

Final Thoughts

Other Children with Cystic Fibrosis

- **Because the bacteria that can grow in the lungs of people with CF can be spread between individuals with CF, children and adults with CF should not be in close contact with each other.**
- Children with CF should not be in the same classroom, eat lunch together, take gym together. If for some reason, i.e. school assemblies, special classes such as music and art, or school events, children with CF must be in the same room, there should be at least a 3 foot radius between the 2 children followed by good hand-washing and hand sanitizer afterwards.
- **Let the teacher/nurse know, if they have additional questions, the team at the CF Center can be reached at (860) 545-9440.**

Tips from the Experts

Packing a High Calorie Lunch

- Invest in a sturdy lunch box/bag that will hold a small ice pack and a small thermos.
- If possible, use peanut butter to increase calories. Try it as a dip for pretzels!
- Always use whole milk products –cheese, yogurt, cottage cheese, sour cream, cream cheese spreads. Powdered milk can be added to whole milk and shakes.
- Use mayonnaise (not light or fat free) and/or creamy salad dressings as a spread for sandwiches and as a dip for vegetables, pretzels, crackers.

Good snacks for lunch boxes

Trail mix w/ nuts	Chocolate milk w/ Scandishake or	Cheese sticks & single servings of
Granola, protein and snack bars	Carnation Instant Breakfast	cheese
Cheese and crackers	Pretzels & hummus or peanut butter	Whole milk yogurt w/granola
Canned/bottled shakes,yogurt drinks	Whole milk pudding cups	Cookies/fig bars
	High fat deli meats & cheese “roll ups”	High fat muffins

Important Phone Numbers

Your Child’s Teacher

Name/Phone Number

School Nurse

Name/Phone Number

Other Important Phone Numbers

Emergency Contacts

Name/Phone Number

Emergency Contacts

Name/Phone Number

Physicians

Name/Phone Number

Make sure to have medication administration forms filled out at least 1 month before the start of school. Don’t forget to leave the school with your phone numbers and the names of emergency contacts.

Good luck!

Talking With Your Child’s School About Cystic Fibrosis

A Conversation Guide for Parents from the Central Connecticut Cystic Fibrosis Center



Developed by the Patient and Family Advisory Board

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Cystic Fibrosis-Key Points



Definition of Cystic Fibrosis

Begin by addressing the following:

- Have you had any experiences with children with CF in the past?
- What do you already understand about CF?

If the teacher/nurse has no previous knowledge of CF this is a general definition to help with a discussion; remember to take into consideration how CF affects your child.

Cystic Fibrosis is a genetic disease that causes the body to produce abnormally thick, sticky mucus, which clogs the airways and can lead to sinus and lung infections. The thick CF mucus can also obstruct the pancreas. This can prevent digestive enzymes from reaching the intestines to break down and digest food. People with CF can lose an abnormal amount of salt when they sweat, so salt replacement and good hydration are important during hot weather. The symptoms of CF are diverse and vary in severity. Each child with CF may present with variable combinations of symptoms.

This would also be a time in which to hand the teacher the CF Foundation's pamphlet with information for the teacher, and use it as a tool to help you in your discussion about CF. (Making sure you have read it yourself first). Cover the following points:

- What questions do you have for me?
- What other information do you need?

Even if the teacher/nurse says they don't have any questions-ask if they would mind talking with you a bit more about CF. Then proceed to discuss the following talking points. Keep in mind-these are general points of discussion which may not apply to every child with CF. This is also the time to discuss your/your child's openness regarding their diagnosis of CF. If your child has specific issues you would like to discuss, list them in this space so you can be sure to mention them as well.

Nutrition

- Emphasize that nutrition with a balanced high calorie/high protein/high-fat diet is a vital component in CF, stating that good nutrition (and higher body weight) appears to correlate with better lung function.
- Ask if there are any rules about peanuts/peanut butter in your school system. Remember, peanut butter is a great way to increase calories!
- Advise that pancreatic enzymes must be taken orally before every meal and snack so your child's food can be digested properly.
- Ask what the school policy is for administering enzymes.
- Teach the nurse/teacher/school staff that enzymes are a nutritional supplement and are not harmful to anyone who takes them accidentally.
- Be sure that the arrangements are in place as to how, where, and when your child will take their enzymes in school.
- Confirm who will administer them each day and be sure that your child is able to go to lunch **with** their class, not follow along after being in the health office.
- Know how enzymes will be handled for snacks and field trips.
- Ask the school staff to focus on having your child spend as little time as possible out of the classroom, so that they do not miss teaching time. If the teacher is willing to give the enzymes or keep them in a safe place for self-administration, that is a very good thing.
- **Ask to be notified if your child is frequenting the bathroom more than usual. This may be an indication that either a.) your child is not taking their enzymes before meals/snacks or b.) your child may require an increase in enzyme dose before meals/snacks.**
- Ask your child to bring home the food that they do not eat from their lunches and snacks so you can judge how much they are eating in school. If possible when they have hot lunch, ask if someone could occasionally check if they are finishing their lunch.
- Ask about double portions, most school districts will allow if requested by family/health care provider. Check to see what documentation is required. Also, your child may require extra snacks or high calorie nutrition supplements. Ask where this would occur.

Respiratory Issues

As you may know, children with CF may have respiratory issues which include:

- An occasional baseline cough which is a way for the lungs to clear secretions.
- This baseline cough is not an emergency nor is it contagious to other people.

It is important for children with CF to be treated like everyone else in the class with few exceptions:

- A box of tissues at the child's desk should be allowed for use during coughing with subsequent disposal in a sanitary manner.
- A child with CF may also have asthma and may need to take his/her inhaler prior to gym class or at other times during the day.
- **Ask for notification if increased cough or inhaler use is noted throughout the day.**

Any kind of exercise is very beneficial for children with CF. Gym is not only encouraged but also can be helpful in clearing secretions from the lung.

Infection Control

- While most children will have a cold for only a few days, children with CF may require antibiotics and other therapies and take longer to "get over" a cold.
- Because children with CF require more calories to maintain normal growth and lose salt easier, illnesses like a "GI bug" that most kids fight off in 24 hours could be more problematic.
- As is true for all children, the use of good hand washing, and an anti-bacterial hand sanitizer such as Purell, prior to meals/medications, after coughing/sneezing, after using the bathroom, is important to avoid the spread of illness.
- **Ask for notification from the nurse/teacher if your child is making frequent visits to the health office-the school nurse does not need to become your child's "best friend".**