

For Your Infant With Cystic Fibrosis (Birth To One Year)

ood nutrition is very important for infants with cystic fibrosis (CF). A balanced diet, which includes adequate calories and the right vitamin and mineral supplements, is key to good nutrition and health. Reaching and maintaining a normal body weight will help your baby be as healthy as possible. The CF dietitian or care provider will teach you how to meet your baby's nutritional needs.

Nutrition

CF is a chronic inherited disease that mainly affects the lungs and digestive system. CF affects each person differently. The basic problem in CF is an error in the salt and water exchange in some cells. This causes the body to make thick, sticky mucus, which clogs the lungs and the pancreas.

Some infants with CF gain weight and grow well, while many others do not. One nutrition goal in CF is to help those who need to gain weight to "catch-up" and reach a normal weight. A second nutrition goal is to help those who have "caught up," or are already gaining weight well, to continue to do so. A high-calorie diet is often needed, even if your baby does not have the digestive problems often associated with CF. For most infants with CF, the extra calories help meet the high energy needs that go along with the disease.

Nutrition and Feedings

Breast milk or infant formula is recommended for the first year of life. Do not routinely offer juice, water or other liquids. Fluids other than breast milk or formula are lower in calories and nutrition. If your baby's weight gain is slow, the CF dietitian or care provider may suggest adding extra calories to breast milk or formula. After your child's first birthday, ask your CF dietitian if whole milk or



a pediatric nutrition supplement is best for your child.

The American Academy of Pediatrics suggests that solid foods be added when your baby is ready, usually at four to six months of age. Single-grain infant cereal (such as rice) is a good first choice. Gradually adding a variety of strained fruits, vegetables and meats will help provide a balanced diet and promote good eating habits. Plain strained meats contain more protein than combination dinners.

For infants who need to gain weight, the CF dietitian will teach you how to give your baby more calories. One suggestion may be to offer high-calorie formula or breast milk before feeding your baby solid food. Another suggestion may be to read baby food labels and choose those with the most calories. The CF dietitian may have other ideas or recipes to help meet your baby's nutrition needs.

Soft or pureed table foods may be introduced into your baby's diet at about six to eight months of age. Talk with the CF dietitian or care provider about other ways to increase calories in your baby's diet once table foods have been started.

Vitamins

Vitamin supplements are important for your baby. People who have CF do not absorb vitamins well. Vitamin supplements and a healthy diet will help meet your baby's nutrition needs. Vitamin supplements will help prevent low levels of the fat-soluble vitamins A, D, E and K. Your CF care center team will recommend the proper type and dose of vitamin supplements.

Spitting Up

Many babies spit up, and a small amount of spitting up is normal for all babies. A large amount of spitting up or vomiting is not normal and may mean your baby has reflux. This may lead to slow weight gain and poor growth. Discuss this with your CF dietitian or care provider if you have concerns.

Pancreatic Enzyme Replacements

Your baby may need pancreatic enzyme replacements, or "enzymes," to help digest and absorb food. These enzymes must be prescribed by your doctor. Enzymes may be started if your baby has any or all of the following symptoms:

• poor weight gain, despite a good (sometimes ravenous) appetite;

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- 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.

Enzymes come in capsule form. Inside each capsule are many small "beads" that contain digestive enzymes. For babies, the capsules are

opened up and the beads are sprinkled in a small amount of acidic food, such as baby applesauce, and given from a spoon. Each bead is covered with a special coating. This coating allows the beads to dissolve in the small intestine. The small intestine is where most of the digestion and absorption of food occurs. Infants with CF who do not digest their food well need enzymes with every feeding (breast milk, formula and most foods).

Do not put beads in food ahead of time for use later that day. Do not increase or decrease the enzyme dose unless you have discussed this with your CF dietitian or care provider.

Salt Replacement

People with CF lose more salt in their sweat than those without CF. Your CF dietitian or care provider may suggest adding a small amount of salt to your baby's food or formula, especially during hot weather.

Tube Feedings

Some infants with CF have a very difficult time gaining weight. Tube feedings (feeding formula through a tube that goes into the stomach) is an excellent way to help your child gain weight. Tube feedings should not be thought of as a last resort and do not mean failure. They can be a great way to help your baby grow and feel better.

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If you have questions about "Nutrition For Your Infant With Cystic Fibrosis," or any aspect of CF care, call your CF dietitian or care provider.

It is very important to keep your regular visits at your CF care center. This will help the CF care providers monitor the health, growth and nutrition needs of your baby.

DIETITIAN NAME

PHONE NUMBER

CARE PROVIDER NAME

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This fact sheet has been favorably reviewed by the Pediatric Nutrition Practice Group of the American Diatetic Association.



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