A TEACHER'S GUIDE

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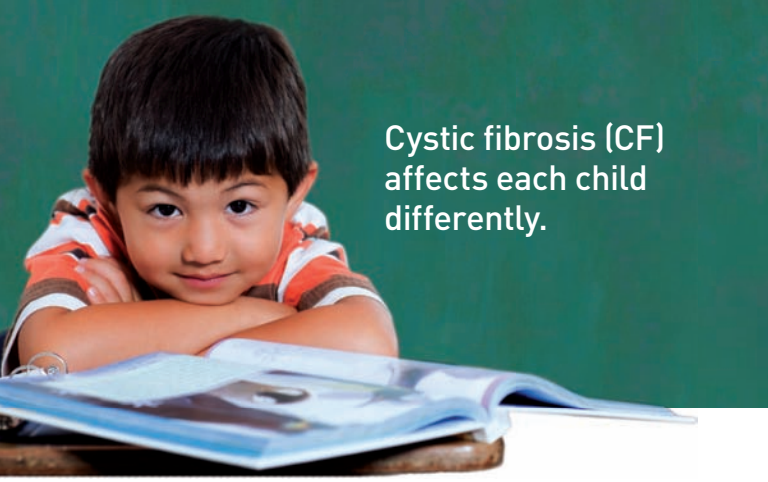

Cystic fibrosis (CF) affects each child differently.

What is CF?

CF is a chronic, genetic disease that primarily affects the lungs and digestive system. Approximately 30,000 children and adults in the United States have the disease. It is typically diagnosed at birth through newborn screening, with the majority diagnosed by age 2. In people with CF, the body produces thick, sticky mucus that can clog the lungs and pancreas. This can make breathing difficult and lead to respiratory and digestive problems.

CF affects each person differently, and with varying degrees of severity. Although the cough associated with CF can be persistent, it is not contagious. CF does not affect mental ability.

Treatment of CF has advanced dramatically over the last 50 years. In 1955, children with CF rarely lived long enough to attend first grade. Today, many people with CF are living into adulthood, and enjoying careers, marriage, and children of their own.

What are the symptoms of CF?

Children with CF may be smaller than their classmates, and they may experience some or all of the following symptoms:

- Persistent coughing, at times with phlegm
- Recurrent respiratory infections
- Wheezing or shortness of breath
- Upset stomach
- Frequent greasy, bulky stools or difficulty having bowel movements
- Fatigue
- Poor growth/weight gain in spite of good appetite
- Gas

People with CF may also have CF-related diabetes, although it is more common as they get older.

When you have a child in your class who has CF, it is important to understand the disease and how it may affect him or her. This brochure will help you to provide support and answer questions regarding any special accommodations that might be needed in the classroom.

How is CF treated?

Treatment of CF varies according to the severity of the disease, and often includes medications—such as pills, capsules, and inhaled medicines—to address different symptoms. Some medications a child with CF may take are:

- Mucus thinners to make it easier to cough out mucus
- Antibiotics to treat lung infections
- Anti-inflammatories to reduce swelling of tissues in the body, such as the lungs
- Pancreatic enzymes to help with digestion and nutrient absorption

Management of CF also consists of daily routines, such as eating a high-calorie/high-protein diet to foster weight gain and growth, as well as different techniques for opening and clearing the airways.

A child's doctor may prescribe a nebulizer or inhaler to help with opening airways. It is also recommended that a child with CF perform airway clearance therapies (ACT). There are a number of exercise methods and devices that can be used as ACT; ask your student and his or her parents what method or device he or she uses and speak to the school nurse about familiarizing yourself with it in case the child requires assistance.

Considerations for the classroom

There are some general issues to be aware of when you have a student in your class who has CF. Since the disease affects each person differently, be sure to speak with the student and his or her parents to learn about specific circumstances and needs. Also, see if your student with CF has an Individualized Health Plan (IHP). An IHP is a document that outlines the management of healthcare conditions and medication needs of a student with special health issues. The goal of an IHP is to address medical issues and to maintain a healthy learning environment in the classroom for those particular students. It may address these issues:

Coughing

CF can cause a lot of coughing, sometimes producing mucus. Coughing helps to clear the lungs, so it should not be discouraged. It's also important to remember that the cough associated with CF is not contagious. If the cough is disruptive, or your student feels embarrassed in front of classmates, he or she should be allowed to leave the room for a drink of water. It is also a good idea for the student to keep a box of tissues nearby.

Snacks

Children with CF need to eat a high-calorie/high-protein diet in order to gain weight and grow. They may need more food at lunch and take longer to finish, and they may need frequent opportunities during the day to have snacks or high-calorie nutritional supplements. Children with CF should have access to high-calorie food choices, such as whole milk, which may otherwise be off-limits to other school children. Remember, before you make any changes or provide the child with any foods, always confirm with the parents or the school nurse.

Taking medication

The use of medication while at school is often guided by the IHP. It will often document which medications a child with CF is taking, when they are to be taken, and who can administer them. Most people with CF need to take pancreatic enzymes along with their meals and snacks to help with digestion. Some schools expect students to go to the school nurse for medications. However, your student may be allowed to handle the medication on his or her own. Having likely taken pancreatic enzymes since infancy, many children with CF are comfortable self-administering their medications. While pancreatic enzymes are not expected to be problematic if taken by another child, you should immediately call **Poison Control (1-800-222-1222)** whenever a child takes medicine not prescribed for him or her.

Restroom privileges

Although pancreatic enzymes help with digestion, people with CF may still experience abdominal pain, and foul-smelling gas and stools. Your student may need to make frequent trips to the bathroom due to bowel-related issues. Access to a private bathroom or the nurse's bathroom may help prevent embarrassment.

Physical education

Exercise is particularly good for many children with CF because it helps clear mucus, build muscles and strong bones, and lowers emotional stress. Participating in games and activities may also help your student feel more like a part of the group. It is important, however, to speak with the student and his or her parents about the kind of exercise and activities that are appropriate. Children with CF may not always have as much stamina as the other students. Because children with CF lose more salt when they sweat, they are at more risk for dehydration. Be on the lookout for signs and symptoms of dehydration in a child with CF, such as:

- Thirst
- Headache
- Dizziness or lightheadedness
- Rapid breathing

In order to prevent dehydration, it's a good idea to have water or sports drinks on hand and encourage drink breaks. Extra salts in the child's diet can also help prevent dehydration.

Staying healthy

Ensuring good hygiene among all—students and faculty—is the most effective way to ensure that people within the school stay healthy. Encourage frequent hand washing with soap and water—one of the simplest ways that all children can reduce exposing themselves, and others, to germs. When use of soap and water is not possible, students and faculty should have access to alcohol-based hand sanitizer gel. In addition to good hygiene habits, to help prevent the spread of germs, the 2013 Cystic Fibrosis Foundation (CFF) Infection Prevention and Control Guideline also recommends minimizing exposure to dust, as well as cleaning and disinfecting multiuse items such as computers, chairs, desks, play toys, and art supplies.

When students become ill, they should be encouraged to be diligent about following good hygiene habits, including frequent hand washing and the use of tissues when sneezing, coughing, or blowing their noses. Allow a child with CF to keep his or her distance from any students who come to school sick. You may also want to notify the parents of a student with CF if any of his or her classmates is ill.

The CFF Infection Prevention and Control Guideline also outlines provisions to consider if there are two or more people with CF in the school. To minimize the spread of CF germs, efforts should be taken to limit the contact between people with CF, including having them in separate classrooms, having them use different school equipment or facilities, and scheduling their participation in common school activities, such as lunch, gym, and recess, at different times.

Students' rights

Certain laws have been enacted to ensure that all children in the United States receive a good education.

The Individuals with Disabilities Education Act (IDEA) is a federal law that requires public elementary and secondary schools to give free and appropriate education to children with disabilities.

Section 504 under the Rehabilitation Act of 1973 is a federal law that prohibits discrimination against a person because of a disability by any group that gets federal funds.

An Individual Education Plan (IEP), which falls under IDEA, or a 504 plan, guides the delivery of special education support and services for a student with a disability.

Some examples of accommodations that may be requested in a 504 plan or IEP include:

1. Allow for time during the school day to take medicines and do airway clearance therapy.
2. Adjust school rules to allow the child to take his or her own medicines, like pancreatic enzymes.
3. Allow for access to snacks, nutritional supplements, or extended lunch time.
4. Allow for a later start time of the school day, due to time-consuming morning therapy.
5. Have a plan to get homework or tutoring when the child is ill or in the hospital. (Children with CF may be absent periodically in order to receive IV antibiotics for lung infections.)
6. Consider Web cameras or DVD recordings of classes the student misses.
7. Adjust or waive attendance guidelines.
8. Provide access to a private bathroom, perhaps in the nurse's office.
9. Allow unlimited access to bathrooms and water.
10. Prepare a medical emergency plan for the school.

Another document that outlines how a student's special medical needs will be managed by the school to foster learning is the Individualized Health Plan (IHP). The IHP may be included as part of a student's IEP or 504 plan, but is usually collaboratively written—by parents or caregivers, the student, the student's healthcare provider(s), and a multidisciplinary team of school staff—and focuses on the administration of healthcare at school. The IHP may include a list of medications the student is taking, who can administer these medications, and the times of day when they should be taken.

Learning more about your student and CF

Dealing with CF creates emotional, physical, financial, and time-management challenges for all involved. When you find out that a child in your classroom has CF, it would be beneficial to you, the child, and the child's family to meet for a conference early in the school year so you can learn about the child's individual needs and how you can best help. While parents are not obligated by law to disclose their child's diagnosis of CF, you may want to ask them to consider sharing this information with classmates to avoid any potential teasing. Keep the communication lines open as the year progresses, and let the parents know if the child is falling behind, seems unusually tired, or is coughing more than usual.

Be sensitive to the medical needs of a student with CF, but also try to minimize their impact so they can get the most out of their school experience—educationally and socially—and not feel as if their CF is preventing them from taking part in everyday school life.

What you have read in this brochure is only a brief introduction to CF. If you would like more information, the following websites may be helpful.

Cystic Fibrosis Foundation: www.cff.org

Mayo Clinic: www.mayoclinic.org/diseases-conditions/cystic-fibrosis/basics/definition/con-20013731

National Heart Lung and Blood Institute: www.nhlbi.nih.gov/health/health-topics/topics/cf

CFF Prevention and Control Guideline for CF: 2013 Update: www.cff.org/LivingWithCF/InfectionPreventionControl

Cystic Fibrosis Foundation – CF at School: www.cff.org/LivingWithCF/AtSchool

When you have a child with cystic fibrosis in your class...

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This information meets the guidelines and standards of the Cystic Fibrosis Foundation's Education Committee.

**Brought to you by Actavis, Inc.,
a company that is committed to improving
the quality of care for people with cystic fibrosis.**

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