Nutrition

School, Enzymes, and Sports
For the Child with Cystic Fibrosis

The Cystic Fibrosis Foundation has prepared this fact sheet for teachers, caregivers, and parents to help them meet the nutrition needs of the school-aged child with cystic fibrosis (CF).

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

CF In The Classroom
The lung disease in CF can cause the child to cough a lot to clear lung mucus. If the coughing disrupts class, the child could leave for a drink of water. The child may cough up some mucus and want a box of tissues in their desk or backpack. CF is not contagious. Coughing helps to keep lungs clear and should not be discouraged.

Thick mucus also clogs the pancreas and blocks digestion. To treat this, oral pancreatic enzyme medicine is taken with all meals and snacks that contain fat, protein, and/or complex carbohydrates. Foods that are mainly simple carbohydrates (like juice, fruits, fruit snacks, sports drinks, and soda) do not require enzymes to be taken since they are easily absorbed. Oral pancreatic enzymes are not addictive and will not change the child’s behavior. Pancreatic enzymes do not cause a problem if taken by another child. As always, when a child takes medicine not prescribed for them, call Poison Control at (800) 222-1222.

Most children with CF have been taking pancreatic enzymes since infancy and can take them on their own. Teachers and parents need to work together to make a medicine schedule for school. The child, school nurse, teacher, or office staff can administer the enzymes. The right dose helps digestion and food absorption. The dose should not be changed without talking to the CF dietitian or caregiver.

When children forget to take their enzymes or do not take enough, they may need to go to the bathroom more often, have stomach pain, or have foul-smelling gas. The child with CF should always feel free to leave for the bathroom to prevent embarrassment because of lung or stomach symptoms.

Nutrition Needs
Children with CF need a high-calorie, high-protein diet and enzymes to gain weight and grow. They need high-fat foods, which are often discouraged for the general public. They may take longer to eat and need more food. Extra snacks at school and high-calorie nutrition supplements may be needed to increase calories. They should be able to get their enzymes and take them in a manner that gives them the most time to eat.

A balanced, high-calorie diet with enzymes gives good nutrition, which helps children with CF be healthy. Good nutrition also helps physical activity.

Exercise And CF
Exercise has benefits for all. For children with CF, exercise also helps clear mucus and increase lung muscle strength. Exercise also can help increase self-image and decrease social differences between them and others.

Children with CF can and should be included in all games and activities. From day to day, CF may limit how much they can do or how long they can do it.

For children with CF, exercise:
- builds muscles and strong bones;
- strengthens lungs;
Nutrition • Schools, Enzymes, and Sports

If you have questions about “School, Enzymes, And Sports Nutrition For The Child with CF,” or any aspect of CF care, call your CF dietitian or care provider.

DIETITIAN NAME ________________________________________

PHONE NUMBER ________________________________________

CARE PROVIDER NAME ___________________________________

PHONE NUMBER ________________________________________

Children with CF lose more salt when they sweat than children without CF. They must replace salt and fluid when exercising. Salt can be replaced by eating high-salt foods like pretzels or potato chips. Children with CF should drink fluids before, during, and after exercise. During aerobic exercise, it is estimated that children with CF should drink six to 12 ounces of fluid every 20 to 30 minutes. Sports drinks, with the added carbohydrates and salt, are great for children with CF to drink while playing sports. The carbohydrates give fuel to the muscles and help keep blood sugars up. The salt quenches thirst and prevents dehydration. Avoid drinks with caffeine during exercise since they can increase fluid loss.

Children with CF should talk to their CF dietitian or care provider before using products that promise better weight gain and athletic performance.

©2002 Cystic Fibrosis Foundation

Contributing Authors:

Judy Fulton, R.D.
CF Nutritionist/Dietitian
Children’s Hospital of Pittsburgh
Pittsburgh, PA

Susan Casey, B.S., R.D.
Pediatric Clinical Dietitian
Children’s Hospital & Regional Medical Center
Seattle, WA

Elisabeth Luder, Ph.D., R.D.
Associate Professor
Mt. Sinai School of Medicine
New York, NY

Karen Maguiness, M.S., R.D., C.S.P.
Dietitian, Pediatric Pulmonary
Riley Hospital for Children
Indianapolis, IN

Annie McKenna, M.S., R.D., C.N.S.D.
Nutritionist
Children’s Healthcare of Atlanta
Atlanta, GA

Leslie Hazle, M.S., R.N., C.P.N.
Director of Patient Resources
Cystic Fibrosis Foundation
Bethesda, MD

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

The following letter may be copied onto the CF care center’s letterhead and filled out accordingly.
To Whom It May Concern,

______________________________________________________ is under our care at the cystic fibrosis (CF) care center at ______________________________________________________. CF is an inherited disease that affects mainly the lungs and digestive system.

As part of ongoing CF medical care, this child must take the following oral pancreatic enzyme medicine with all meals and snacks. The only usual exception is drinks that are mostly sugar, water, or fruit.

| ENZYME BRAND NAME | NUMBER OF CAPSULES WITH MEALS | NUMBER OF CAPSULES WITH SNACKS |

These enzymes are not addictive and will not change behavior. Most children with CF have been taking enzymes since infancy and take them on their own. If children with CF are allowed to take them on their own, they are usually more compliant with this vital part of their care. As always, if a child takes medication not prescribed for them, contact Poison Control at (800) 222-1222.

Please call with questions.

Sincerely,

________________________________________________________________________

PHYSICIAN SIGNATURE

________________________________________________________________________

PRINT NAME

________________________________________________________________________

PHONE NUMBER

________________________________________________________________________

DATE