

Don't miss any of your CF care center visits! This

will help your CF care team

growth and nutrition needs. Call your CF dietitian or

health care provider if you

have any questions.

DIETITIAN NAME

PHONE NUMBER

PHONE NUMBER

CARE PROVIDER NAME

meet your baby's health,

Nutrition

Adding tomorrows every day.

For Your Infant with Cystic Fibrosis (Birth to 1 Year)

# Getting Off to a Good Start

Infants with cystic fibrosis (CF) must have good nutrition. Higher body weight seems to be linked to better lung function. Get your baby off to a great start. A balanced diet that includes enough calories and the right vitamin and mineral supplements is key to good nutrition and health.

Reaching and keeping a normal body weight helps babies be healthy. Your CF dietitian or health care provider will teach you how to meet your baby's nutrition needs.

CF is a chronic disease that you inherit. It affects the lungs and digestion. CF affects people in varied ways. The basic problem in CF is an error in the way some cells move salt and water. This causes the body to make thick, sticky mucus. The mucus clogs the lungs and pancreas. This mucus also keeps enzymes in the pancreas from reaching the intestines. Without enzymes, the body doesn't digest and absorb food well. This causes large, greasy bowel movements, slow growth and slow weight gain.



Some infants with CF gain weight and grow well. Others do not. One goal in CF care is to help those who need to gain weight "catch up" and reach a normal weight. A second goal is to help those who have "caught up" or are gaining weight well to keep doing so. A high-calorie diet is often needed, even if your baby does not have the digestive problems that often come with CF. For most infants with CF, the extra calories help meet the high-energy needs for growth and CF.

It is vital to work with your CF health care team between visits if you are concerned about your baby's growth.



## **Nutrition and Feedings**

Breast milk or infant formula is best during the first year. Do not often give your baby juice, water or other liquids. Fluids other than breast milk or formula have less calories and nutrition.

If your baby's weight gain is slow, the CF dietitian or health care provider may suggest adding extra calories to breast milk or formula. After your child turns 1 year old, ask your CF dietitian if whole milk or a nutrition supplement is best for your child.

The American Academy of Pediatrics suggests that solid foods be added when your baby is ready. This is often at 4 to 6 months of age. Single-grain infant cereal (like rice) is a good first choice. Slowly adding many types of strained fruits, vegetables and meats will help create a balanced diet and promote good eating habits. Plain strained meats have more protein than meats mixed with other foods.

If your infant needs to gain weight, the CF dietitian will teach you how to give extra calories. One idea may be to offer high-calorie formula or breast milk before feeding your baby solid food. Another 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 added to your baby's diet at about 6 to 8 months. Talk with the CF dietitian or health care provider about other ways to add calories to your baby's diet once table foods have been started.



## Vitamins

Babies with CF need vitamin supplements. People with CF do not absorb vitamins well. Vitamin supplements and a healthy diet help meet your baby's needs.

Vitamin supplements help prevent low levels of fat-soluble vitamins A, D, E and K. Your CF dietitian or health care provider will tell you which type and dose of vitamin supplements are best.

## Spitting Up

Many babies spit up. A small amount of spitting up is normal. A large amount of spitting up or throwing up is not normal. This may mean that your baby has reflux. Reflux can lead to slow weight gain and poor growth. Share any concerns you have with your CF dietitian or health care provider.



## Pancreatic Enzyme Replacements

Your baby may need pancreatic enzyme replacements ("enzymes") to help digest and absorb food. Enzymes must be prescribed by your baby's doctor.

Enzymes may be started if your baby has any or all of these symptoms:

- Poor weight gain, even when your baby likes to eat and eats a lot
- Lots of large, loose, dirty diapers
- · Dirty diapers that smell very bad
- Dirty diapers that are oily or have mucus
- Lots of gas and/or stomach pain
- Bloating or a full-looking tummy

Enzymes come as capsules. Each capsule contains many small enzyme "beads." For babies, the capsules are opened and the beads sprinkled on a small amount of baby food fruit, like applesauce, that is then fed with a spoon. The beads have a coating that helps them dissolve in the small intestine. This is where most foods are broken down and absorbed into the blood.



Infants with CF who do not digest their food well need enzymes every time they eat. When your baby has breast milk, formula or food, you will need to give enzymes.

Put beads in food right before feeding your baby. Do not change the enzyme dose without talking to your CF dietitian or health care provider.

### Salt

People with CF lose a lot of salt in their sweat. The more they sweat, the more salt they lose. In hot weather, your baby may need more salt. Your CF dietitian or health care provider may tell you when and how to add extra salt to your baby's formula or food.

### **Tube Feedings**

Tube feedings are formula feedings through a tube into the stomach. Some infants with CF have a very hard time gaining weight. Tube feedings are a great way to help these babies grow and feel better.

Tube feedings are not a last resort. They do not mean failure. Don't forget: Higher body weight seems to be linked to better lung function. Do what is needed to help your baby get to a healthy weight.

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This fact sheet is approved by the Pediatric Nutrition Practice Group of the American Dietetic Association.



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