

# Cystic Fibrosis: Infant & Child Nutrition



*Working together for  
happy and healthy children!*



**PEDIATRIC PULMONARY CENTER** | To Teach.

Dear Caregiver,

We understand the journey of raising a child with cystic fibrosis can be quite the adventure with many ups and downs. We want you to know that we are here to support you through this journey!

Often times it can be difficult to sort through an abundance of information via the internet, brochures, videos, textbooks, and so forth. This flip chart of educational materials on infant and child nutrition has been created by Registered Dietitians to help ease that process. The resource where the information is primarily obtained from is the Cystic Fibrosis Foundation ([www.cff.org](http://www.cff.org)). Please let the dietitian or other team member know if you would like to take any of the materials home.

Thank you,

The Cystic Fibrosis Team



# Hunger and Satiety Cues



Infant's Approximate Age	Hunger Cues	Satiety (Fullness) Cues
<b>Birth through 5 months</b>	<ul style="list-style-type: none"> <li>• Wakes and tosses</li> <li>• Sucks on fist</li> <li>• Cries or fusses</li> <li>• Opens mouth while feeding to indicate wanting more</li> </ul>	<ul style="list-style-type: none"> <li>• Seals lips together</li> <li>• Turns head away</li> <li>• Decreases or stops sucking</li> <li>• Spits out the nipple or falls asleep when full</li> </ul>
<b>4 months through 6 months</b>	<ul style="list-style-type: none"> <li>• Cries or fusses</li> <li>• Smiles, gazes at caregiver, or coos during feeding to indicate wanting more</li> <li>• Moves head toward spoon or tries to swipe food towards mouth</li> </ul>	<ul style="list-style-type: none"> <li>• Decreases rate of sucking or stops sucking when full</li> <li>• Spits out the nipple</li> <li>• Turns head away</li> <li>• May be distracted or pays attention to surroundings more</li> </ul>
<b>5 months through 9 months</b>	<ul style="list-style-type: none"> <li>• Reaches for spoon or food</li> <li>• Points to food</li> </ul>	<ul style="list-style-type: none"> <li>• Eating slows down</li> <li>• Pushes food away</li> </ul>
<b>8 months through 11 months</b>	<ul style="list-style-type: none"> <li>• Reaches for food</li> <li>• Points to food</li> <li>• Gets excited when food is presented</li> </ul>	<ul style="list-style-type: none"> <li>• Eating slows down</li> <li>• Clenches mouth shut or pushes food away</li> </ul>
<b>10 months through 12 months</b>	<ul style="list-style-type: none"> <li>• Expresses desire for specific food with words or sounds</li> </ul>	<ul style="list-style-type: none"> <li>• Expresses desire for specific food with words or sounds</li> <li>• Shakes head to say "no more"</li> </ul>

Starting solid foods is very important for your baby's development and health.

## WHAT CAN EATING SOLID FOODS DO FOR MY BABY?

1. Eating new foods will add to the calories he gets in breast milk or formula. Eating new foods will help him get closer to eating the calories needed for good nutrition and growth. The goal is for your baby to grow well.
2. Eating solid foods gives your baby the chance to practice important skills including moving the tongue, using the gums, and swallowing.
3. Starting a wide range of solid foods over a long time helps your baby to eat a variety of foods and flavors as he gets older. This makes your job easier in the long run!

## HOW DO I KNOW IF MY BABY IS READY FOR SOLID FOOD?

Around 4 to 6 months most babies are able to hold their head, keep food in their mouth, and sit up with some help. This means they are ready. When he is ready for the highchair, have him sit at the table. This is a great time to have your baby start eating dinner with the rest of the family.

## WHERE DO I START?

Give solid food when your baby shows signs of hunger, such as when he is ready for a bottle. It is easier to feed your baby solid foods when he is calm. If your baby is too hungry, you may need to give a few ounces of breast milk or formula before offering solids. It is hard to learn a new skill, like eating solid foods, when a baby is really fussy.

Rice cereal is a common and good first food. It is high in iron, which is important for babies. Strained meats make a good second food to try. They are high in iron and calories. Babies can eat a variety of pureed foods, as well. Slowly adding a variety of strained fruits, vegetables and meats will help with a balanced diet and good eating habits. Try one food at a time to make sure that your baby does not develop a rash or have diarrhea. Call your doctor if you think your baby may have a rash or diarrhea because of food.

There are no clear rules about what order foods need to be started as long as your baby can swallow safely. Ask your CF dietitian how to get started.

## WHAT DO I DO IF MY BABY REFUSES TO EAT SOLID FOOD?

**Stay calm!** The main goal during the first few weeks of eating solid foods is to allow your baby to practice the new eating skills. These skills are keeping the food in the mouth, working food toward the back of the mouth, and swallowing. Your baby needs to overcome the reflex (which is out of his control) to push anything other than liquids out of his mouth. Infants as young as 6 months of age are able to show interest (or lack of interest) in food and eating. Some behaviors that show lack of interest are:

- Swatting at the spoon
- Turning head away from food
- Tightening lips when the spoon comes near the mouth
- Spitting out food that enters mouth
- Crying

**Keep it up!** It is very important to remain calm and keep offering foods when your baby does any of the things listed above. During the first few weeks of learning to eat solids, your baby may only eat a few tablespoons of food at each meal. This is okay. Remember, your baby is getting most of his nutrition and calories from breast milk or infant formula. Babies will make faces when trying a new food. This is a natural reaction. When your baby makes faces it does not always mean that he does not like the food. It just means that it is new! Very small amounts of new food should be given. You may have to give foods 8 to 10 times before your baby starts to like it.

**Expect messes!** Older infants want to feed themselves. At this age, making messes is a part of learning to eat. A baby needs to learn to move food around in his mouth, and grip and pinch with his hands in order to eat on his own. This may include spitting food out, as well as making messy art on the highchair tray or on his body. Remember, this is a normal part of your baby learning to eat!

## WHAT DOES MY BABY NEED TO EAT AND DRINK IN ORDER TO GROW?

You will work with your CF dietitian to make a plan as to how many calories your baby will need to grow. Most babies are born knowing when they are hungry and full. Your baby will not eat *more* food than other babies at this

age, no matter how hard you try! Here are some daily amounts and suggested serving sizes for all children, including those with CF. You can also offer strained/pureed foods, one teaspoon at a time.

Food Group	Food	Daily Amounts	Suggested Serving Size
Milk	Breast milk	On demand	
	Formula	4–6 feedings	6–8 ounces
Grain	Iron-fortified baby cereal	2	1–2 tbsp

The trick is to look for ways to add more calories in his formula and foods without adding more food for him to eat. You will work with your CF dietitian and learn how to add calories to food. Here are a few:

1. Mix your baby’s cereal with high-calorie breast milk or formula in a bowl. You can ask your CF dietitian how to make high-calorie formula.
2. Add oils (olive, canola, or safflower), butter, or margarine to fruits and vegetables (1 teaspoon to a ½ cup or 4 ounces). With time your baby will get used to the taste of the oil and butter. This is an easy way to add more calories.
3. Check food labels to find the baby food with the highest calories. It is very important that your baby gets food high in calories.

### PREPARING FOR THE FUTURE

Parents are in charge of starting high-calorie foods and making mealtime enjoyable. Because babies who have CF need more calories than those without CF, parents often feel a great pressure to feed their baby **more**. They often feel frustrated by normal infant mealtime behaviors. Try the ideas below to prevent big mealtime problems:

1. Give most of your attention to your infant when he accepts a bite and swallows food.
2. Give less attention when he spits out food or shows other ways of “saying no” to eating, such as turning his head or tightening up his lips.
3. Praising your baby when he eats makes mealtime more enjoyable. Talk to your infant and praise him saying “Good bite!” “That’s my big boy, trying new vegetables.”
4. Show him that you are excited (e.g., clapping, smiling) when he tries, and eats new foods. This will keep him excited about eating and make mealtime more fun!

5. It is normal for a baby to refuse a food or make a mess by spitting out foods. This is true in the early stages of feeding. Since infants love any response from parents, it is important to not respond (do not say anything to your baby and try not to get angry) when the baby refuses food or spits it out. Even talking about this behavior by saying, “Oh you don’t like your peas” can give your baby the attention that he loves. He may be more likely to spit food out in the future to get your attention. It is better to say nothing and calmly keep on feeding him. Remember, give all your attention to the behavior that you want to see more of.

6. It is important not to force-feed your baby. This can make mealtimes stressful and your baby will not be excited to eat. Save your energy and give lots of praise for good eating!

### TALK WITH YOUR CF CENTER

Be sure to talk to your CF center dietitian at *every* visit about your baby’s eating. Your CF dietitian can help you make decisions about food choices, how to add calories, getting your baby to eat, and making mealtime fun. The earlier you ask the better. Good eating habits start at a young age and last a lifetime. If your child does not eat well for two or three days, you should talk with your CF care center or your primary care doctor.

# HIGHER CALORIE BABY FOODS

Stage 2 Foods >80 calories per serving (Vegetables >60 calories per serving)



Gerber Stage 2 (3.5oz tub, 4oz jar)



Stage 2 (4oz jar/bowl)



Stage 2 (4oz jar)

**Fruits:** (calories per pack)  
Banana Plum Grape 100

**Vegetables:**  
Sweet Potato & Corn 70

**Meats:**  
Chicken & Chicken Gravy 100

**Dinners:**  
Chicken Noodle 80  
Macaroni & Cheese 80

**Desserts:**  
Banana Yogurt 110  
Vanilla Custard Pudding w/ Bananas 110  
Peach Cobbler 80  
Fruit Medley 80

**Mixed Cereals & Fruit:**  
Mixed Cereal w/Applesauce & Banana 100  
Oatmeal & Pears with Cinnamon 100  
Rice Cereal with Applesauce 100

**Organic:**  
Sweet Potatoes 60  
Banana Oatmeal Peach 90  
Bananas 90

**Fruits:** (calories per pack)

Applesauce Banana & Rice Cereal 100  
Applesauce Banana & Oatmeal 120

Apples & Blueberries 90  
Apple Raspberry 90

Apples & Strawberries 100  
Bananas & Applesauce 120

Mixed Fruit 100  
Prunes 120

Banana Grape Plum 120  
Apple Mango Kiwi 80

Banana Mandarin Orange 100  
Apple Plum Raisin 110

Bananas & Prunes 120  
Banana Acai Pomegranate & Cranberry 110

**Vegetables:**  
Creamed Corn 80

**Dinners:**

Sweet Potato & Turkey 90  
Beef with Broth 150

Chicken with Broth 140  
Lamb with Broth 150

Veal with Broth 100

**Desserts:**

Apricot Dessert 90  
Banana Dessert 100

Banana Tapioca Dessert 124  
Custard 130

Fruit Salad Dessert 80  
Hawaiian Delight Dessert 130

**Fruits:** (calories per pack)

Apples & Bananas 100  
Apples, Mango, Kiwi 100

Apricots with Pears & Bananas 80  
Chiquita Bananas 100

Chiquita Bananas & Strawberries 90  
Guava 100

Mango 100  
Papaya 90

Peaches & Bananas 80  
Pears 90

Pears & Pineapple 80  
Pears & Raspberries 90

**Vegetables:**

Corn & Sweet Potatoes 90  
DHA Plus Butternut Squash & Corn 80

Tender Golden Sweet Potatoes 70  
Tender Sweet Peas 70

**Dinners:**

Creamy Chicken Noodle Dinner 90  
DHA Plus Macaroni & Cheese 110

DHA Plus Pasta Vegetable Medley 90  
Good Evening Ham Pineapple & Rice 120

Good Evening Hearty Vegetable Stew 80  
Macaroni & Beef with Vegetables 100

Pineapple Glazed Ham 80  
Sweet Corn Casserole 80

Sweet Potatoes & Chicken 80  
Turkey Rice Dinner 100

Turkey Tetrazzini 110  
Vegetables & Beef 90

**Cereals:**

Good Morning Cinnamon Raisin Granola 100  
Good Morning Country Breakfast 80

Mixed Cereal & Apples 100



**Beech-Nut 2<sup>nd</sup> Baby Foods (cont)**

<b>Cereals:</b>	
Good Morning Mixed Fruit Yogurt	120
Good Morning Peach Oatmeal Banana	100
<b>Desserts:</b>	
Banana Apple Yogurt	120
DHA Plus Apple Delight	90
DHA Plus Banana Supreme	110

**Organic Stage 2 (4oz jar)**

<b>Fruits:</b>	(calories per jar)
Bananas	80
Bananas Peaches & Raspberries	90
Banana Mango	90
Plum Banana Brown Rice	80
<b>Vegetables:</b>	
Corn & Butternut Squash	70
Garden Vegetables	60
Peas & Brown Rice	70
Sweet Potatoes	70
Sweet Potato Apricot	80

**Dinners/Meals:**

Chicken & Brown Rice	80
Sweet Potatoes & Chicken	80
Chicken Mango Risotto	90
Creamy Chicken Apple Compote	90
Tender Beef Spinach	110
Sweet Pea Turkey Wild Rice	80
Apple Turkey Cranberry	80

**Cereals:**

Pear Apple Oatmeal	100
Apple Yogurt Oatmeal	90
Apple Peach Barley	120
Prunes & Oatmeal	100



**Organic (4oz pouch or frozen cup)**

<b>Vegetables:</b>	
Sweet Potato Corn & Apple Stage 1 (pouch)	80
Spinach Peas & Pear Stage 1 (pouch)	60
Multigrain Super Greens (frozen cup)	70

**Cereals:**

Banana Peach Rice Pudding (frozen cup)	90
Mango Museli (frozen cup)	80

**Ella's Kitchen Organic (3.5oz pouch)**

Only stage 1 foods are available in US.  
All are less than 60calories per pouch.

## YOU ARE ON YOUR WAY TO TEACHING YOUR CHILD GOOD EATING HABITS!

At this age, there are two important feeding tasks to get done:

- Keep offering your child a variety of foods and more calories.
- Start finger foods that will help your child eat a high-calorie diet.

Now that your child has been eating cereals and pureed solid foods, it is important to continue to offer a wide range of new foods, flavors, and textures (such as chewy, crunchy, and soft). Be sure to serve solid foods in small pieces and supervise your child to decrease the risk of choking.

**Slow and steady!** Keep adding calories to your child's food. Your cystic fibrosis (CF) dietitian can help you plan how to add calories, such as cream, oil, butter, margarine, and syrup. As your child gets used to the way that high-calorie foods taste, you can slowly add more calories to her food. Also, you can start to use new ways to add calories, such as ranch dressing. Remember, use small amounts of the new calories until your child gets use to the new flavor. Then you can slowly start to add more. Try to add calories that match the color or feel of the food, or blend in well. If you add calories slowly, sometimes your child won't even notice the difference! Talk to your dietitian about other ways to add calories.

**Something new to keep in mind!** Start looking for healthy finger foods with the highest calories to give to your child. Many of the snacks for children without CF do not have enough calories for children with CF. Below are some examples. You can ask your CF dietitian for more ideas.

Snack foods for children without CF	High-calorie snack foods for children with CF
dry cereal	bite-sized muffins
snack crackers	Full-fat cheese crumbles with high-calorie crackers
bite-sized fresh fruit	bite-sized canned fruit in heavy syrup or fresh fruit with high-calorie dip, whole milk yogurt, or heavy cream
snack puffs	cheese puffs, soft cereal bars, or high-calorie crackers
low-fat yogurt	full-fat yogurt, pudding, or cottage cheese

## MEALTIME: READY, SET, GO!

### Get ready for mealtime.

- Choose high-calorie foods.
- Add calories to all foods and drinks.

### Set up the meal for success.

- At the start of mealtime, it is a good idea to remove toys and other distractions. Toys and the television may distract your child from eating because many children would rather play than eat. Your child may say that she is not hungry if a meal or snack will stop her playtime.
- Have your child sit in her high chair for only 15 minutes for meals and 10 minutes for snacks.

It is important to have meals and snacks at about the same time every day. Having meals and snack time as part of a daily routine will help your child be hungry when it is time to eat. It is important to limit the amount of time that your child sits at the table for meals and snacks. This helps you make sure that your child sits long enough to eat enough. This can help avoid food battles between parents and children. It teaches children who take a long time to eat to eat more quickly. Food should be removed at the end of the time limit until the next meal or snack time. One of the best things about a set time limit is that it helps parents feel like they are in control of mealtime!



**Go, go, go!** At this age it is okay to feed your baby, and let her try to eat on her own at family meal and snack times. It is important to try to make meals enjoyable, so try these suggestions!

- Be your child's cheerleader when she eats well. You can praise her for so many mealtime behaviors that help her grow big and strong and learn good manners! Try these praises:

“Good job sitting in your chair!”

“Nice job taking your enzymes!”

“You tried a new food! Good job!”

“You took a big bite. Mommy loves that!”

“Yeah! You took one bite right after the other!”

- Be very clear when saying what you like about your child's mealtime behavior. Telling your child that she is a “good girl” does not tell her what action she did that you liked.
- **Caution:** Children are more likely to do something again if they get attention for it. Given the most important thing for your child to do during mealtime is eat, try to give your attention when your child is EATING! It is normal for parents to encourage, tell, and beg their child to eat. We know that in the long run these do not work to get children to eat more or eat faster. If they worked, parents would not need to keep using them! Instead, stay calm and give your attention to other family members when your child is not eating or is distracted (such as when playing with food). Wait until your child takes a bite and then praise her for taking a bite, or give her a loving touch.

**Wait, wait, wait!** Waiting to praise your child for taking a bite (rather than telling them to take a bite) can be **very** hard. You might feel nervous or frustrated when your child is not eating. Remember, save your mealtime attention for when your child *is* eating. If you pay attention when your child is not eating, she is less likely to eat well. Your child learns that she can get your attention for not eating. It is hard to break this habit. You will be surprised how much and how fast your child can eat the more you give your attention to her when she eats.

## HAVE A PLAN FOR SICK DAYS.

- When not feeling well, children usually eat less.
- Be sure to check with your CF dietitian about how to best add calories when your child is sick.
- Once your child is feeling better and is hungry again, slowly increase the amount of food that is given until she is back to eating the same amount of food as before she was sick.

## TALK WITH YOUR CF CENTER

Talk to your CF center at *every* visit about your child's eating. Your CF dietitian can help you make food choices, add calories, get your child to eat, and make mealtime fun. They can also help you if you are having problems. The earlier you ask the better! If your child does not eat well for two or three days you should talk with your CF care center or primary care doctor.

# Feeding Your 12-24 Month Old

At one year of age, your child will be able to eat and drink more foods on his own. The more practice your child gets with eating and drinking (especially new things), the more options you will have to meet Cystic Fibrosis (CF) Foundation nutrition and calorie recommendations. Be sure to ask your CF Center for ways to make sure your child gets the nutrition and calories needed to grow. Let's get started!

## WHAT ABOUT DRINKING?

1. After your child's first birthday, offer all liquids from a "sippy cup" to allow him to work on how to drink by himself. Do not let him sip from the cup throughout the day. This may make him less hungry for meals and snacks.
2. After the first year, most children do not need to rely on infant formula or breast milk to achieve good nutrition. At this point children can have full-fat cow's milk to drink. Children with CF should not be offered reduced-fat milk, as the added fat and calories are needed for good growth and nutrition.
3. Limit the amount of water that your child drinks. Water does not have the calories your child needs.
4. Limiting juice is recommended. It does not have the same fat and calories that are found in breast milk or whole milk. Children may also learn to favor the sweet taste of juice over milk, which may lead to them not drinking milk. Also, you should limit the amount of juice to 4 ounces per day until the child is 6 years old. If your child fills up on juice, he will not have room for foods with more calories.

## WHAT ABOUT EATING?

At this age, your child can eat any food, as long as it is in a form that is safe for him to chew and swallow. Here are some examples of foods and ways to boost calories. This gives you a few ideas, and your CF dietitian can give you even more!

Food options	Ways to boost calories
Easily chewed meats (soft and ground)	Add high-calorie gravy for dipping, or drizzle with oil or melt a tablespoon of butter/margarine
Coarsely chopped table foods	Add cheese, oil and/or butter (or all, if needed)
Chopped finger foods	Serve with ranch dressing for dipping
Well-cooked pasta	Add butter, cheese, and/or olive oil
Graham crackers	Serve with full-fat cream cheese on top

Go ahead and let your child have a child-sized spoon. He can practice holding it as you feed him. The more practice, the faster he will learn to eat on his own! Be sure to offer small safe pieces of finger foods and supervise your child to avoid him choking. Chunks of hot dog, raw apples, grapes, carrots, raisins, candy, and popcorn can cause choking.

## TIPS FOR MEALTIME SUCCESS

1. Have a regular schedule. You can teach your child's body when to be hungry by having meals and snacks at the same time each day. All of your child's caregivers should try to follow the same routine and have the same expectations as you have at home.
  - Announce that it is mealtime and it is time to come to the table.
  - Get rid of distractions during a meal. For example, turn off the television and remove toys from your child's sight. Children at this age can be easily distracted. This will lead to slower eating and less eating.
  - Teach your child what you expect during mealtime. Praise him for behaviors that are okay. Do not respond (no discussion or eye contact) when your child does an action that is not okay at your family table. For example, if you laugh or get upset when your child drops or throws food, he may think that you are playing a game and do this over and over again just to get your response.

2. Breakfast is a very important meal. It gets the body ready for the rest of the day. It might be a surprise to you, but if your child eats a good breakfast, he will usually be more hungry during the rest of the day. This could help him eat more and get more calories by the end of the day!
3. Make eating fun! Organize food into shapes on your child's plate to make new foods seem more appealing! Give your child praise for good eating. If your child does a good job of eating give him a special reward after the meal, such as extra playtime or a special toy.
4. Offer a variety of foods. Try to offer two different types of foods for breakfast, such as scrambled eggs made with heavy cream and cooked in butter/margarine and fruit packed in heavy syrup or a breakfast meat such as bacon or sausage. You can offer three different types of foods for lunch and dinner. Try offering food such as bite sized chicken, green beans with margarine or butter, pasta or grilled cheese sandwich and soft fruit.
5. Offer 2 to 3 snacks a day in between meals. Snacks are a great way for your child to get the daily calories that he needs! Always serve snacks that require enzymes; that way your child can get the high-calorie and high-fat diet needed for children with CF to grow.
6. Try not to let your child "graze" (eating and drinking small amounts throughout the day). Allowing your child to eat outside of regular meal and snack times can lead to many challenges. It makes it harder to give enzymes if he is always eating. Your child will also not be as hungry during meals. This can lead to eating less at meals.

### **TALK WITH YOUR CF CENTER**

Talk to your CF center at *every* visit about your child's eating. Your CF dietitian can help you make food choices, add calories, get your child to eat and make mealtime fun. They can also help you if you are having problems. The earlier you ask the better. Good eating habits start at a young age and last a lifetime. If your child does not eat well for two or three days, you should talk with your CF care center or your primary care doctor.

# Help! My Child Will Not Eat!

You are not alone. Many parents of young children feel that their child does not eat enough. Most research has found that children with cystic fibrosis (CF) eat *just as much* as children without CF. However, research has also found that children with CF are not eating enough to meet CF calorie needs. It is normal to want your child to eat more, but it is hard to get a child to eat a larger amount of food. That is why it is important to add calories by using things like oil, butter, margarine, cream, and dipping sauces (such as cheese sauce or creamy dips). You can also choose foods that have *more calories per bite*.

**Other common eating worries** (reported by parents of children with CF):

- Picky eating
- Being distracted during mealtime (playing with food or asking questions)
- Crabby about food, throwing food
- Refusing to eat

**What parents of all young children commonly and naturally do about these behaviors:**

- Prompt child to eat
- Ask questions about why child is not eating
- Coax child to eat by making “deals”
- Feed child
- Become frustrated!

**Caution:** We know these responses do not usually help a child eat more or more quickly. These seem to make it more fun *not to eat* because it is so fun to get their parent’s attention.

**What to try instead:**

1. Watch your child. Ask yourself: Is my child eating?

The way that you react to your child’s behavior at mealtime teaches her what you want her to do. Your child will learn what to do (and not to do) more quickly if you react one way when she is eating, and a different way when she is not eating. For example, if your child is praised for eating, she will probably spend more time eating. In fact, if your child starts to learn that the way to get your attention is to eat, she might try new foods, eat more of what you serve, and eat more quickly!

Behaviors that can be considered part of “eating” are:

- Coming to the table when told
- Being helpful when taking enzymes
- Staying in the chair
- Picking up a utensil
- Putting food on the utensil
- Taking a bite
- Taking a BIG bite
- Taking one bite after another
- Trying a new food

2. If your child is eating: Praise your child. This creates positive family mealtime and builds the child’s self-confidence. After all, who doesn’t like praise and attention!

- Be specific. Tell your child EXACTLY what she did that you liked.
- Be excited. Make eating seem like a big deal.
- Show love. Children love a pat on the back, kisses, and hugs.
- Here are some examples to help get you started:
  - “You came to the table when mommy asked. I love that!”
  - “You took your enzymes so fast! Great job!”
  - “You picked up your fork! Yahoo!”
  - “Daddy loves it when you take one bite after another!”
  - “Good job drinking your milk. That will make you big and strong.”

3. If your child is not eating: Do not react.

- Stay calm.
- Look at another member of your family or your plate.
- Do not talk to your child until she takes a bite, then PRAISE HER RIGHT AWAY!

- Eating behaviors to ignore
  - Looking around the room
  - Taking a long time between bites
  - Lots and lots of talking (such as grumbles or questions) that gets in the way of eating
  - Playing or throwing food

4. Prepare others who eat with your family at mealtime.

- Make sure that everyone eating at the table knows ahead of time how to respond to your child's behavior during mealtimes. This may include siblings, other family members, neighbors, or friends.
- Tell them to watch how you give him praise for eating, and remove attention when your child is not eating.
- Getting different responses from people will confuse your child and slow down his ability to learn what is expected at mealtime.

### **TALK WITH YOUR CF CENTER**

Talk to your CF center at *every* visit about your child's eating. Your CF dietitian can help you make food choices, add calories, get your child to eat, and make mealtime fun. They can also help you if you are having problems. The earlier you ask the better! Good eating habits start at a young age and last a lifetime. If your child does not eat well for two or three days you should talk with your CF care center or your primary care doctor.

Getting toddlers to eat a well-balanced diet can be hard. For parents of children with cystic fibrosis (CF), it is hard to serve a high-calorie diet. The CF nutrition guidelines state that children with CF should eat between 20% and 50% more calories than children without CF. Talk to your CF team about your child's calorie needs and how you can take *slow but sure* steps to meet them.

### HOW DO I GET MY CHILD TO EAT ENOUGH CALORIES TO GROW AND BE HEALTHY?

#### Be informed!

- When grocery shopping, look at labels so that you can find brands and foods with the most calories per serving or even per bite. For example, most glazed donuts are two times higher in calories than cake donuts. Ice creams vary greatly in their calories per serving too, so search for the ones that have the most calories!

#### Be consistent!

- Offer your child 3 meals and 2 or 3 snacks each day. This may mean that you have to plan ahead if you are going to be away from the house. Eating many times during the day makes it more likely for her to get enough nutrition and calories each day. It also gets her in the habit of eating many times during the day, which is a habit that will be great for her in the future too!
- Limit fruit juice to 4 ounces a day. Always having something to drink may make your child not want to eat at meal and snack times. If your child is thirsty and it is not a regular time to eat, offer water.
- Serve a high-calorie milk for meals and snacks. This drink has the highest calories and has important nutrition that other beverages do not have.

#### Be creative!

- Find places where you can add calories. This will help your child eat a normal amount of food and get the calories she needs.
  - Look for ways to add oil, cheese, mayonnaise, butter, margarine, heavy cream, and syrup. You can also fry and crumble bacon and add it to many things such as rice dishes, soup, pasta, eggs, or sandwiches.

- Fish sticks and chicken strips can be fried in butter or oil, rather than microwaved or baked.
- High-calorie tortillas can be turned into a fun and quick quesadilla or a roll-up with cheese and meats, such as pepperoni.
- Offer new, healthy, high-calorie foods such as avocado in bite-sized pieces.
- Serve breakfast foods for dinner! Eggs, pancakes, waffles, and French toast allow for adding more calories.
- Foods you may think of as “junk foods” may be good choices for children with CF. This may mean that your child can eat more ice cream and pastries than other children.

#### Set limits!

- Remove distractions, such as television, toys, or anything more fun than eating.
- Keep to a 20 to 30 minute time limit for meals and 10 to 15 minutes for snack. Children tend to eat the most during the first part of the meal. This is when eating behavior is easier to work with. Use this to help your child eat better! Praise good eating a lot during the first part of the meal. This will help you fight the urge to beg or coax your child to eat because the food will be gone.
- End the meal on a good note. Let your child out of the chair after she takes a bite or drink.

#### TALK WITH YOUR CF CENTER!

Talk to your CF center at *every* visit about your child's eating. Your CF dietitian can help you make food choices, add calories, get your child to eat, and make mealtime fun. They can also help you if you are having problems. The earlier you ask the better! If your child does not eat well for two or three days you should talk with your CF care center or your primary care doctor.

Toddlerhood can be a challenging, yet enjoyable time for families. Children at this age are trying to become more independent. They may also resist trying new foods! Both of these factors can make mealtime very hard.

### WHY DOES MY CHILD SAY “NO” TO NEW FOOD?

It is very common for toddlers to want to eat the same kinds of food, over and over again. It is also common for toddlers to resist many things that they are not used to, such as people they do not know AND trying new foods. The key to getting kids used to a new food and more likely to want to take a bite is to make the *new* food a *known* food. The best way to do this is by serving the new food to your toddler over and over again to have him “warm up” to it.

### WHAT DO I DO WHEN MY CHILD SAYS “NO” TO FOOD?

1. Prepare for your child’s “no.” Do not react. Respond by breaking eye contact and not talking about eating the food.
2. Offer the new food in small amounts (such as a teaspoon).
3. Do not remove the food from your child’s plate when it is refused. Even if your child does not eat it, just having it on his plate is a good way to have your child get used to the food and increase the chance that he will try it.
  - Did you know it takes children up to 8 to 12 times before they develop a liking for a food?
  - Most parents stop trying a new food after 3 or 4 times.
  - Offering foods many times can move them from yucky to yummy for your child!
4. Look for your child’s successes! Praise your child for touching, trying, and eating the new food.
5. Parents usually make their child swallow a food once it is in his mouth. This can make children afraid to taste new foods. You can let your child spit a new food in the garbage can after he tastes it. This will help him be more willing to try new foods. Be sure to praise him for trying a new food, even if he doesn’t swallow it! Do not talk to

him about spitting it out. Instead say, “I like how you tried a new food; you are very brave!”

6. Instead of labeling a food as one he “doesn’t like” try calling it one that “he is not old enough for yet.” You can say: “I like the way you tried [*insert name of food*]. It does not look like you are old enough for [*name of food*] yet.”
7. At the end of the meal, remove your child’s plate. Do not offer food again until snack time. Your child will catch up for the missed food at snack time. Do not make another meal or change foods during a meal. You do not want to become a short-order cook!

### SICK DAYS

Food refusal often happens on days that your child is not feeling well. Because children with CF can lose weight very quickly, it is important to have a plan for managing sick days. Be sure to check with your CF dietitian about how to best give high-calories when your child is sick. Here are a few tips:

1. Offer high-calorie foods that you know your child likes, rather than a new food. This will set you up for success! Shakes and smoothies may be good choices.
2. Use your praise to encourage your child to eat.
3. Offer your child an extra reward if he finishes his meal or snack. Since your child will not feel like being active, watching a movie may be an option.
4. Do not pay attention to your child when he refuses to eat. If you do, he will learn that one way to get your attention is to refuse to eat. Instead, you want to teach him that he gets attention for eating what you offer.
5. Once your child starts to feel better be sure to slowly increase the amount of food you give and how much you expect him to eat.

### TALK WITH YOUR CF CENTER

Talk to your CF center at *every* visit about your child’s eating. Your CF dietitian can help you make food choices, add calories, get your child to eat, and make mealtime fun. They can also help you if you are having problems. The earlier you ask the better! Good eating habits start at a young age and last a lifetime. If your child does not eat well for two or three days you should talk with your CF care center or your primary care doctor.

# Encouraging Pill Swallowing in Young Children with Cystic Fibrosis (ages 3-8 years): A Behavioral Intervention for the CF Team

Alexandra L. Quittner, Ph.D., Kristen K. Marciel, Ph.D.,  
Avani C. Modi, Ph.D., & Ivette Cruz, M.S.

## Why is pill swallowing important?

Difficulty swallowing pills is a significant barrier to adherence in young children with CF. In a survey of patients from general pediatric practices, 26% of children had difficulty swallowing pills (Anderson et al., 1995). In a study of barriers to adherence for CF, "difficulty swallowing pills" was listed by the child as the second most important reason for missing enzymes or oral medications (after "forgetting"; Modi & Quittner, 2006). Learning to swallow pills is important for children who must regularly take oral medications. Swallowing pills without difficulty increases adherence, convenience for parents, and the efficacy of enzymes.

## Behavioral Intervention

- Uses successive approximations (steps) to establish the behavior (swallowing pills)
- Positive reinforcement (rewards) help to get the behavior going and maintained (Beck et al., 2005)
- Program was developed and evaluated in an NIH study to improve adherence (Quittner et al., 2001)

## Preparation

- Create a pill swallowing kit including: candy (sprinkles, mini M&Ms, Nerds), small cups for water, empty gel capsules, stickers, sticker charts.
- Ask parents to save gel capsules when they remove enzyme beads; these capsules can be used later!

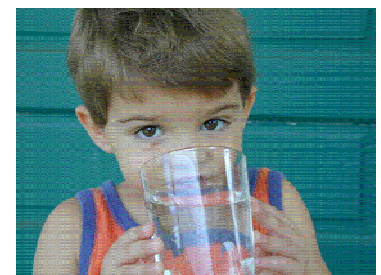


## Assessment

- Get approval from the CF team; Check for allergies to the candies
- Ask parents if eating candy is okay

## Instructions for Successive Approximations

- Step 1:** Ask the child to swallow a sip of water. Praise the child, "great job swallowing the water!" Let the child pick another sticker for this first success!
- Step 2:** Start with the smallest candy (sprinkles). Let the child feel the candy on their tongue and melting down their throat.
- Step 3:** Ask the child to "place the candy on the middle of your tongue. Feel how the sprinkle, take a drink of water, and swallow the 'pill'."
- Step 4:** If the child is comfortable with Steps 1-3, go on to the next larger candy.



## Hierarchy

After several consecutive successes, the child may move on to the next size candy "pill." You can set the pace for moving through the hierarchy below:

- Sprinkles
- Mini M&Ms
- Nerds
- Empty pill gel capsule.
- Finally, take the enzyme!





## First Session

- Praise the child for both effort and success.
- Most children find swallowing these sprinkles surprisingly easy.
- Sessions generally last 5 to 10 minutes and should be fun!
- Length of the session should be based on the child's attention and skill.
- If the child has difficulty with a larger piece of candy, end the session with a success by having the child swallow a smaller piece.
- {You can move backwards on the hierarchy at any time!}

## Homework

- Give the parent samples of each candy, blank sticker charts, and stickers to continue the program at home.
- Encourage the parent to practice each day and to reinforce progress with praise and stickers.
- Be specific about when they will practice (e.g., before dinner).
- After the child earns a certain number of stickers (determined by the parent), the child can earn a small prize, such as crayons, a coloring book, or extra time playing video games or with parents.
- Check progress and continue the pill swallowing program at the next clinic visit.
- This can also be done if child is in hospital.



A sticker chart for a pill swallowing program. The chart is a grid with days of the week as columns and meal/snack times as rows. The rows are: Breakfast, Snack, Lunch, Snack, and Dinner. The columns are: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, and Saturday. Each cell in the grid contains a smiley face sticker. The chart is titled 'Sticker Chart for Pill Swallowing Program' and has a small icon of a pill bottle in the top right corner.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast
Snack	Snack	Snack	Snack	Snack	Snack	Snack
Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
Snack	Snack	Snack	Snack	Snack	Snack	Snack
Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner

## Future Sessions

- Begin the next session with the size candy the child swallowed at the end of the previous session.
- Once the child progresses through the 3 types of candy, he/she can swallow the empty enzyme capsule.
- Some children move through the hierarchy easily in one or two sessions. Other children may require 2 to 6 sessions.
- Be patient and make it fun!
- Continue to praise and reinforce pill swallowing until the behavior is well-established.

## Other Strategies at Home

- Put the pill into a spoonful of ice cream, applesauce, or pudding and let it slide down your child's throat.
- Swallow the pill with milk or juice instead of water to change the thickness and taste of the liquid.

## References:

- Anderson, O., Zweidorff, O.K., Hjelde, T., Rodland, E.A. (1995). Sola legesenter: Problems with swallowing tablets. A questionnaire study from general practice. *Tidsskrift for den Norske laegeforening (NORWAY)*, 115, 947-949.
- Beck, M.H., Cataldo, M., Slifer, K.J., Pulbrook, V., & Guhman, J.K. (2005). Teaching children with attention deficit hyperactivity disorder (ADHD) and autistic disorder (AD) how to swallow pills. *Clinical Pediatrics*, 44(6), 515-526.
- Modi, A.C. & Quittner, A.L. (2006). Barriers to Treatment Adherence for Children with Cystic Fibrosis and Asthma: What gets in the way? *Journal of Pediatric Psychology*, 31, 846-858.

We acknowledge the support of NIH grant #R01 HL69736.