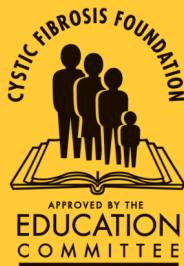


# Managing Nutrition & Digestive Problems



For Parents of Children  
with Cystic Fibrosis





**PROGRAM DEVELOPED BY:**

The CF Family Education Project  
Baylor College of Medicine  
and Texas Children's Hospital



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## YOUR CHILD'S NUTRITION

In this module, you will learn how to manage problems your child with **cystic fibrosis\*** (CF\*) may have with nutrition and **digestion.\***

### INTRODUCTION

Most people with CF are at risk for nutrition and digestion problems. With CF, problems can occur in any part of the **digestive system.\*** To learn more about the digestive system, see “CF FACTS – THE DIGESTIVE SYSTEM” in Appendix 1. Learning the parts and functions of the digestive system will help you better understand your child's nutrition and digestion problems and treatments.

To help your child stay as active and healthy as possible, you will be using skills from the CYSTIC FIBROSIS FAMILY EDUCATION PROGRAM (CF FEP) module *Becoming a CF Manager*.

### Skills for Managing CF

- 1) **Watch and Discover.\*** Observe how your child is growing and developing. Look for **signs\*** and **symptoms\*** of **malabsorption\*** and Watch and Discover problems early.
- 2) **Think and Act.\*** Take action to treat your child's malabsorption with **pancreatic enzymes,\*** help your child eat a diet high in **calories\*** and **protein,\*** and treat other problems that may arise, such as **constipation\*** or **liver\*** disease (See “OTHER CF DIGESTIVE SYSTEM PROBLEMS” in Appendix 2.)
- 3) **Communicate:** Talk with your child, the CF health care team, and others about your child's nutrition and digestive problems. You will want to tell your child's CF health care team what you observe, what problems you discover, what you are doing to solve these problems, and how your solutions are working.



### NOTE TO PARENTS:

You may recognize some of the same information here that is in the CF FEP module *Beginning CF Care*. *Managing Nutrition and Digestive Problems* has more information for parents to manage CF as their child grows.

### GOOD NUTRITION FOR YOUR CHILD

Most children with CF need more calories than children without CF to grow and stay healthy.

Growing taller and gaining weight is a major task in childhood. Babies and teens grow the fastest. For a child to get taller and gain weight, he or she needs to get enough calories and **nutrients.\*** As the child grows, the organs of the body, such as the brain and **lungs,\*** also continue to grow and develop. A problem with nutrition can stress the body and cause poor growth as well as poor health.

Scientists studying CF are learning more about the link between good nutrition, healthier lungs, and longer and healthier lives. People with CF who have good nutrition may have fewer lung problems. Lung health and good nutrition are closely related and a **CF manager\*** pays attention to both.

\*See CF Words to Know Glossary.



Your CF health care team will work with you as you learn how to Watch and Discover signs and symptoms of growth and nutrition problems. They will help you Think and Act to make a plan for what to do to prevent and treat them. The team will work with you to help make sure that your child grows well and enjoys an active life by eating a high-energy, healthy diet.

Parents and health care professionals often discover a child with CF has poor nutrition by watching the child's weight. Even with poor nutrition, children will usually keep basic body functions working and even grow taller at a slower rate. The outward sign of poor nutrition is a low weight. A child with CF who has poor nutrition may have very slow weight gain, no weight gain at all, or weight loss, especially with **acute\*** illness.

### Calories

Weight below what is expected for a child's age and height is a sign that a child with CF is not getting enough calories. Calories are a measure of the amount of energy the body gets from food. Energy from calories is what the body needs to grow and work well. Most people with CF have problems getting enough calories without making the extra effort to eat a high-calorie diet. The symptoms of poor nutrition (very slow or no weight gain, or weight loss) mean that a child with CF is not getting enough calories. These symptoms or problems may be caused by:

- **Malabsorption:** The body has trouble **absorbing\*** nutrients from food and may not get enough calories even though a child is eating as much as children without CF. The child may not be getting the right **dose\*** of pancreatic enzymes (also called **replacement enzymes\*** or **enzyme supplements\***), or is not taking them as the CF doctor has prescribed.
- **Breathing problems:** The body uses more calories when it has to work harder to breathe and to cough. Babies may find it hard to eat if they are having trouble breathing.

- **Infections:** The body needs more calories when it is fighting an **infection\*** (**Respiratory infections\*** can also reduce a child's appetite.)
- **Poor appetite:** The child is not eating enough calories to meet his or her daily energy needs and demands from having CF.

Getting enough calories is not the only thing that makes a child's body healthy and able to grow. The right amounts of protein, **vitamins\*** and **minerals\*** are also very important for growth and body function. Because of malabsorption, infection, and trouble breathing, a child with CF may have problems not only getting enough calories, but also getting enough protein, vitamins, and minerals.

### Protein

Protein in your child's diet is important in many ways. Protein is a source of energy and helps **cells\*** work. Protein helps the body grow and repair damage. Certain proteins help the body's **immune system\*** resist and fight infection. Protein also helps build and maintain muscles, which are important not just to run and play, but also to breathe and to cough.

### Vitamins

The body needs vitamins for many different functions. Even though the body needs only small amounts of each vitamin, without these vitamins, the body would not be as healthy. The two main groups of vitamins are **fat-soluble\*** and **water-soluble\***.

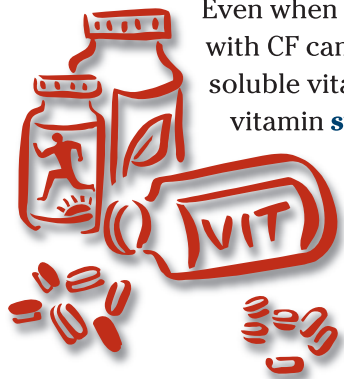
#### Fat-Soluble Vitamins

Pancreatic enzymes are needed to **absorb\*** fat-soluble vitamins. The fat-soluble vitamins are A, D, E, and K. Fat-soluble vitamins help the body in several ways.

- Vitamin A is important for normal vision, cell function, and building bones. It helps the body resist infection and helps keep the **intestines\*** healthy.
- Vitamin D is important to build and maintain strong bones and teeth.



- Vitamin E is important for red blood cells and helps keep the intestines healthy. It is an **antioxidant\*** that helps protect cells from injury, harmful chemicals, and **inflammation\***.
- Vitamin K is needed for normal **blood clotting\***. It also helps maintain healthy bones.



Even when they take enzymes, people with CF can have low levels of fat-soluble vitamins if they do not take vitamin **supplements\*** in addition to what is in the food they eat. Vitamin D can come from other sources, such as sunlight. But many people do not spend enough time in the sun. If they use sunscreen to prevent sunburn, this could also reduce the amount of vitamin D produced in their bodies.

#### Water-Soluble Vitamins

People with CF are able to absorb water-soluble vitamins (for example, vitamin C), and usually get enough of these vitamins from their diets.

#### Minerals

The body also needs different minerals from food. Minerals are important for several body functions.

- **Calcium\*** is the most common mineral in the body. Calcium makes teeth and bones strong. If the body does not get enough calcium, the bones can become weak and may break easily. Calcium also is important in a number of cells including muscles, blood vessels, and nerves.
- **Chloride\*** combined with **sodium\*** forms salt in the body. Chloride is important in cell functions and fluid balance. The high chloride level found in sweat through a **sweat test\*** is used to make a diagnosis of CF.
- **Iron\*** helps red blood cells carry oxygen to all parts of the body. Iron is also involved in many cell functions and helps support a healthy immune system to fight infection.

- **Magnesium\*** is found in our bones—in fact, magnesium is found in almost every cell in the body. Magnesium helps maintain normal muscle, heart, and nerve function; helps support a healthy immune system to fight infection; controls **blood sugar\*** levels; and keeps bones strong.
- Sodium combined with chloride forms salt in the body. Sodium is important for many cell functions. People with CF have sodium levels higher than normal in their sweat, and with extra sweat loss, they can become **dehydrated\***.
- **Zinc\*** supports a healthy immune system, heals wounds, and maintains the body's sense of taste and of smell. It also helps with other cell functions. Zinc also supports normal growth and development.

A person with CF can have low levels of these minerals and may need to take extra mineral supplements, along with eating a healthy diet.

You can learn more about vitamins and minerals from the National Institutes of Health Office of Dietary Supplements Web site at <http://www.ods.od.nih.gov> and from the CF Foundation Web site at <http://www.cff.org/>.

#### Exercise and Energy Needs

Being active uses energy. The more active a person is, the more calories he or she will need to eat to stay healthy and strong. If you are tempted to keep your child inactive to save calories, don't do it! Staying active is important for your child's health and well-being. Regular exercise has many benefits. A child who is active will have good fitness and muscle strength. Being active helps a person feel good and have a better appetite. Being active also can help your child clear out the **mucus\*** in his or her lungs and resist infection. And, of course, the CF health care team wants children with CF to enjoy all the same activities as other children. Your CF health care team can help you figure out your child's extra calorie needs based on his or her activities. To learn more, see "EXERCISE AND CF" in Appendix 3.

\*See CF Words to Know Glossary.



### Growth and Development in Puberty

There are two periods in a child's life when growth is faster: during the first year of life and during **puberty**\*. Puberty is the period of time when a child's body changes and becomes sexually mature. Poor nutrition in adolescents who have CF and are going through puberty can result in several problems. Poor nutrition can delay the start of puberty and even limit how tall a teen may grow. Further, when a teen with poor nutrition does grow in puberty, his or her overall health can become worse. To learn more, see "PUBERTY AND FERTILITY IN CF" in Appendix 4.



### WATCH AND DISCOVER

#### NUTRITION PROBLEMS

Watch how your child is growing so you can Discover early if there is a problem. You will learn more about how to watch for malabsorption problems on pp. 19-27.

#### Watching Your Child's Growth

A problem with growth can be hard to see just by looking at your child. Because children of the same age vary in body size, parents may not realize when their child is not growing well. Sometimes weight is lost so slowly that it can go unnoticed. Ten pounds lost over six months, for example, are not as obvious as ten pounds lost in six weeks. Sometimes a person eats just enough calories to keep the body going. There may be no weight loss, but there may not be enough calories to gain weight and grow.

Watch for problems with your child's weight and growth by asking yourself several questions:

**Does my child look thinner?** Do people who don't often see your child comment on your child's appearance? They may notice your child has lost weight before you do.

**How do my child's clothes fit?** Are clothes that used to fit well now too big or too loose? Does my child seem to wear the same clothes for a long time without outgrowing them?

**Do my child's friends or siblings who do not have CF seem to be growing taller while my child stays the same?**

#### Energy Level and Activity

Often being tired can be a sign of poor nutrition because the body is not getting enough energy. Most children, however, like to be active so this may be a late sign of a problem for your child. Being less active than usual can also be a sign of an infection starting. Keep an eye on your child's energy level day to day.

#### Paying Attention to Your Child's Diet

Watch what your child eats for meals and snacks. Pay attention to how much your child eats and what kinds of food he or she likes. You will want to ask others on your child's CF care team who are at home and at school to help you watch what your child eats and encourage your child to get enough calories. Watch the schedule your family keeps to be sure to make time for eating. You can keep a

diary of foods your child eats to review with your CF health care team. (See the worksheet "My Child's Food Diary" in the back pocket of this module.)



#### Appetite and Hunger

People often use the words hunger and appetite to mean the same

thing. Hunger is something the body feels when it needs food—a normal function of the body. Appetite is the desire to eat. Often, appetite is a





response to things that happen around mealtime. We get in the habit, for example, of eating at certain times of day. Even when we are not very hungry, we typically eat every day at mealtimes. Eating can be a social time. We may enjoy eating because of the people we eat with. A pleasant setting and attractive, good-tasting food also help to build a good appetite. Helping children with CF develop a good appetite may prompt them to eat better even when they do not feel hungry. Children may say they are not hungry if they don't want to stop playing. Having a schedule for meals and for playtime can help young children get used to a routine and develop an appetite around mealtimes.

If your child loses his or her appetite, it can be a sign of a problem in CF. **Sinus\*** infections can affect how food tastes or prevent a child from being able to smell and taste food normally. Stomachaches from swallowing mucus or malabsorption can reduce appetite. Poor nutrition sometimes interferes with hunger. Being too tired can affect a person's appetite at times. Everyone has ups and downs in appetite, but if your child seems to have a poor appetite every day, you should be concerned and Watch and Discover the reason, then Think and Act the solution.

### Weighing Your Child

If you are concerned that your child has lost weight or is not gaining weight, weigh your child. Weighing your child once a month at the same time of day is usually often enough. You should weigh your child in the morning before breakfast.

**Note:** *Parents may be tempted to weigh their children often as a way to make sure they are not having a problem. Weighing children every day or two may cause needless worry and is probably not the best way to monitor. Weight normally changes a little throughout the day and from one day to the next.*



In general, if your child is eating well, has energy for active play, has good checkups, and has no obvious signs of weight loss, you do not need to be concerned. If your child's weight needs to be watched more closely, you and the CF health care team may want your child to be weighed at the CF center or at your child's **primary care provider's\*** office.

### Staying in Touch with Your Child's Feelings About Growth Wanting More Muscle

Some children don't like to look skinny. They want to look strong and have bigger arm and leg muscles. A child who is underweight often does not have very big muscles. Building muscle can be a goal that may help a child work to eat more. Building strong, healthy muscles does not require special diet products. Instead, a good diet high in calories and protein and regular exercise can help your child build a stronger, healthier body. You and your child can talk to your CF **dietitian,\* physical therapist,\*** and other CF health care team members to plan a good diet and exercise schedule.

### Worrying About Getting Fat

Some children, and in particular some teenage girls, may want to watch what they eat to stay thin. This problem may be a special concern for a child with CF if she has gotten

attention for being tiny and thin. If your teen is concerned about getting "fat," make an appointment for your child to talk with the CF health care team. Your CF health care team can talk with your child about nutrition and growth. The team will help you and your child set up a plan for

weight gain. To try to prevent the issue of wanting to stay thin, work hard to have your younger child with CF be as close to a normal weight as possible and to feel good about himself or herself in ways that are not related to size or appearance.

\*See CF Words to Know Glossary.



### Being Too Short

Some children do not like being small or short. A child with poor nutrition may not grow as tall as he or she could. How tall a person is depends on **genetics\*** as well as nutrition. The heights of a child's parents can be used to estimate how tall a child may be. For some children the desire to grow taller can be a reason to work hard to improve their nutrition.

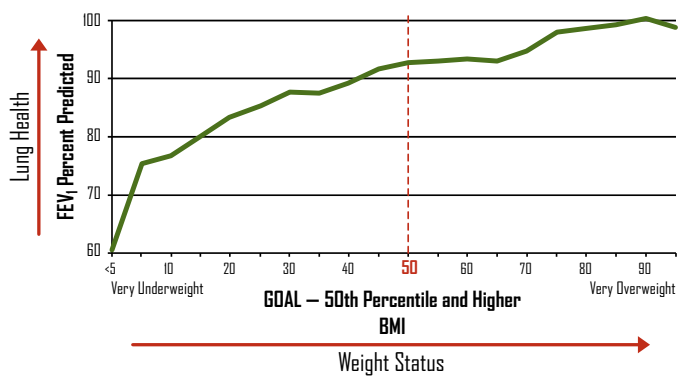
### Tracking Your Child's Growth

With good management of CF, your child should grow at a normal rate. At every visit to the CF clinic and your primary care provider's office, your child will be measured. Your child's weight and height will be tracked on a chart called a **growth chart\***. The chart shows the ranges of weights and heights for children at each age in the United States. There are separate charts for boys and girls. Growth charts allow you to track the pattern of your child's growth by looking at the **percentiles\*** of your child's weights and heights. Using the weight and height percentile, you can compare your child's size with the size of other children of the same age. Even when you notice that your child has grown, you need to refer to the growth chart to see if your child's rate of weight gain is typical for his or her age and if the child's weight gain has kept pace with his or her gain in height. Ask to see your child's growth chart at each visit.

For children 2 years of age and older, the CF health care team will also look at a measure called the **body mass index (BMI)\***. Body mass index is a number that compares a person's weight with the person's height to estimate the amount of body fat.  $BMI = \text{Weight in kilograms} / \text{Height in meters}^2$ . With children, **BMI percentiles**, rather than BMI, are used to compare children. The CF Foundation recommends that children with CF have a body mass index at or above the 50th percentile for their age. CF research has shown that having this level of weight for

height best helps people with CF maintain their lung health. Children who have a BMI that is less than the 25th percentile are considered to be at risk for increased problems with CF. For children less than 2 years of age, weight compared to length is used instead of BMI. The CF health care team tracks both your child's BMI and weight for length on growth charts.

### Lung Health and Weight Status in Children with CF (20 Years Old and Younger)



*This figure shows that lung health (as measured by FEV<sub>1</sub> percent predicted) is better for children who have better weight (a higher body mass index or BMI). The CF Foundation recommends a BMI goal of the 50th percentile or above for children from 2 to 20 years old. (Data from the 2008 CF Foundation Registry.)*

*FEV<sub>1</sub> stands for forced expiratory volume in 1 second. During pulmonary function testing, this is the amount of air that a person blows out in the first second of exhaling forcefully. If a person's FEV<sub>1</sub> is average for sex, age, and height, it is said to be 100 percent predicted. The CF Foundation recommends an FEV<sub>1</sub> goal of at least 90 percent or a child's personal best, whichever is higher.*

*A higher weight at the same height means a higher BMI. The BMI percentile compares the child's BMI to the BMIs of children of the same age and sex. A BMI at the 50th percentile means that half of the children of the same age and sex have a higher BMI percentile and half have a lower BMI percentile.*

### Using Blood Tests to Watch Nutrition

Your CF health care team will also help you watch your child's nutrition with blood tests. Blood tests are done at least once a year and sometimes more often when a child is ill or has been having a weight problem.

### Protein Levels

Protein levels, including total protein, **albumin\***, and **prealbumin\***, can be measured in the blood. Low levels most often suggest



that the child is not getting enough protein in his or her diet or is not absorbing protein because of a problem with malabsorption. Low protein levels can affect many body functions, including the body's ability to heal and to fight infection.

### Vitamin and Mineral Levels

Vitamin levels, including vitamins A, D, E, and K, can be measured in the blood. These four vitamins are of special interest in CF because they are fat-soluble and harder to absorb. The levels are checked to make sure your child is getting enough fat-soluble vitamins.

Blood levels of minerals, such as calcium, magnesium, iron, and zinc, may also be checked. Some minerals are also **electrolytes**.\* Electrolytes include sodium, chloride, **potassium**\*, and **bicarbonate**.\* Children with CF can have low electrolyte levels because they often lose more salt (sodium and chloride) in their sweat. Electrolyte levels can be checked in the blood.

### Causes of Low Weight and Poor Growth

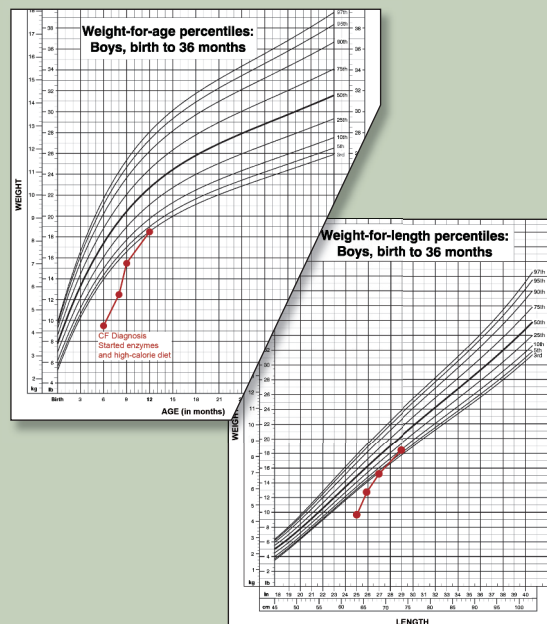
When your child has a weight problem, you need to Watch and Discover to find the reason. Work with your child's CF health care team to find the possible causes.

- Look for signs of malabsorption. If there are symptoms, treat the malabsorption.
- Watch to see if your child is taking his or her pancreatic enzymes correctly.
- Look at your child's diet. Your child may not be eating enough calories. Working with your CF health care team, you can make a plan and set goals with your child so he or she will eat more calories and gain weight.
- Look for signs of respiratory infection. If there are signs of infection, it must be treated. To learn more about managing respiratory infections, see the module *Managing Lung and Other Respiratory Problems*.

### WHAT YOU CAN DO

#### Using a Growth Chart

Ask for a copy of your child's growth charts. Have the CF dietitian or another team member show you how to keep track of your child's growth. You can bring the growth charts with you to future clinic visits and have new measures added as your child gets older. You can learn more about growth charts for children in the United States at the Centers for Disease Control and Prevention Web site (<http://www.cdc.gov/growthcharts/>).



*Example Growth Charts: A newly diagnosed infant whose growth improved after he started eating a high-calorie diet and taking enzymes.*

#### Using a Food Diary

If you are not sure whether your child is getting enough calories, you can keep a food diary. Write down everything your child eats and drinks, including the amount. (For example, record 6 ounces of whole milk or 1/2 cup of Jell-O brand chocolate snack pudding.) Your CF dietitian can tell you how to keep a diary. You may keep the diary for a few days or for a week. The dietitian can look at it and give you an estimate of how many calories your child is getting. The dietitian can also look to see if your child is getting the right balance of different types of nutrients, such as protein or calcium. You can use "My Child's Food Diary," a worksheet in the back pocket of this module.

\*See CF Words to Know Glossary.



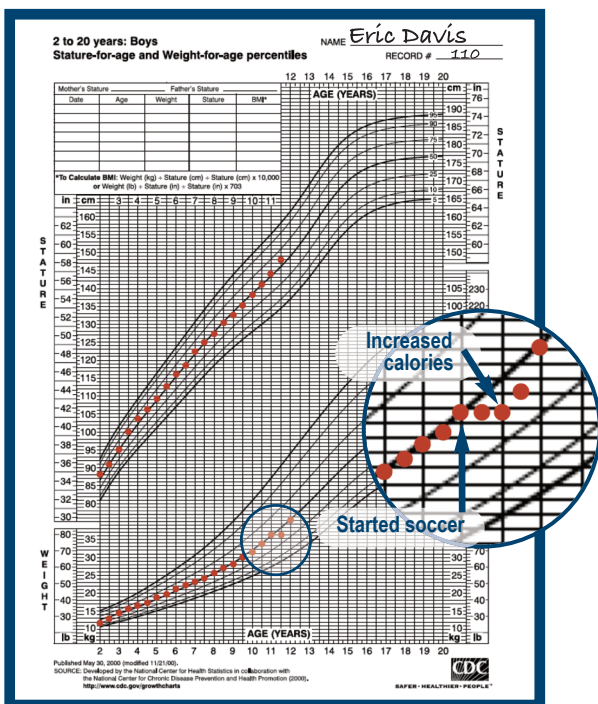
## LEARNING FROM OTHER FAMILIES

# Eric

"I'm worried—Eric is not gaining weight and I don't know why."  
(Mrs. Davis, mother of 11½-year-old Eric)

Even though he has CF, Eric Davis never had trouble gaining weight. His BMI (body mass index) had been at the 50th percentile for his age (which means that half of the boys of the same age weigh more and half weigh less than Eric). At Christmas, Eric weighs 77 pounds. Eric's mother notices that he is still in the same clothes he had worn a year ago. She is concerned and has him check his weight at home every few weeks.

### Eric's Growth Chart



The bottom curve shows Eric's weight at age 11½. Notice how his weight stays the same (flat or level) after he starts soccer and how it starts to improve (go up) after he increases his calories. The top curve shows that Eric had height growth all through this time at the 50th percentile for boys his age.

At his March checkup he weighs the same. Eric has not gained any weight but he should have for his age. Mrs. Davis asks his CF doctor about Eric not gaining weight. The problem is not that



Eric is losing weight, but that he is not gaining. They look together at Eric's growth chart. At age 11½, Eric should weigh 82 pounds, not 77, to remain at the 50th percentile.

The doctor describes Eric's lack of weight gain as "falling off his growth curve." This means Eric has not continued to gain weight as well as he had in the past. Eric's height, however, is still increasing at the 50th percentile.

Before the visit, Eric and his mother had watched together to try to discover why he wasn't gaining weight. Eric took his enzymes with all his meals and snacks. They talked about and did not see any signs of malabsorption. He was not having any respiratory problems. The only change they noticed was in Eric's activities. This year he was on a soccer team and practiced two times every week, with games on the weekend.

Eric and his mother talk with the CF dietitian and doctor and decide that he's not gaining weight because he needs more calories. The doctor congratulates them for discovering that Eric has a nutrition problem and coming in to figure out how to fix it. Eric wants to keep playing soccer and the doctor tells Eric to keep playing. The doctor points out that exercise is good for Eric's health and fitness. The CF dietitian talks about how many calories a boy Eric's age typically needs and the extra calories he needs because of playing sports and having CF. They talk about how to Watch and Discover to make sure his weight improves. Eric and Mrs. Davis make a plan with the CF dietitian to take action and have Eric eat more calories.



## THINK AND ACT

### MAINTAINING GOOD NUTRITION

#### Meeting Calorie Needs

For your child to eat more calories, you may need to take specific steps and set a calorie goal with your CF health care team. For example, along with regular meals, your child may need to have several healthy, high-calorie snacks to get enough calories. (See p. 10, **WAYS TO BOOST CALORIES.**)

Your dietitian, CF doctor, and you will decide if your child's calorie needs are being met. The dietitian and doctor can help you define calorie goals for your child and help you decide what actions you and your child can take to reach them. If meals and snacks are not enough to meet your child's calorie needs, the dietitian may suggest special formula or **high-calorie supplements\*** (such as PediaSure<sup>®</sup> or Ensure<sup>®</sup>) to increase calories and help your child reach his or her goal. (See **HIGH-CALORIE SUPPLEMENTS**, p. 12.)

#### High-Calorie Diets for Babies

##### Breastfeeding and Formula Feeding

Babies drink all or most of the calories they need. Most babies with CF will be hungry and eager to drink. Babies who have malabsorption will need enzymes to help them **digest\*** breast milk and infant formula.

Breast milk is good nutrition for babies and has other benefits, such as helping fight infection. If you are breastfeeding your baby, talk with the CF health care team about his or her nutrition. Some infants who have CF grow well on breast milk alone. Other babies need formula, along with breast milk, to get enough calories.

If you are bottle-feeding your baby, the CF health care team may suggest that you use a stronger version of regular infant formula that

has more calories per bottle. The team will show you how to mix the formula if your child needs more calories. **This is NOT something you should do on your own. Follow the team's instructions carefully.** Just as adding too much water to powder formula can cause problems, adding too little water can also cause medical problems. The team may recommend an infant formula higher in calories or easier to digest to meet your child's needs.

#### Solid Food

Your baby is no different from babies without CF when he or she starts on solid foods in the first two years of life. During a baby's first year, most of the calories he or she needs will still come from milk or formula. Babies need to learn to eat solid foods. This is an important **developmental task\*** as babies reach six months and older. Before you start your infant on baby food and other solids, talk with the CF dietitian or doctor about any changes in your child's enzymes.

#### Whole Milk

When babies are a year old and gaining weight well, they are probably ready to switch from formula or breast milk to whole cow's milk. Talk with the CF dietitian and doctor so they can help you make any needed change in your child's enzyme dose. They can tell you how much milk your child should drink every day. Talk with the CF dietitian about when and



how to change your child to whole milk. Whole milk has more calories, fat, and protein than other milk (such as skim, 1%, or 2%) and is better for children and adults with CF.

\*See **CF Words to Know Glossary**.



### High-Calorie Diets for Children

Many children are not able to eat large amounts of food at one time. To help children with CF get plenty of calories, parents need to give them foods for meals and snacks that are packed with calories—we call these foods **calorie dense**.\* For example, one cup of macaroni and cheese has many calories and is considered calorie dense. On the other hand, one cup of strawberries has very few calories. If children take the same amount of time to eat a cup of food, they will get many more calories in that same time from the calorie-dense food. Many children are interested in eating for only a short period of time. For these children, foods that fill them up without providing lots of calories should be limited. Your CF dietitian can also tell you what you can add to everyday foods so that your child gets extra calories in each meal and snack.

### Adding Fat

**Fat**\* contains more calories than other types of nutrients and also makes foods taste better. Fat can be added in many ways to increase the calories in food. Often foods high in fat, such as cheese, milk, ice cream, and meat, are also good sources of protein. Protein helps increase calories in food and also helps the body recover from illness or infection.

For most people with CF, however, fat is the most difficult kind of food to digest. In the past, people with CF often limited the amount of fat they ate because they did not digest it well. Now that there are better enzyme supplements available, children with CF can and should eat fat. Most people with CF find that by taking enzymes they can digest the extra calories in fat without having symptoms of malabsorption. Even so, enzymes may not always solve all of the problems with digesting fat. Some people find that even when they take enzymes, the amount of fat they can eat is limited. If they eat too much fat, they have symptoms of malabsorption. (See pp. 19-21, **SIGNS AND SYMPTOMS OF MALABSORPTION**.)

### WAYS TO BOOST CALORIES

Limit low-calorie foods that fill up your child without supplying very many calories (for example, salads, fruits, and vegetables). When you serve lower-calorie foods, add "extras" to increase calories.

Add margarine or butter to bread, cereal, rice, noodles, potatoes, and vegetables. Use mayonnaise or margarine on sandwiches.

Add sour cream to meat, potatoes, vegetables, casseroles, and fruit.

Use cream sauces or gravies with meat, vegetables, and casseroles.

Add extra salad dressing to salad.

Add whipped cream to hot chocolate, fruit, pudding, pie, and other desserts.



Add syrup, jam, or jelly to ice cream.

Use peanut butter, or extra jam, jelly, and honey on toast, bread, muffins, biscuits, and crackers.

Use cream to prepare soup, cereal, hot chocolate, and pudding with half-and-half or cream.

Serve whole milk and other whole-fat dairy products, such as American cheese and yogurt.

Add cheese to scrambled eggs, sauces, vegetables, soups, casseroles, and salads.

Add extra eggs to sauces, casseroles, and salads.

**Note:** Extra calories may be added to foods the rest of the family is eating or just to the portions served to the child with CF. If the rest of the family doesn't need the extra calories, you may find it easier to use only the ideas that allow you to add calories to your child's portion. If none of these ideas fit your family's diet or food preferences, talk with the dietitian on your CF health care team.



Using the ideas in **WAYS TO BOOST CALORIES**, you can add extra calories to the foods your child eats. Many are ways to add fat to everyday foods. Watch for signs of malabsorption as you add these calories and check with your CF doctor or dietitian to see if your child needs more enzymes. Some of the foods with added fat become very rich and filling. You may have to



gradually increase the amount of extra fat that you add to help your child become used to eating richer food.

### Building Your Child's Appetite

Here are five ideas for helping your child build his or her appetite and develop good eating habits.

- 1) Schedule regular eating times. Your child will form a habit and expect to eat at the regular meal and snack times. Your child's body will begin to prepare for food at these times. Children may also feel less pressured to eat when they do not face food all the time.
- 2) Limit meals to a reasonable length of time—about 20 minutes. By limiting mealtimes, you can space meals three or four hours apart. This will give your child a chance to get hungry and to look forward to the next meal. A shorter mealtime may prevent endless meals that seem like punishment for the child and the family. Children are less likely to eat as the meal drags on. Don't threaten your child with ending the meal; when the time limit is reached, the family simply leaves the table.
- 3) Make meals positive, social times. Have the family sit together, eat, and visit with each other. Watching TV or reading can be done at other times. Avoid conflicts or unpleasant topics of conversation during meals. Eat in a specific eating room, such as the dining room or kitchen. This special place will begin to signal eating. Many children prefer to eat with other people around. Starting from an early age, children can enjoy sharing mealtimes with parents and other family members.
- 4) Limit distractions. Try to limit having things in view, such as toys or video games, that would tempt your child to leave the table or distract him or her from the task of eating. Turn off the television for mealtime.
- 5) Use your child's developing skills. Allow children to feed themselves when they are ready. Children eat better when they feed themselves than when parents continue to feed them. Children can also help with menu planning and preparing the food. Having some say about what is prepared can create excitement about meals.



## TIPS

### From Other Families

Make a list of high-calorie bedtime snacks for your child to choose from.

Think of ways to turn lower-calorie snacks (such as crackers, apples, and cereal) into higher-calorie ones by adding peanut butter, butter, or cheese. (Adding calories may make snacks a bit more messy—when you're on the go, put snacks in small plastic bags and bring along some wipes.)



Don't get hung up on traditional foods for each meal. If your child doesn't like breakfast food, but will eat a hamburger, sandwich, or creamed soup at breakfast, let him or her have it (but only if it's convenient to make—if not, serve a high-calorie breakfast food).



Change your thinking that access to all foods has to be "fair" within the family. Your child with CF may be able to eat all the chips he or she wants, but your other children probably need to limit their high-fat snacks. By the time your other children reach school age, they can learn that their brother or sister with CF needs to take medicine *and* gets to eat all the high-fat snacks he or she wants. But, they can also understand that eating lots of high-fat foods is not okay for children without CF.

### Using Snacks Wisely

Some children who snack all the time don't eat well at meals. Snacks are not a substitute for meals. Children should have regular mealtimes in addition to snacks. But, if snacks are used wisely to help develop a child's appetite, they can add calories without interfering with mealtime eating.



To help your child eat enough calories, serve him or her snacks that are like small meals. Instead of caramel corn, for example, a child might have peanut butter crackers and a box of raisins. You might even serve leftovers from lunch or dinner. Make sure the snacks are high in calories.

#### HIGH-CALORIE SNACK IDEAS



Here is a list of high-calorie snacks. Your CF health care team and other parents may have more snack ideas you can try.

- Peanut butter or cheese spread on crackers, bread, muffins, bagels, fruit, and vegetables
- Milkshakes or smoothies made with ice cream, cream, powdered milk, breakfast drink powders, yogurt, fruit, or several of these ingredients
- Breakfast or granola bars



#### Eating Jags

Some children select a favorite food and, for a time, they may want to eat little else. Toddlers and preschoolers are most likely to go on food jags. Parents can try to get their children to select high-calorie foods for these food jags. Or they may be able to add calories to the favorite food. A child who wants to eat crackers for every snack may eat them with peanut butter, cheese spread, or a bologna slice.

#### Feeling Full

Children may complain that they are too full to eat more. Rather than pushing your child to eat more at any one time, try to provide high-calorie snacks in between regular mealtimes. You may want to give snacks (“small meals”) more often throughout the day if your child often feels full and cannot eat very much at one meal. If this happens often, talk with your CF dietitian and doctor about what else you could do or if there is another problem.

Children are more likely to eat well if eating is pleasant for them. Once children are 10 or older, they can start to understand the value of extra calories and may be able to push themselves to eat more than they really want for the sake of their health.

#### When High-Calorie Foods Aren't Enough Catch-Up Times

Catch-up times often come after a child has had an infection or a problem with malabsorption. To gain weight, the child will need even more calories than usual. At these times, you will need to make a special effort to help your child get more calories. Your child may be able to eat enough calories if you use the ideas discussed above. But some children find it hard to eat the large amount of food they need to catch up. Working with the CF health care team, you might set a target for your child's weight gain and decide to have your child try a high-calorie supplement.

#### High-Calorie Supplements

Very high-calorie, ready-to-drink beverages or supplements are available. Your child may drink these high-calorie products between and with regular meals and snacks. Your CF center will have more information about these and other products. Some examples for young children are PediaSure<sup>®</sup> and Enfamil<sup>®</sup> Kindercal<sup>®</sup>. For older children, high-calorie supplements include Ensure<sup>®</sup> and Ensure Plus<sup>®</sup>, Equate<sup>®</sup> and Equate Plus<sup>®</sup>, Boost<sup>®</sup> and Boost Plus<sup>®</sup>, and SCANDISHAKE<sup>®</sup>. Breakfast drink powders (such as Carnation<sup>®</sup> Instant Breakfast<sup>®</sup>) mixed with whole milk have about the same amount of calories as some of these supplements. You can also make your own high-calorie milkshakes. The dietitian or another member of the CF health care team can help you figure out what your child needs.







### Finding a High-Calorie Formula or Supplement

You can find many formulas and supplements at the grocery or drug store. If you are unable to find something the CF health care team has suggested, call and talk with the CF center dietitian or nurse. He or she may know who carries it. You can also talk to the store manager or pharmacist to see if it can be ordered for you.

### Paying for Formula or Supplements

If you need help to pay for formula or supplements, talk with your CF social worker. In some states, Medicaid will cover the cost of formula or supplements for people who qualify. The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is a government program that, if you qualify, may also be of help to you. Some insurance companies pay for vitamin and mineral supplements if they are available only by prescription. Some companies that make enzymes offer special programs that will provide some vitamins and high-calorie supplements. Your CF dietitian can tell you more about how your child might qualify.

### High-Calorie Food Additives

The CF health care team may suggest some products (called **high-calorie food additives\***) that can be added to food to increase the number of calories. Talk with your CF dietitian or doctor to find out the correct amount of additives to use. Some examples are:

- **Polydose** – a **carbohydrate\*** powder that can be added to food and drinks to add calories without changing the taste. One example is SCANDICAL<sup>®</sup> Calorie Booster, a taste-free powder that adds 35 calories per tablespoon.  
**Note:** *Make sure you find out how much polydose your child should have. Eating too much polydose may cause **diarrhea\***.*
- **MCT oil** – a fat solution that can be added to food and is easier for children with CF to digest than other fats.
- **Corn oil** – a liquid form of fat that can be added to food to increase calories.

### Other Ways to Get More Calories

If your child cannot eat enough food and supplements, you can talk with your CF health care team about other ways to help your child get more calories. You should talk about these options before your child has severe nutrition problems. If your child needs extra help to get enough calories, it does not mean you are not trying or have failed. There are times when most children with CF need extra help. Keep in mind that your goal is to help your child be well and make sure his or her nutrition is the best it can be.

### Nasogastric Feeding Tube

A **nasogastric tube\*** (or NG tube) is a very small, flexible plastic tube that is put in through the nose, down the back of the throat, and into the stomach. High-calorie liquids are put down the tube into the stomach. Young infants or children who have been very sick and are not able to eat enough may sometimes have an NG tube. When the child no longer needs the tube, it is easily removed. Children who have an NG tube can have feedings throughout the day or a **milk drip\*** at night. A feeding pump drips formula in slowly overnight. Usually the child takes enzymes by mouth before a **bolus feeding\*** or before and after a night feeding. A child can still eat food even with the NG tube in place and the tube will not interfere with breathing. The feeding tube can be left in place for weeks and then changed if the child needs to be on nasogastric feedings longer.

### Gastrostomy Tube or G-Button

Instead of an NG tube, the CF health care team may sometimes recommend a **gastrostomy tube\*** (also called GT, G-tube, or G-button) if a child needs help getting extra calories for a long time. A **surgeon\*** inserts a flexible tube or a small plastic device through a small incision in the **abdominal wall\*** and directly into the stomach. The tube or button is left in

\*See CF Words to Know Glossary.



place all the time. A child can still swim and play with a GT in place. Children with a G-tube or button can be given high-calorie liquids either during the day (called a bolus feeding) or as a milk drip at night. A feeding pump drips formula in slowly overnight. Usually the child takes enzymes by mouth before a bolus feeding or before and after a night feeding.

Some people prefer using a gastrostomy tube because they find it more comfortable and less noticeable than the NG feeding tube. If a child gains weight and does not need the extra feedings, the G-tube can be removed. The opening closes as it heals.

Children with CF and their families learn how to take care of the G-tube. If the tube gets pulled out by accident, it can usually be replaced without more surgery. Your CF health care team and surgeon can tell you more about the risks of having gastrostomy surgery and whether this is something that would help your child. Your CF health care team can also show you and your child what a gastrostomy tube looks like and how it works before you actually make a decision.

#### **Intravenous (IV) Total Parenteral Nutrition (TPN)**

Occasionally a child receives special fluids through a **catheter\*** placed directly in a large vein. This is called an **IV\***. Children who are in the hospital and are too sick to eat anything or to have tube feedings may receive all of their nutrition **intravenously\*** (through an IV). It may also be used by children who can only take some nutrition through the intestines. This is called **total parenteral nutrition (TPN)\***. Total Parenteral Nutrition has a greater risk of problems, such as electrolyte imbalance, liver irritation, and infection. How long IV nutrition is used depends on how many calories the child needs, his or her ability to eat, and how well the intestines are working.



#### **ADDING VITAMIN-MINERAL SUPPLEMENTS AND SALT** **Vitamin and Mineral Supplements**

Most people with CF do not get enough vitamins and minerals from the food they eat and they need to take vitamin and mineral supplements. Your child's CF health care team will prescribe the type and amounts of vitamins and minerals you should give your child. Be sure to give only the amount prescribed by your CF health care team. Taking greater amounts of vitamins does not make



a child healthier. In fact, too much of some vitamins can be harmful. ADEKs,<sup>®</sup> AquADEK,<sup>™</sup> SourceCF,<sup>®</sup> and Vitamax<sup>®</sup> are some examples of vitamins made for people with CF. If you buy vitamins not made for children with CF, such as the chewable vitamins you get at the grocery store, your doctor may need to prescribe doses of other vitamins. Check with your CF dietitian to see how many your child should take and what is included in the vitamin supplement. Bring the label or a list of ingredients to the CF center and go over it with the CF dietitian.

**Note about vitamin K:** *Some children may also need to take extra vitamin K when they are on antibiotics. Normally half of the body's vitamin K comes from diet and the other half is produced by the bacteria in the intestines. Antibiotics can sometimes destroy the good bacteria in the intestine, which means there will be less vitamin K available for the body. Ask your CF health care team if your child needs extra vitamin K.*

#### **Salt**

People with CF lose more salt in their sweat than do other people. This can cause dehydration and a dangerous imbalance in the body's electrolytes.





Breast milk, commercial baby foods, and infant formulas contain very little salt; therefore, you may need to add extra table salt to your baby's diet. Talk with your CF health care team about how much extra salt you should add.

As children get older, they usually begin to like more salty foods and will usually get enough

salt in their diets. Allow your child to add extra salt to foods as he or she wishes. In hot weather and during sports or other physical activities, however, your child may need even more salt and fluids. Talk with your CF doctor or dietitian about how to add enough salt to your child's diet.

#### WHAT YOU CAN DO

Use the worksheets "What to Feed My Baby" or "What to Feed My Child" in the back pocket of this module when you talk with the CF dietitian or another member of the CF health care team about what to feed your infant or child. Most children with CF take enzymes with food. You will notice there are blanks to list the brand and number of enzymes your child needs to take with each meal or snack. Many families prefer having information about enzymes and meals in one place. You will learn more about malabsorption and using enzymes in this module. You can photocopy the worksheet and share it with others who help feed your child.

#### Planning a High-Calorie, High-Protein Diet

- Fitting extra calories into your child's diet may take some planning. Make a list and plan ahead what to buy at the grocery store.
- Find high-calorie snacks that are easily available (or snacks your child can prepare alone).
- Allow for extra time to prepare and add extra calories and protein to meals. Writing out daily or weekly menus may make it easier to plan and buy the food you need.

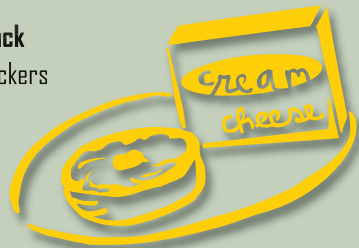
Here is a sample menu for a day.

#### Breakfast

- Cereal with half-and-half
- Toast with butter or margarine, peanut butter and jelly
- Whole milk
- Orange juice

#### Mid-Morning Snack

- Cheese and crackers
- Grape juice



#### Lunch

- Cream soup
- Meat spread or lunch meat sandwich with margarine or butter, mayonnaise, and cheese
- Fresh fruit in cream
- Whole milk



#### Afternoon Snack

- Graham crackers or apple with peanut butter
- High-calorie milkshake

#### Supper

- Fried chicken
- Rice with gravy
- Broccoli with cheese sauce
- Bread and margarine or butter
- Strawberry shortcake with whipped cream
- Whole milk



#### Evening Snack

- Banana pudding with whipped cream
- Vanilla wafers
- Whole milk



## LEARNING FROM OTHER FAMILIES

# Chloe

"My daughter has always been a picky eater and would rather play than eat, but she is not growing and gaining enough weight for her height. Even the extra calories from supplements aren't making a difference. I feel like I'm doing something wrong." (Mrs. Strake, mother of 4-year-old Chloe)

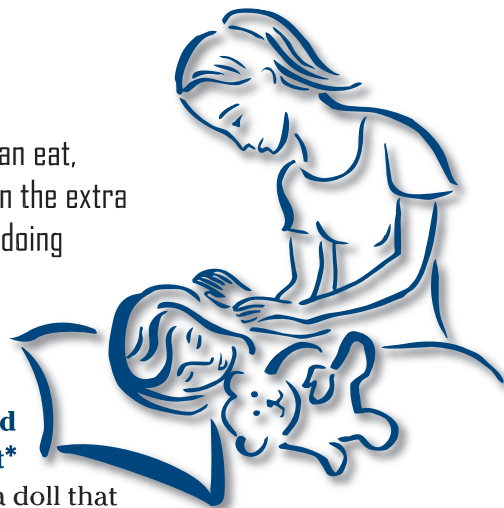
Chloe Strake, a 4-year-old with CF, has always been a picky eater. Her family has struggled to get her to eat enough calories. She likes to play more than eat. Chloe has no problem taking her enzymes. At her most recent CF clinic visit, she had not gained enough weight. She had several respiratory infections during the winter and when she is sick, she does not want to eat and loses weight. The CF dietitian suggests that Mrs. Strake add two cans of Pediasure® daily to Chloe's snacks.

Chloe and Mrs. Strake return to the clinic in six weeks. Mrs. Strake looks at Chloe's growth chart with the CF dietitian. Chloe has stayed in the 25th percentile for height. She has gained some weight since her previous visit, but compared to her height, her weight is still low. Chloe's body mass index (BMI) is only in the 10th percentile. Her mother has watched and has discovered no signs of malabsorption. Chloe's CF doctor shares the team's concern about Chloe's lack of growth and how it increases her risk of lung infection. He talks with Mrs. Strake about putting in a gastrostomy tube (GT) to give Chloe more calories as a milk drip at night while she sleeps. During the day, Chloe would still be able to eat. Mrs. Strake is worried about Chloe having surgery. The team gives Mrs. Strake a booklet to share with Mr. Strake about the surgery to insert a GT. The CF dietitian also gives her a booklet about using a GT to look over with Mr. Strake. She talks with Mrs. Strake about how a GT would work

with Chloe's diet. The **child life specialist\*** shows them a doll that has a GT. Before a decision is made about surgery, Mrs. Strake will keep a food diary and try to get Chloe to drink three cans of Pediasure® each day. They will return to check her weight in three weeks.

Three weeks later, the family returns to the clinic. Chloe has not been sick. She gained a little weight. Her mother still struggles to get her to drink the Pediasure® and eat her meals. Based on her diary, it appears that Chloe only eats about 80 percent of the calories she needs. The family also talked with another parent whose child has CF and uses a GT. The parent told them how at first she felt like a failure because she couldn't get her child to eat enough. After getting the GT, she realized it was the right decision. It has really helped her child and made their mealtimes better. Chloe's parents talk with the surgeon and make a plan for surgery. A child life specialist works with Chloe to prepare her for surgery.

Chloe has surgery and spends a few days in the hospital. Chloe's parents find that she tolerates the milk drip well and has started to gain weight. She still is picky at mealtime but the Strakes do not have to worry as much. They hope that Chloe will be able to have the GT taken out when she is older and starts to eat better. Chloe even helps her mother hook up the milk drip at night.





## MAKING IT WORK FOR YOU

### FEEDING PROBLEMS

Every parent has trouble at times feeding a baby or toddler, or getting an older child to eat. Young children often have times when they are not interested in eating or only want to eat certain foods. You may have special problems

feeding your child with CF. You will want to use Watch and Discover and Think and Act to work out these problems.



Eating should be a normal and pleasant part of life. When parents are anxious or pushy at mealtimes because a child doesn't eat enough, the child will find it hard to enjoy eating. Older children (usually 10 years or older) may begin to understand that they need more calories. They may be able to push themselves to eat beyond their hunger or appetite. But all children will eat more if mealtimes are a pleasant experience.

If you are worried that your child is not eating enough, talk with your CF health care team. Don't push or force food on your child. Eating could easily become a battle between frustrated parents and their child. The CF health care team can help you figure out if your child needs more calories and how he or she might get them most easily. You may find it helpful to work with a child **psychologist\*** if you continue to struggle with your child's

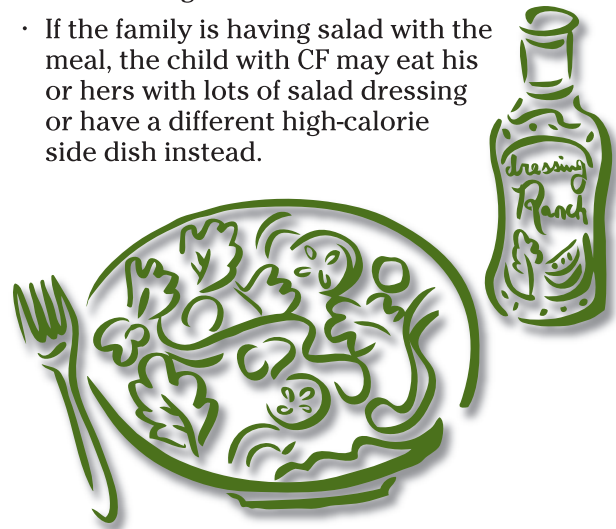
eating behavior. You can learn more about helping your child cooperate in the module *Working with Your Child*. Another resource you might find helpful is the book *Child of Mine: Feeding with Love and Good Sense* by Ellyn Satter (3rd Edition, 2000).

### Planning Meals for the Whole Family

Good nutrition is important for everyone. But the high-calorie diet of a child with CF may not be healthy for other members of the family. The recommended diet for most people older than 2 years is low in fat and high in fiber.

Juggling two types of diets in one household can be hard. Your children who do not have CF need a diet that will be healthy for them in the long run. Here are some ways other families have managed two diets:

- Separate pitchers or containers are used for high-calorie drinks and foods.
- The same main ingredient may be used for everyone's meal. The portion for the child with CF, however, may have extra sauce or added margarine or cheese.
- If the family is having salad with the meal, the child with CF may eat his or hers with lots of salad dressing or have a different high-calorie side dish instead.



\*See CF Words to Know Glossary.



## LEARNING FROM OTHER FAMILIES

### Eric PART 2:

"Now that we know Eric needs more calories, I'm trying to figure out how I can make the time to plan meals for everybody in our family. Even though Eric needs to gain weight, the rest of us don't!" (Mrs. Davis, mother of 11½-year-old Eric)

Eric Davis has not been gaining weight well. He and his mother met with the CF health care team and figured out that he was using more energy playing soccer and not getting enough calories to grow. Now Eric and his family need to make a plan to get more calories into his meals and snacks. At first Eric's mom was afraid that she would not have the time she needed for extra meal planning. She did not feel confident in knowing how to increase Eric's calories without making the rest of the family's diet unhealthy.

Eric and his mother talk to the CF dietitian about how to add more calories to his diet. Mrs. Davis is surprised that she is able to make a fairly simple plan to help Eric gain weight. As they talk, she realizes that the family has been skipping meals together as their schedules have gotten busier. Because Eric's favorite foods are fruits and vegetables that is what she has been



buying. With the CF dietitian's help, Eric and his family make a food plan.

#### ERIC'S FOOD PLAN

- Work with the whole family to eat meals together and get back on a schedule.
- Work out a list with Eric of his favorite high-calorie foods. Add them to his lunches and snacks.
- Arrange for Eric to get extra-large servings when he eats the school hot lunch.
- Add butter to Eric's vegetables, buy the full-fat dressings for Eric's salads and vegetables, and have whipped cream and pudding available to go with his fruit.
- Make sure Eric eats salty snacks before and after soccer and drinks fluids containing extra electrolytes when he is playing soccer.

Eric and his mother plan to go shopping on the way home to stock up on foods he likes so he can start his plan right away.

#### WATCH AND DISCOVER: HOW IS YOUR PLAN WORKING?

You have noticed a problem, talked about the problem, made a plan, and have taken action to solve the problem. Now you have to see if your plan is working. You will be watching closely any time you make a change in enzymes or increase calories. Talk with your CF health care team about how long a time you can expect to WATCH before you know if something is working. For example, with a change in enzymes, your

child should show improvement in symptoms within a week or less. If your child does not improve, or if your child's symptoms get worse, talk to your CF health care team.

With your efforts to increase your child's calories, your child should gain weight. But this may take time. If you are not seeing any improvement in the expected time, talk to your CF health care team about changing your plan.



## MALABSORPTION

**M**ost people with CF have trouble digesting and absorbing the calories and nutrients from the food they eat. This problem is called malabsorption. To grow and gain weight, people with CF need to take enzymes when they eat. You will learn how to give your child enzymes and how to WATCH AND DISCOVER symptoms of malabsorption.

### CF AND DIGESTION

The **pancreas\*** (a gland behind the stomach) makes **enzymes\*** that are used in the **small**



**intestine\*** to digest food. The enzymes break down fat and protein. Cystic fibrosis often causes a **blockage\*** in the **ducts\*** (tubes) going from the pancreas to the small intestine. If there is a blockage, the enzymes cannot reach

the small intestine. As a result, breast milk, formula, and any foods that contain protein and/or fat are not digested well. The calories from fat and protein are not absorbed from the intestines into the rest of the body. The body is not able to use these foods for energy and growth. (For more information, see “CF FACTS – THE DIGESTIVE SYSTEM” in Appendix 1). When children with CF are unable to digest their food very well, they have malabsorption. A child with malabsorption may have poor nutrition, problems growing, and trouble fighting infections.

How severe malabsorption is varies from one person with CF to the next, and can change over time. Some people with CF do not have malabsorption. Sometimes the CF health care team will order lab tests to check for malabsorption. The CF health care team will depend on you (and your child as he or she gets older) to watch for symptoms of malabsorption.

The CF health care team will work with you as you learn how to:

- Watch and Discover the signs and symptoms of malabsorption.
- Think and Act to make a plan for what to do when you notice signs and symptoms.



### WATCH AND DISCOVER

#### MALABSORPTION

##### Signs and Symptoms of Malabsorption

You will want to Watch and Discover for signs and symptoms of malabsorption even when your child is taking enzymes. Your child’s enzymes will need to be adjusted as your child eats more. Watch for the following signs and symptoms in your child.

##### ■ Change in the Number of Stools

Watch to see how often your child has **bowel movements\*** (stools) each day. Undigested food causes a child to have larger and more frequent stools. You will notice you have to change diapers more or that your child may have to make more trips to the bathroom. People tend to develop bowel habits that are “normal” for them. As you watch for malabsorption, you may find it helpful to know how many stools a day are “average” for children of different ages.

**Infants** – One to four bowel movements a day (breast-fed babies may have a bowel movement with nearly every feeding)

\*See CF Words to Know Glossary.



**By age 2 years** – Two or three stools a day

**Children aged 4 years and older and adults** – One or two bowel movements a day

More stools than is usual for your child is a sign of malabsorption and your child's enzymes may need to be adjusted.

#### ▪ **Change in Stools**

Stools can also change in look, size, and odor with malabsorption. Changes to watch for include:

- **Size** - Larger stools.
- **Loose stools** - Stools that look bulky and soft and are not well-formed may be due to malabsorption. The stool is not usually watery with malabsorption (See OTHER CAUSES OF LOOSE STOOLS, p. 21). Many children do not have well-formed stools until they are 2 years old. Look for a change in what is usual for your child.
- **Greasy or floating stools** - The stool may look as though it has grease or oil in it. If your child is toilet trained, the stool may also float or there may be oil in the toilet. These are signs that your child's body is not able to absorb enough fat.
- **Odor** - Stools may smell worse than usual.

If you notice any of these signs or symptoms, talk to the CF health care team. They may need to adjust your child's enzymes.

#### **Other Signs and Symptoms of Malabsorption**

##### ▪ **Slow Weight Gain or Weight Loss**

If the body does not absorb enough calories, a child will lose weight or will not gain weight as expected. You should look at your child's growth chart during visits to your CF center and to your child's primary care provider to make sure he or she is gaining enough weight.

##### ▪ **Excess Gas**

This may be the first change you notice with malabsorption. Bacteria that live normally in our **large intestine\*** (**colon\***) can break down undigested food that passes from the small

intestine. This makes gas (**flatus\***). The more food that is left undigested, the more gas that is made. The gas may also smell bad.

##### ▪ **Bloating**

With malabsorption, the child's **abdomen\*** may become distended, which makes the belly look more round and bloated. Excess gas and extra stool in the intestine cause the bloating. Bloating can make your child feel full. When this happens, your child may not eat enough. Sometimes the child's belly will also feel firmer than usual.

**Note:** *Bloating caused by gas is different than the temporary bloating caused by having a full tummy. After infants and young children eat, their bellies look round and full. This fullness goes away as they digest the food or milk. When gas causes bloating, the bloating does not start when the child is eating and does not go away in the hours after the meal.*

##### ▪ **Cramps and Abdominal Pain**

Your child may say he or she has a stomach-ache. Young children, however, may not be able to tell their parents if they have a stomachache. Instead, parents may notice that their infant or young child seems uncomfortable or fussy, especially during or after their child eats. Sometimes parents can tell when young children are uncomfortable and their belly hurts before they have a bowel movement.

##### ▪ **Increase in Appetite**

Children's appetites normally change a little from one meal to the next and from day to day. Look for longer-term changes. If your child seems to be eating a lot more than before it may be a symptom that he or she has malabsorption and is not absorbing enough calories. Even though your child may be eating more, his or her hunger is not satisfied because the food is not absorbed well. If you notice a change in your child's appetite, look for the other signs and symptoms listed here.





### ■ Rectal Prolapse

In **rectal prolapse**\*, part of the **rectum**\* sticks out of the **anus**\*. The rectum is the very end of the large intestine that is connected to the anus (the hole where stool comes out). When a child strains to push stool out, the rectum may push out. Poor muscle tone and large, bulky stools that are hard to pass cause prolapse. Children younger than 3 years have rectal prolapse more often because of malabsorption. Although it can be frightening to see, usually it is not dangerous. The rectum often goes back in by itself when the child relaxes or it can be gently pushed back in. If it does not go back in, the child needs to be checked right away. If your child has rectal prolapse, talk with your CF doctor to find out how to prevent it.

### OTHER CAUSES OF LOOSE STOOLS

Sometimes the symptoms of malabsorption are similar to those of acute diarrhea or **lactose intolerance**\* (inability to digest a sugar found in milk and other dairy products). Here are some clues that can help you and the CF health care team figure out if another problem is causing a change in digestive symptoms.

### Acute Diarrhea

Sometimes parents are confused about whether their child is getting too few enzymes or having acute diarrhea. Diarrhea is not treated by adjusting enzymes.

Diarrhea is most often caused by infection with certain **bacteria**\* or **viruses**\* and is a common illness among young children. In both diarrhea and malabsorption, you often see a greater number of stools in a day. Diarrhea usually creates different changes in a child's stools than those you will see with malabsorption. In diarrhea, the stools are watery and runny rather than large and bulky.

Here are some clues that your child has diarrhea:

- Many watery stools
- Friends or family members have the same illness
- Symptoms appear suddenly rather than gradually
- Symptoms last one to two days
- Fever (usually more than 100.4° F)
- Stomach pain
- Nausea (stomach upset)
- Vomiting (this does not happen with malabsorption unless there is a severe blockage in the intestines)

If you notice any of these clues, more than likely your child has acute diarrhea. Talk to your child's primary care provider or CF health care team about managing diarrhea. If your child does not have any of these signs or symptoms, it is more likely that your child is having a problem with malabsorption.

### Diarrhea from Antibiotics

**Antibiotics**\* can sometimes also cause diarrhea. In this case, there will be many watery stools, but it is unlikely your child will have a fever, nausea, or vomiting. The diarrhea will usually stop when the antibiotics are stopped. If you think your child is having diarrhea because he or she is taking an antibiotic, talk to your CF center nurse or doctor. If the symptoms are not too serious, the doctor may want you to continue the antibiotics. The doctor may have suggestions about how to prevent the diarrhea from getting worse. If the diarrhea is severe, the CF doctor may want to change your child to another antibiotic.

\*See CF Words to Know Glossary.



Diarrhea can lead to **dehydration\*** (not enough water in the body). Children younger than 2 years who have diarrhea are more likely to become dehydrated than are older children. Dehydration is a serious problem. Your primary care provider or CF doctor may need to see your child, depending on your child's age and the amount of diarrhea. When your child has diarrhea, do not give him or her just water or clear liquids for a long time because your child could lose weight. If you are not sure what to do, check with your doctor.

### Lactose Intolerance

Milk and dairy products have protein and fat, which provide good calories and nutrients. (Many high-calorie supplements also contain milk or milk solids.)

Some people have problems digesting the sugar or lactose in cow's milk. Cystic fibrosis does not cause lactose intolerance. Children with and without CF can have lactose intolerance.

Tell your CF doctor if you notice your child has diarrhea, gas, and/or bloating right after eating or drinking milk and other dairy products that contain cow's milk. One of two things could be the problem: either your child needs to take more enzymes or your child is having trouble digesting lactose. Symptoms of lactose intolerance are similar to those of malabsorption. Your CF doctor can do a test to check for lactose intolerance. If your child does have lactose intolerance, the CF dietitian and doctor can help you learn how to manage the problem.



### TESTING FOR MALABSORPTION AND PANCREATIC FUNCTION

Your CF health care team can do several tests to help discover if your child has malabsorption. Your CF doctor can help you decide if and when one of these tests is needed.

#### Blood-Serum Immunoreactive Trypsinogen (IRT\*) –

The IRT is used to screen for possible CF in newborns and infants. Immunoreactive trypsinogen is a chemical that forms one of the pancreatic enzymes. The level of this chemical can be high in an infant with CF and indicates that there is a problem with the pancreas.

**Fecal\* Elastase\* Level** – For this test, a sample of the person's stool ("fecal" also refers to stool) is sent to the lab to test for the level of the pancreatic enzyme called elastase. If the level is very low, it suggests the pancreas cannot get the enzyme to the intestines to digest the food, causing malabsorption.

**72-Hour Fecal Fat Study** – This test checks for fat malabsorption in stool. The stool is collected for 72 hours (three days). If too much fat is found in the stool, the person has malabsorption. The test can also check to see if people with CF are taking enough pancreatic enzymes.

The lab gives instructions on how to collect stool. A food diary is kept of all the food and liquids the person has had during the test. The test compares the amount of fat eaten (recorded in the food diaries) to the amount of fat that is in the stool.



### WATCHING YOUR CHILD'S STOOLS

When you first start to give enzymes for malabsorption, you need to watch what your child's stools look like to find out how well your child is digesting food. Once your child's malabsorption is well managed, you don't have to check the stools every day. You cannot, however, forget about malabsorption completely because it changes over time. Watch for other symptoms (such as excess gas or lack of weight gain), which could mean your child is having problems. If you notice other symptoms, you need to look at your child's stools again.

Parents often are concerned when they see enzyme beads in their child's stools. Do not be concerned. The bead coating may not have dissolved completely. Infants are more likely to have enzyme beads in their stools because there is a shorter time between when they finish eating and when they have a bowel movement. As long as your child is not having malabsorption, the amount of enzymes does not need to be adjusted. For infants, if you see beads in the diaper, coat your baby's bottom with diaper cream to prevent a rash.

### Your Growing Child

Privacy and independence are an important part of growing up. For this reason, checking your child's stools every day is usually not a good idea, unless he or she has a problem with malabsorption. Daily checking is, of course, not an issue for children still in diapers or those who do not yet go to the bathroom on their own. Encouraging your child's independence is important. But you also want to make sure your child knows how to monitor for malabsorption. If children have had no symptoms of



malabsorption (or very few) over a long period of time, or if they gradually begin to have more symptoms as they grow older, they may not notice that they have a problem. They may not mention the symptoms to their parents or the CF health care team. Below is a brief guide to how children of different ages may feel about having their stools checked and how you can talk with your growing child about malabsorption symptoms.

### Toddlers

After they start to use the toilet, most children are interested in "poop." Checking toddlers' stools can be done when helping with wiping.



### Preschoolers

Preschool children are more independent and getting ready to go to school. At this age, check occasionally, or if your child has symptoms or a problem with malabsorption. When you do check the stools, explain in simple terms what you see and what action you will take. For example, "See how there's a lot of stool. It looks kind of greasy. See how it floats in the toilet water. We need to try taking an extra enzyme and see if that helps." Your child will learn that checking stools for signs of malabsorption is a routine part of life.

### School-Age Children

During elementary school privacy becomes more important, but, happily, by 7 or 8 years old, many children can start checking their own stools. Ask your child to tell you if he or she thinks there is a problem. If malabsorption has not been a problem, your child may not know what to watch for. You can talk directly to your school-age child about malabsorption and its symptoms. For example, "You said you had some gas at school today. Remember you told me you had ice cream at Joel's house yesterday? Did you take your enzymes? Did



you notice if your stool was different this morning? Check your next stool to see if it looks loose or floats. Your body probably didn't digest the ice cream very well. Ice cream has fat and protein in it and you need enough enzymes to handle it right."

You may want to ask the CF doctor to write a letter to your child's school to allow unrestricted bathroom privileges if your child needs to go more often or at a time when the classroom usually is not allowed to go. The letter can also mention if your child needs more time in the bathroom. If your child has problems with smelly stools, you could also ask if he or she might be allowed to use a bathroom in the nurse's office or in the main office to help avoid teasing.

### **Teens**

Teens are closer to becoming their own CF managers and are capable of watching for malabsorption on their own. For some, the embarrassment about stool or gas can make them reluctant to bring up the topic, so they may need some matter-of-fact prompting. Your teenager should know what symptoms to watch for and whom to talk to when he or she notices any change.

### **TALKING ABOUT STOOLS**

Children may find talking about stools silly, embarrassing, or gross. All children normally become more concerned with privacy and modesty as they grow older. Not until adulthood do most people accept having stools as normal and a way to know how the body is working.

Being businesslike makes talking about stools easier. When you look at your child's stool, you can be matter-of-fact and describe what you see in clear, simple words. Your child will learn what to watch for, and it may also help him or her learn to talk about stools and malabsorption. If there are signs of malabsorption, make it clear what action you will take. Your child will see that the purpose of looking at the stools is to solve problems.

To respect your child's privacy, avoid talking about the child's stools when other people are present. Parents should discuss the topic only with their child and other caregivers.

If your child has a babysitter, goes to a day-care center, or is cared for by other family members, you will need to talk to them about your child's stools. When you need to talk about stools, make sure you do it in a way that does not embarrass your child.

MAKING IT WORK FOR YOU (see p. 27) has situations other parents have experienced and what has helped them when monitoring malabsorption with their child.



## LEARNING FROM OTHER FAMILIES

### Jasmine

"Jasmine is getting ready to go to preschool for the first time and I need to make sure she is able to ask her teacher for help when she has a bowel movement."  
(Mrs. Hendrix, mother of 3-year-old Jasmine)

Jasmine Hendrix is completely potty trained and is very proud that she knows how to go to the bathroom by herself. She likes her pretty panties, too. She knows how to swallow her enzyme beads in applesauce. Sometimes she even remembers all by herself that she needs to take the enzymes with meals. She has two stools every day. She calls her stools "poop." Her mother usually goes in the bathroom with her to help her wipe her bottom and to look at her stool. Mrs. Hendrix talks to Jasmine about her poop.

Jasmine is getting ready to go to preschool next month for the first time. Mrs. Hendrix tells Jasmine that if she has to go poop at preschool she can ask her teacher for help. Jasmine is not sure she wants to have the teacher help her. Her mother tells her that she will talk to her teacher and Jasmine can help tell the teacher why they look at poop with CF. Mrs. Hendrix tells Jasmine, "You want to be sure your enzymes are working so you will grow big and strong!"



Mrs. Hendrix sets up a time to talk with the preschool teacher. Jasmine goes with her mom and brings her book about CF to show the teacher. She tells her how she can take her enzymes all by herself. Mrs. Hendrix helps Jasmine explain why she might need help if she has to go poop. They plan to have a chart at preschool that the teacher can mark on if Jasmine has a stool and what it looks like. The teacher tells Jasmine that other children need help sometimes, too. She also shows Jasmine where the bathroom is and how to wash her hands when she is done. Now Jasmine is more excited about going to preschool. She has a good plan to watch for malabsorption with her teacher.



## LEARNING FROM OTHER FAMILIES

# Michael

"I think Michael was embarrassed to mention anything to us when he started having problems with malabsorption — he really hasn't had to deal with it very much at all. Now that he's 14, he really doesn't want to talk with his parents about this." (Mr. Brown, father of 14-year-old Michael)



For as long as he can remember, Michael Brown has taken two enzymes with a meal and one with a snack. He rarely has problems with malabsorption. Because there has not been anything to talk about, he had not thought about it much and his parents did not ask.

For the past several weeks Michael has noticed a lot of gas, and he has had three large bowel movements a day. At first he thought he might have eaten something bad or had a slight stomach virus. But today he gets on a scale and discovers he has lost three pounds.

Michael is embarrassed to talk to his parents. Finally, he mentions his weight loss to his dad. He asks Michael about other symptoms. Michael's dad realizes they have not talked for a long time about how to watch for malabsorption or what to do.

Mr. Brown calls the CF center and reports the change to Michael's CF nurse. The CF health care team suggests that Michael increase his enzyme dose and keep watch to see if his symptoms improve. He and his dad talk about what to look for. Michael makes a plan to check his weight weekly for the next few weeks. The Browns will call to schedule an appointment sooner than Michael's regular CF visit if Michael's symptoms don't improve in one week.

### WHAT YOU CAN DO

#### Knowing My Child's Usual GI Symptoms

Use the worksheet "My Child's Usual **Gastrointestinal\*** (GI) Symptoms" in the back pocket of this module to help figure out your child's **baseline symptoms\*** (including your child's usual pattern of stools) with the dietitian or other CF health care team member. Write down what gastrointestinal symptoms are usual for your child so that you, and others who help care for your child, can **WATCH AND DISCOVER** to see if there is a change.

If you think your child has new or increased symptoms, you should talk with the CF health care team. Sometimes it takes days to decide if there is a real change, but if you see a pattern that is different, it is always better to check with the team. Other helpful information you can report includes:

- **Change in Diet:** Have there been any recent changes in your child's diet?
- **Enzymes:** Have you had any problems giving your child enzymes or has there been a change in your child's enzyme brand or dose?

#### Using a Symptom Diary

You may find it helpful to keep a diary or chart of how many stools your child has each day and any symptoms of malabsorption. (You can use the worksheet "My Child's Usual Gastrointestinal (GI) Symptoms" in the back pocket of this module.) A diary of your child's stool pattern over time can help you **WATCH** for a problem and **DISCOVER** if it is related to any specific type of food, activity, or time of day. Make note of what foods your child ate on days when he or she had symptoms and what you did. If your child's enzyme dose or brand changes, make notes in the diary and observe your child to see if the change is working. Check with the CF dietitian about mailing or faxing a copy of the diary or bring it to the CF clinic. Although some people keep a record every day, this is not necessary for everyone. You can decide how a diary may help you work with your child and the team and when and how you want to keep it.



## MAKING IT WORK FOR YOU

### TIPS FOR MONITORING MALABSORPTION

Monitoring for malabsorption is not always easy, especially as your child grows and spends time away from home. Here are several situations parents of children with CF have come across and what has helped them solve the problem.

**Situation:** First-time parents may not realize that their infant's stools are not normal because the baby's stools have always been loose and smelly.

#### Tips:

- Talk with your CF health care team. Watch how your baby's stools change once he or she starts taking pancreatic enzymes. Bring a stool sample to the clinic to show the team.
- Check out the CF FEP module *Beginning CF Care* for more information about babies' stools.

**Situation:** Talking about bowel movements can be embarrassing.

#### Tips:

- Be sensitive to this possible embarrassment, but don't avoid talking about it. More frequent talks, handled in a sensitive and appropriate way, will make the conversation more normal and less embarrassing. Talk with your child in private without other siblings and friends present.
- Use a standard set of words to describe stools and make sure your child knows what the words mean (such as stool, formed, mushy, watery, runny, greasy, floating, smelly).
- If your child is having problems, have him or her keep a chart of what the stools look like, how often he or she goes to the bathroom, and other signs (such as odor or gas). Look at your child's GI baseline symptom form. (See the worksheet "My Child's Usual Gastrointestinal (GI) Symptoms" in the back pocket of this module.) Make sure your child knows why looking at stools is important.

### PROBLEMS WATCHING FOR MALABSORPTION

If you have had problems with monitoring malabsorption, ask yourself these questions:

What problems have you had watching for malabsorption?

How did you solve those problems?

What can you do to encourage your child to WATCH AND DISCOVER for malabsorption problems?

How often have you and your child talked about watching for malabsorption?

Who does your child talk to on the CF health care team about malabsorption?

What steps can you take to encourage your child to talk with the CF health care team?

- When your school-age child tells you about his or her stools, ask "What should we do about that?" This will help connect the reason for looking at stools and take the focus off any embarrassment.

**Situation:** Other caregivers—babysitters, day-care workers, even grandparents—may not know about malabsorption and what to look for.

#### Tips:

- Work out a system for your child's caregivers to tell you about your child's stools. Many day-care centers have daily report forms, which include a record of bowel movements. The staff can fill out and show you this report. Be sure that you tell them to take note of the size and appearance of the stool as well.
- Review the GI baseline symptom form with caregivers (see "My Child's Usual Gastrointestinal (GI) Symptoms" in the back pocket of this module) and offer to let them read MALABSORPTION, starting on p. 19.



## THINK AND ACT

### TREATING MALABSORPTION

#### Giving Your Child Pancreatic Enzymes

Many people with CF need to take pancreatic enzymes. In CF, the enzymes from the pancreas cannot get to the small intestine to help break down and digest food. Enzymes come in several brands and types. Enzymes usually come as capsules full of powder or beads. People with CF take the enzymes by mouth with food, breast milk, or formula. The CF health care team will work with you to find the best type and number of enzymes to meet your child's needs.

The enzymes your child takes travel into the stomach and then pass into the small intestine. Once in the small intestine, the enzymes help digest the food your child has eaten. Nutrients from the digested food can then be absorbed into the body.

How many enzymes your child needs depends on:

- 1) How much of your child's natural enzymes reach the small intestine
- 2) How much your child eats
- 3) What kinds of foods (especially how much fat and protein) your child eats

When people with CF eat foods high in protein or fat, they may need to take more enzymes. To prevent malabsorption, you need to make sure your child gets the right amount of enzymes.

As a CF manager, you will Think and Act to:

- Learn when and how to give enzymes
- Make a plan for adjusting enzymes based on the amount and types of food your child eats
- Solve problems related to your child's enzymes

#### How to Give Enzymes

##### Enzyme Beads or Powder

Infants and young children who cannot swallow enzyme capsules whole can take the enzyme beads or powder. The enzyme beads or powder are inside the capsule. When the capsule is opened, the powder or beads are mixed with 1 to 2 teaspoons of soft food (such as applesauce or baby food fruits).

**Note:** Do not use foods with fat or protein to mix with the enzymes. The fat and protein will make the enzymes work too soon. If this happens, the enzymes won't work as well in your child's body to absorb the nutrients from the food. Ask your CF dietitian what foods you can use to mix with the enzymes.

Your child should swallow the enzymes as soon as possible (within 30 minutes) after they are mixed with food. The beads should not be chewed or crushed. They will not work as well and could irritate the mouth or damage the **teeth enamel\*** if they are chewed. If you breastfeed, be sure to wipe out your baby's mouth to remove any extra enzymes. Enzymes can irritate your breast, so wipe off your breast each time your baby finishes feeding.

##### Enzyme Capsules

School-age children and older can swallow enzyme capsules whole. Most children can learn to swallow pills by age 6 or 7 years, and some learn much earlier. Taking enzymes is one CF task that will be much easier when your child can swallow the capsules. If you need ideas for how to teach your child to swallow capsules, ask your CF psychologist, nurse, or child life specialist.



##### Daily Routine

Give enzymes just before your child eats or drinks. Talk about enzymes with your child as you give them. Even toddlers can begin to see that enzymes are a normal part of every





meal and snack. You might say, for example, “Time for your enzymes,” or “Where are your enzymes?” or “Let’s get your food helpers.” Encourage your child to ask for enzymes before he or she eats and then praise your child for asking. Have your child get the bottle or help count the enzymes for that snack or meal.

### When to Give Enzymes

Enzymes need to arrive in the small intestine at the same time as the food. Give your child enzymes just before or at the start of the meal or snack. If your child, however, forgets to take enzymes, he or she can still take them within 30 minutes after the meal or snack. Infants and young children often do better when they take their enzymes before the meal. They may become full or bored toward the end of the meal, and this can make it harder to get them to take the enzymes.

The amount of enzymes a child takes varies depending on how much he or she eats at each meal. Talk with your CF dietitian or doctor about when the best time is to give enzymes to your child. If you are not sure how much your child will eat, you may want to give some of the enzymes at the beginning of the meal. Then, as you see how much your child is eating, you can decide how many more capsules to give. If you give your child enzymes before a meal and then your child eats little or nothing—don’t worry. It will not harm children if they take enzymes and then do not eat.

If your child is taking several enzyme capsules at a time, talk with the CF health care team about changing to a different strength enzyme so that your child can take fewer capsules.

Children who use a milk drip at night to get extra calories will usually take enzymes at the beginning and end of the milk drip. If your

child wakes up at night during the milk drip, sometimes you can give him or her enzymes then. Some formulas used in nighttime tube feedings (milk drips) do not require enzymes or may require fewer enzymes.

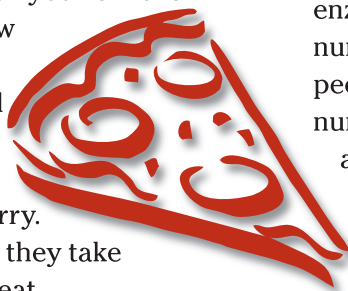
### How Many Enzymes to Give

Unlike most medicines, how many enzymes children need does not depend on their ages or how much they weigh. Instead, the amount of enzymes people with CF take depends on how much blockage there is in the ducts between the pancreas and small intestine, and how much fat or protein they eat. The more blockage, the smaller the amount of enzymes from the pancreas that will get through to the small intestine, and the more replacement enzymes they will need to take.

For example, Sarah is 4 years old and weighs 33 pounds. She needs four enzyme capsules with most meals and two with snacks. On the other hand, Anita, who is a young adult and weighs 115 pounds, takes two capsules with an average meal and one with each snack. The CF health care team will work with you to find the amount of enzymes your child needs to prevent malabsorption.

Many people with CF take the same amount of enzymes with every meal. They also take a set number of enzymes with every snack. Other people with CF need to adjust or change the number of enzymes they take with some meals and snacks. When they eat meals that are higher in fat than normal, they take more than their “usual” number of enzymes.

For example, a pizza with cheese and meat has more fat and protein than a lower-fat food such as turkey. Changing the number of enzymes to match what your child eats may seem hard at first. Over time, as you work with the CF health care team and watch what happens when your child eats certain foods, you will become more comfortable adjusting the number of enzymes.





### Number of Enzymes: As Your Child Gets Older

As your child grows older, signs of malabsorption may start to appear even though your child is taking the usual amount of enzymes and malabsorption has not been a problem for a long time. Malabsorption may begin or change at any time. Any major changes in your child's diet can lead to malabsorption. The pancreas may get worse over time so that it produces less natural enzymes to help digest food. If your child has signs of malabsorption that do not go away, you may need to find the new “right amount” of enzymes. Your child will begin to take this new (“usual”) amount of enzymes with every meal and every snack. For example, Roberta was taking three enzyme capsules with meals and one with snacks. She began to have signs of malabsorption. After she talked with the CF health care team, she increased her usual number of enzymes. Roberta tries taking four capsules with meals and two with snacks. After five days, her signs of malabsorption are gone.

### Balancing Enzymes and Different Foods

Your child may have symptoms of malabsorption after some meals or snacks. Usually this means that your child has eaten a lot more food than usual or has eaten foods that are harder to digest. Foods higher in fat usually cause problems. The plan you create with the CF health care team may include a range for the number of capsules your child can take at meals and snacks. (See the worksheet “Plan for Adjusting My Child's Enzymes” in the back pocket of this module.) Depending on whether your child eats low-fat or high-fat foods, your plan will help you adjust your child's enzymes. For example, Jared takes three to five capsules with each meal and one or two capsules with snacks. With most meals, he takes three capsules. When he eats a meal higher in fat or larger than usual, he takes one or two more (a total of four or five capsules). With a large or high-fat snack, Jared takes two capsules rather than the usual one.

### High-Fat Foods

Watch what happens when your child eats high-fat foods, especially if your child eats a larger amount than usual. Keep track of the foods that cause signs of malabsorption. Use the worksheet “High-Fat Foods Checklist” in the back pocket of this module to check off foods that have caused your child to have signs of malabsorption. Next time your child eats these high-fat foods, use the plan you worked out with your CF health care team for adjusting enzymes. Once you have figured out how many extra enzymes your child needs to digest high-fat foods, you will be able to adjust enzymes routinely.

### High-Carbohydrate Foods

Your child will not need pancreatic enzymes to digest some foods. Foods high in carbohydrates are broken down by different enzymes found in the intestine. Here are examples of foods that your child usually will not need to take enzymes with:

- Fruits
- Fruit juices and fruit-flavored drinks
- Gelatin (such as Jell-O)
- Carbonated beverages (such as sodas and sparkling waters)
- Sports drinks
- Jelly, jam, sugar, or honey
- Candies made only with sugars, such as jelly beans and gum (will need enzymes for candies made with chocolate, coconut, or nuts)
- Frozen pops
- Low-fat dry cereals (check with your CF dietitian about types of cereal)



Although these foods may make easy snacks, they usually do not have as many calories as foods with fat and protein. Your child will still need the calories from a variety of foods higher in fat and protein.



### Avoiding Generic Enzymes

**Generic\*** enzymes are not designed for treating CF. All enzyme products are not the same. Some enzyme products work better than others. Generic enzymes are not as reliable and may not control malabsorption as well as brand-name enzymes. A pharmacy may substitute a generic enzyme for the enzyme your doctor has prescribed. Even if the cost may be lower, the generic enzymes are not a good choice. Do not change the brand of enzymes without checking with your CF health care team.

You may find some herbal supplements or natural products with enzymes listed in their ingredients. These types of enzymes are usually not the same as the prescribed enzymes your child needs for CF. If you have a question about a product, bring it to the CF clinic and ask a team member to check it out for you.

### Storing and Refilling Enzymes

Heat and cold can damage enzymes and make them not work as well. Store enzymes at room temperature (between 59° and 86°F). Do not store enzymes in extreme hot or cold areas (such as in the glove box of a hot car or in the refrigerator). Store enzymes away from moisture (not in the bathroom). Keep the bottle closed tightly so the enzymes do not get exposed to damp air. Check your supply of enzymes to make sure you know when you need to order a refill—don't wait until you run out. If the enzymes are past their expiration date on the side of the bottle, throw them away and order fresh enzymes.

### Enzymes and Diaper Rash

Some of the pancreatic enzymes can pass through in your baby's stools and can cause a diaper rash. The rash is usually around your child's anus. Change your baby's diaper right away. As soon as you notice irritation (redness, rash), cover the area with petroleum jelly or zinc oxide at every diaper change. If the diaper

rash continues to be a problem, talk to your CF doctor. The doctor can prescribe a special cream to help protect your child's bottom. The doctor may also need to adjust the amount of enzymes your child is taking. Your child can also have other kinds of diaper rash, just like any other baby. Check with your primary care provider about other types of diaper rash.

### Teaching Others How to Give Enzymes

Your child may have other people (a grandparent, a day-care center, a babysitter) who help care for him or her during mealtimes. They will need to understand how to watch for malabsorption and how to give enzymes. Be sure other caregivers know that your child needs to take enzymes before meals and snacks.

A school or day-care center will treat enzymes as a medicine. You will need to sign forms, bring a pharmacy-labeled bottle, and leave written instructions. You may also need to bring applesauce or other food to mix with the enzymes.

### Taking Enzymes at School

Make sure your child has a supply of enzymes at school. Each school year you will need to complete a school medication form for the school nurse. Talk to your child's teacher about making sure your child takes his or her enzymes **before** lunch. If your child does not swallow capsules, you may need to bring applesauce or other food to mix with the enzymes. If your child is old enough to be responsible for keeping and taking the enzymes, ask the CF doctor to write a note to the school for permission to have your child keep the enzymes, so he or she can take the enzymes at lunch. For those schools where this is permitted, not having to go to the office for enzymes gives your child more time to eat.



\*See CF Words to Know Glossary.



If your child is self-conscious about taking enzymes at school, listen to his or her concerns. You may be able to help your child find solutions to this problem. Remember if you help your child hide that he or she takes enzymes, you may be giving the message that this is something to be embarrassed about. If taking enzymes is routine at home, when you go out to eat, or even when you have company—your child may have less trouble taking them at school. Sometimes the real problem is that school-age children have not figured out how to talk about CF and enzymes with classmates and teachers. Usually very short explanations, such as “I need these to help me digest my food better” is all that is needed. You or the CF health care team can help your child find ways to handle these situations more easily.

Ideas on how to handle taking enzymes at school are examples of strategies that other parents have come up with when they have used problem-solving skills. Problem solving is a skill you learn. You can learn more about how to problem solve in the module *Becoming a CF Manager*. Problem solving is a part of Think and Act. You can find more information about working with your child to take enzymes and helping your child overcome problems with cooperation in the module *Working with Your Child*.

### **Stomach Acid Blockers**

Sometimes your doctor will prescribe another medicine to help the pancreatic enzymes work better. In CF, the enzymes your child takes have to pass through the stomach. The stomach has acid that can destroy some of the enzymes before they reach the small intestine. Usually your child still has enough enzymes that will reach the intestine to digest food. If children with CF have frequent problems with malabsorption, the CF doctor may start an acid blocker to reduce the acid level in the stomach. Sometimes acid blockers are also used to treat **gastroesophageal reflux\*** (GER). You can learn more about GER in “OTHER CF DIGESTIVE SYSTEM PROBLEMS” in Appendix 2. You should not have your child take acid blockers or antacids regularly without talking with your CF doctor first.



## LEARNING FROM OTHER FAMILIES

### Susie

"Susie just had her birthday and we ate a lot of things we don't normally have at one meal. We knew the number of enzymes she usually takes wouldn't be enough." (Mr. Johnson, father of 6-year-old Susie)

Susie Johnson goes out to eat with her family on her birthday. She has a cheeseburger, french fries, and a chocolate milkshake. Instead of giving Susie the two enzyme capsules she normally takes, her father gives her three.



Why? Susie's father knows that these foods are higher in fat than Susie's typical lunch. Fried foods, cheese, ground beef, chocolate, and ice cream in the milkshake are all high-fat foods.

### David

"I hung out with my friends last Saturday. I knew I was going to need more enzymes with me because we usually eat food with a lot of fat." (16-year-old David)

David goes out with some friends. After eating double-cheese pizza for lunch, they go to the movies. Afterward they go out for ice cream sundaes. David takes five capsules with lunch instead of his usual four. With his sundae, David takes two capsules, although his usual dose is one capsule with snacks.

Why? The cheese pizza and large serving of ice cream are high-fat foods. Because David also eats more than usual, he takes two extra enzyme capsules.



#### WHAT YOU CAN DO

You can put your child's enzyme doses on the worksheets "What to Feed My Baby" or "What to Feed My Child" in the back pocket of this module. You may have different doses for meals and snacks. Share this worksheet with everyone who helps you feed your child.

Ask your CF dietitian or doctor if you can make any adjustments or changes in enzymes on your own based on what your child eats and what you WATCH AND DISCOVER that is not working. Use the worksheet "Plan for Adjusting My Child's Enzymes" in the back pocket of this module when you work out a plan with the dietitian or doctor.



## MAKING IT WORK FOR YOU

### REMEMBERING ENZYMES

For some families, remembering enzymes can be a problem at times. Here are some suggestions from other families:

- Take time to get organized. Think of ways to remind yourself, such as putting the enzyme bottle near where your child eats and where you will notice it, or writing yourself a note and posting it on the refrigerator.
- Keep enzymes in your purse, backpack, or in your child's diaper bag. Always carry a small supply with you in case your child gets hungry and needs enzymes when you are away from home. Use a pill box for travel.

Parents can also make a chart and have their children check off the doses of enzymes every day to show them what a good job they are doing. The chart might also include other "jobs" the child does each day, such as brushing teeth or picking up toys.

After you have used these cues or signals for a while, giving enzymes will become a habit. In time, you and your child will connect meals and snacks with enzymes.

#### NOTE TO PARENTS: CF MEDICAL RESEARCH

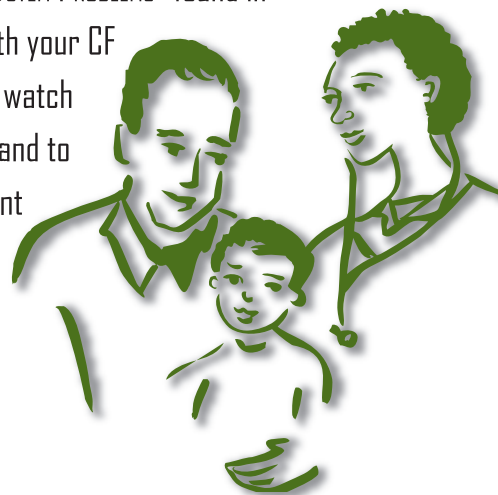
Basic and clinical **research\*** studies help scientists learn more about CF and develop new treatments. Research can improve quality of life and help people with CF live longer. For example, CF research has led to better and more effective pancreatic enzymes. Your help is needed to make research successful. To learn more about research and how you and your child can be involved, see "CF Medical Research" in the back pocket of this module.

## SUMMARY

Many people with CF have problems with nutrition and digestion, but you and your child, with the help of the CF health care team, can manage these problems.

- **WATCH AND DISCOVER** (with your CF health care team) to keep track of your child's growth and diet. Know what to watch for so you can tell if your child's malabsorption is a problem.
- **THINK AND ACT** together with your CF health care team to control and prevent nutrition and digestive problems. A high-calorie diet is important for your child's overall health. Remember, being underweight puts a person with CF at risk for infection and lung damage. If needed, have your child take high-calorie supplements to get extra calories.
- Pancreatic enzymes help your child's body digest food. You need to be sure he or she takes enzymes before all meals and snacks.
- Make sure your child takes vitamin supplements, such as the fat-soluble vitamins A, D, E, and K. Your child may also need mineral supplements, such as calcium and zinc, or electrolytes, such as sodium and chloride.

Be aware of the other nutrition and digestive problems related to CF that are described in "OTHER CF DIGESTIVE SYSTEM PROBLEMS" found in Appendix 2. Work with your CF health care team to watch for these problems and to take action to prevent them, if possible.



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**CF FAMILY EDUCATION PROJECT TEAM MEMBERS**

**1988 and 1994 Editions**

**Baylor College of Medicine and  
Texas Children's Hospital:**

Dan K. Seilheimer, MD  
*Principal Investigator*

Marianna Sockrider, MD, DrPH

Danita Czyzewski, PhD

Susan Spinelli, BS, RN

**University of Texas Health Science Center  
School of Public Health-Houston:**

Guy S. Parcel, PhD  
*Co-Principal Investigator*

L. Kay Bartholomew, EdD, MPH  
*Project Coordinator*

**University of Houston:**

Marco Mariotto, PhD

Paul R. Swank, PhD

**CF FAMILY EDUCATION PROJECT TEAM MEMBERS**

**2010 Edition**

**Baylor College of Medicine and  
Texas Children's Hospital:**

Marianna Sockrider, MD, DrPH  
*Project Director*

Danita Czyzewski, PhD  
*Associate Project Director*

Sally Mason, RN  
*CF Coordinator*

Elizabeth Spoede, MS, RD, CSP, LD

Jennifer J. Smith, CCLS

**University of Texas Health Science Center  
School of Public Health-Houston:**

L. Kay Bartholomew, EdD, MPH

**Special Thanks to Reviewers and Contributors:**

**The CF Foundation**

The CF Foundation's Education Committee

Leslie Hazle, MS, RN, CPN  
*Director of Patient Resources*

Melissa Chin, BA  
*Clinical Programs Project Coordinator*

**The Ohio State University**

Dana S. Hardin, MD  
*Professor of Pediatrics and Nutrition*

**University of Indianapolis**

**Krannert School of Physical Therapy**

Annie Mejia Downs, PT, MPH, CCS  
*Assistant Professor*

Members of the Baylor College of Medicine  
Pediatric CF Center Education Committee

**CREATIVE/PRODUCTION TEAM**

Brenda Congdon

*Writer/Editor and Production Team Manager*

Cynthia Pinsonnault, Pinsonnault Creative  
*Design and Production*

Becky Heavner, Cynthia Pinsonnault, and  
Rubén Esparza, *Illustrators*

Michelle Quirk, *Proofreader*

Simon Printing

Printed in the USA



<http://www.cff.org>

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College  
of Medicine



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6931 Arlington Road, Suite 200  
Bethesda, MD 20814  
1-800-FIGHT-CF