

A Teacher's Guide to Cystic Fibrosis

As a teacher, you play an important role in developing and strengthening your student's self-image, which will help to stimulate the development of meaningful relationships with classmates. You also play a role in ensuring the optimal health environment for your student with cystic fibrosis (CF).

In addition to reading the information provided here, it is recommended that you talk with your student's parents, and the CF healthcare professionals (including physician, nurse, dietitian, respiratory therapist and social worker) about the best ways to help your student maximize his or her overall learning experience, while maintaining his or her health.

- [What is cystic fibrosis?](#)
- [What are the symptoms?](#)
- [Treating Cystic Fibrosis](#)
- [Digestive Problems](#)
- [Clearing the Lungs](#)
- [Infection Control](#)
- [Exercise](#)
- [Individualized Education Plan](#)
- [In Summary](#)
- [About the Cystic Fibrosis Foundation](#)

What is cystic fibrosis?

CF is a life-threatening, genetic disease that affects approximately 30,000 children and adults in the United States. In people with CF, a faulty gene causes the body to produce abnormally thick, sticky mucus that can clog the lungs, pancreas and other organs. This can lead to severe respiratory and digestive problems. One in 31 Americans—10 million people—is a symptomless carrier of the defective CF gene. A person must inherit two such genes, one from each parent, to have the disease.

CF is not contagious and affects each individual differently. Therefore, one should not make a generalized assumption about the health of someone with CF. Some people with CF are in good or even excellent health, while others are severely limited by the disease and are unable to attend school regularly.

When the CF Foundation was started in 1955, a child with CF was not expected to live to attend elementary school. Today, dramatic advances in CF research and treatment have extended the median predicted age of survival for people with CF to the mid- to late 30s.

The future goals and plans for children with CF should not be limited—they should be encouraged to pursue their academic, career, and life goals to the fullest.

[back to top](#)

What are the symptoms?

Because CF produces various effects on the body, the disease may be confused with other gastrointestinal or respiratory conditions such as pancreatitis or asthma. In some cases, people with CF do not appear to be seriously ill. Symptoms may include some or all of the following:

- upset stomach;
- physically smaller than classmates;
- fatigue;
- persistent coughing, at times with mucus or phlegm;
- recurrent respiratory infections, perhaps including pneumonia; and
- wheezing or shortness of breath.

[back to top](#)

Treating Cystic Fibrosis

If you have a student in your class with CF, it is helpful to understand the medical routines your student may experience. The treatment for CF varies, depending upon the disease severity and the organs affected. Most current treatments for CF are designed to treat digestive problems or to clear the lungs to make breathing easier.

[back to top](#)

Digestive Problems

CF mucus also can obstruct the digestive system and prevent pancreatic enzymes from reaching the small intestine. Without treatment, the body cannot digest food and nutrients properly, so children with CF can be smaller and grow more slowly than their classmates. Most people with CF need to take pancreatic enzyme supplements with meals and maintain a high-calorie diet to help their bodies absorb the proper level of nutrients. When eating meals and snacks, your student may take pills including pancreatic enzymes and antibiotics.

Please note that these medications are not habit-forming and will not alter your student's mental or emotional behavior. Although enzymes are not harmful, no medication should be shared with other students.

Some children prefer to take their medication privately just before eating. Other children, unless supervised, may skip their enzymes by hiding, "forgetting," or throwing away their pills to avoid taking them in front of their classmates. Some schools may require that the child go to the school nurse to obtain enzymes before meals. Discuss with your student and his or her parents the most comfortable routine.

In addition, although enzymes aid digestion, people with CF may still experience abdominal pain, foul-smelling gas and/or diarrhea. It is important to give a student with CF frequent access to the bathroom. If a student with CF passes gas frequently, it is best not to draw attention to this. Try to make the student feel comfortable and at ease about excusing himself or herself to the bathroom when needed.

To learn more about the nutritional needs of children with CF, visit the [Living With Cystic Fibrosis](#) section of this Web site, or contact the [CF Foundation-accredited care center](#) in your area.

[back to top](#)

Clearing the Lungs

The thick, sticky mucus produced in CF airways clogs breathing passages and is a breeding ground for lung infections. Coughing is the body's primary method of clearing the mucus that clogs CF lungs. It is important that children with CF not hinder their coughs. However, your student may feel embarrassed to cough in front of others. You can help your student feel comfortable by making it easy for him or her to slip out of the classroom for a drink of water. Paying undue attention to coughing may only embarrass the student. Classmates are likely to follow your lead as the teacher—if you accept the coughing as normal, the rest of the class likely will do the same. The mucus should be expectorated into a tissue and thrown away. Encourage your student to keep a box of tissues and a means of disposal at his or her desk or nearby.

Your student also may be hospitalized or at home to receive intravenous (IV) antibiotics. IV antibiotics help fight infections and minimize lung damage to improve the overall health of those with CF.

A more common, everyday treatment, however, is known as "airway clearance." Performed once or twice a day for approximately 30 minutes at a time, airway clearance requires that the person with CF do special mucus clearance or breathing exercises.

Other therapies include aerosolized medications, which are delivered to the lungs via a nebulizer, to help open the airways and prevent or treat respiratory infections.

To learn more about the different airway clearance techniques used, read "[An Introduction to Airway Clearance](#)," which can be found in the [Treatments](#) section of this Web site. Other therapies include aerosolized medications, which are delivered to the lungs via a nebulizer, to help open the airways and prevent or treat respiratory infections.

[back to top](#)

Infection Control

One of the most important things a child with CF can do to stay healthy is to minimize exposure to germs and harmful bacteria. Frequent hand hygiene, which includes washing one's hands with soap and water and/or using alcohol-based hand gel, is best. The CF Foundation's infection control guidelines state that people with CF should perform hand hygiene after coughing or sneezing, after blowing their noses, before eating, after going to the bathroom, before and after breathing treatments, before and after airway clearance and before taking medicine. Either method of hand hygiene is effective in minimizing or eliminating germs. A good rule of thumb is if there is visible dirt on a child's hands, he or she should use soap and water. If there is no visible dirt, use an alcohol-based hand gel.

Please keep in mind that the germs often carried by children who do NOT have CF can be harmful to those with CF. Therefore, a child with a cold or flu should be encouraged to stay home. If a child with an illness is in the classroom, he or she should do hand hygiene frequently and use tissues when sneezing, coughing or blowing his or her nose.

CF-specific germs, such as *Pseudomonas aeruginosa* (Pseudomonas) and *Burkholderia cepacia* complex, usually are not harmful to people who do not have CF. Therefore, a child with CF who has a lung infection cannot pass it on to a child who does not have CF. However, these germs can be harmful to others with CF. If there is more than one person with CF in the school, such as another student or a teacher, you may want to pay special attention that infection control guidelines are followed.

Please contact your local [CF Foundation-accredited care center](#) with any questions regarding [infection control and CF-specific bacteria](#).

[back to top](#)

Exercise

Exercise is beneficial to children with CF because it helps loosen the mucus that clogs the lungs and helps strengthen the muscles used to breath. Children with CF should be encouraged to exercise and play as much as possible. Because of breathing difficulties, however, some children with CF may not have as much stamina as other children and may tire easily.

Use sound judgment when assessing a student's physical capabilities. Talk to the student and parents to determine an appropriate level of physical activity. Try to include a child with CF in all games and activities in which he or she is physically able to participate.

Children with CF are at higher risk of dehydration, especially when exercising or in hot weather. A child with CF may need to eat salty snacks and drink extra fluids. Water or sports drinks should be easily accessible during physical activities. During aerobic exercise, children with CF should drink six to 12 ounces of fluid every 20 to 30 minutes. Drinks with caffeine should be avoided during exercise. Instead, stick mainly with water and sports drinks.

[back to top](#)

Individualized Education Plan

Sometimes, students with CF and their families choose to prepare an individualized education plan or IEP, under the Individuals with Disabilities Education Act or the Rehabilitation Act.

Although most people with CF are not visibly "disabled," they often have difficulty digesting food and breathing. Therefore, these laws help people with CF obtain services they need to secure a free public

education, while maintaining their health. For example, IEPs can help establish ways that students can obtain special tutoring if they are absent due to illness or hospitalization.

To learn more about CF and school issues, read "[School and CF](#)."

[back to top](#)

In Summary

With new medications and better care, people with CF are living longer, healthier lives. More people with CF are attending school, graduating and pursuing careers. People with CF have chosen to become doctors, lawyers, teachers, health care workers, electricians, and even race car drivers. Learning is the key to living life fully in spite of the daily demands of a chronic illness. You can help to inspire your student with CF to reach for the stars and plan for the future. To learn more about CF contact the local CF Foundation-accredited care center (<http://www.cff.org/LivingWithCF/CareCenterNetwork/CFFoundation-accreditedCareCenters/>).

[back to top](#)

About the Cystic Fibrosis Foundation

The mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. Although CF scientists have made remarkable advances, much more research needs to be done to actually cure this complex disease.

The CF Foundation has taken the lead in encouraging and funding the necessary research at medical institutions and companies. It also has established the infrastructure, through grants and a clinical trials network known as the Therapeutics Development Program, to enable the discover and development of new CF treatments. The program facilitates and expedites clinical trials of all promising CF therapies, including the refinement of gene therapy technology. In brief, the CF Foundation continues to support research on a variety of promising treatments simultaneously to find a cure.

For more information on CF, the CF Foundation, and how you can help, please visit [Ways to Give](#), call **(800) FIGHT CF** or send an e-mail to info@cff.org.

[back to top](#)