes with every feeding. If a child cannot swallow an enzyme capsule, the capsule can be opened up and the "beads" inside put in a small amount of acidic food like baby food fruit. Talk to your CF dietitian or care provider about problems with enzymes.

Symptoms of maldigestion or malabsorption may include:

- poor weight gain despite a good (sometimes ravenous) appetite;
- frequent, loose and/or large bowel movements;
- foul-smelling bowel movements;
- mucus or oil in the bowel movement;
- excessive gas and/or stomach pain
- distention or bloating.

If any of these symptoms occur for more than three days, call your CF dietitian or care provider. The enzyme dose may need to be changed or a medicine to control stomach acid may need to be added to help the enzymes work better. Do not change the enzyme dose without talking to the CF dietitian or care provider.

Poor Growth Or Poor Weight Gain

Normal height and weight and good nutrition are vital in the care of CF. People with CF may need to eat 20–50% more calories than people without CF. This can be hard to do. Even if people with CF eat often and well, they still may not get enough calories to grow normally.

Here are some ways to increase calories in the diet:

- Eat high-calorie/high-fat foods (ask your CF dietitian or care provider for ideas).
- Eat meals and snacks often.
- Supplement meals and snacks with homemade milkshakes and smoothies or store-bought nutrition supplements.

Tube Feedings

Some people still do not gain weight or grow normally even after adding extra calories. Because of the connection between a higher body weight and better lung function, your CF dietitian or care provider may suggest tube feedings to help your child gain weight. Tube feedings may give the extra calories needed to grow taller or gain weight. They are often given at night during sleep, but also may be given during the day. Tube feedings are a supplement to eating, not a substitute.

Tube feedings can be given through:

- the mouth (orogastric tube or OG);
- the nose (nasogastric tube or NG);
- the stomach (gastrostomy or GT);
- the intestine (jejunostomy or JT).

Cystic Fibrosis–Related Diabetes (CFRD)

Diabetes related to CF occurs in 10–20% of people with CF. It usually begins in the teen or young adult years. CFRD is different from Type 1 or Type 2 diabetes. People with CF should have their blood glucose (blood sugar) checked yearly to test for CFRD. If CFRD is found, it is vital to get care from a doctor specializing in diabetes (an endocrinologist) and a CF dietitian and care provider. Right now, the best treatment for CFRD is insulin and checking glucose often.

If a person has CFRD, it is vital to learn good diabetes care. Good diabetes care leads to good diabetes control and fewer problems. A person with CF who has poor diabetes control may get sick more often, take longer to heal, and have trouble gaining or keeping weight. Poor diabetes control may lead to blindness, kidney disease, and poor blood flow.

Osteoporosis

People with CF are at risk for poor bone health. This increases their risk for osteoporosis and broken bones later in life. Getting enough calcium and vitamin D in the diet builds bone mass in children and teens and helps keep adult bones healthy. Weight-bearing exercise (walking, jogging, jumping rope, dancing, weight lifting, etc.) is also very important in building and keeping healthy bones. A DEXA scan (a type of x-ray) screens for bone health. Your CF dietitian or care provider can answer questions about preventing osteoporosis.

CF And Pregnancy

Women with CF can have healthy pregnancies. Severity of lung disease, presence of diabetes, and nutrition status before pregnancy seem to affect outcomes the most. Women whose pulmonary function tests show moderate to severe lung disease (FEV_1% predicted <50%) have a higher risk of having a preterm infant and reduced lung function than women with milder lung disease. It is vital for ALL women of childbearing age to take extra folic acid to help prevent birth defects of the spine in their babies.

A woman with CF should discuss with her CF dietitian or care provider which vitamin supplements are best to take *before* she gets pregnant. Once pregnant, she will need extra calories each day to gain enough weight. Good weight gain will help her and her baby be healthy. The woman with CF also should be tested every trimester for pregnancy-related diabetes. If she decides to breastfeed, she will still need extra calories each day to keep healthy and her milk supply enough for the baby to grow. Good nutrition is crucial during pregnancy and breast feeding for the mother and baby.

In CF, nutrition is the key to good health through life. You must eat well to grow normally, maintain lung function, and fight infections.

If you have questions about "Cystic Fibrosis: Changes Through Life," or any aspect of CF care, call your CF dietitian or care provider.

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