



Cystic Fibrosis and School Issues

Information for teachers and other school staff

What is cystic fibrosis (CF)?

CF is a genetic disease. More than 30,000 people in the United States have CF.

People with CF are living longer than ever before, often into adulthood (age 30 or older). CF is almost always diagnosed in early childhood. It is not contagious; others cannot “catch it.” CF has no effect on brain development. People with the condition are of normal or above-normal intellect.

What are the symptoms of CF?

CF affects how cells work in the body. A chemical imbalance leads to cells that cannot hold water. This makes mucus outside the cells thick and sticky.

Common symptoms of CF are respiratory and digestive problems.

Respiratory symptoms include thick, sticky mucus buildup in the lungs. This leads to frequent lung infections and permanent damage to the lungs.

Digestive problems occur when mucus blocks enzymes from moving from the pancreas to the small intestines. These enzymes are used by the body to properly digest foods, especially fat and protein. The result is fat and protein are not absorbed well. This leads to poor growth, stomach cramping and frequent, loose, foul-smelling stools.

CF can also lead to other physical problems, such as liver function problems, diabetes mellitus and effects on the reproductive system.

What can a teacher do to help in the classroom?

Although CF is not a common chronic illness in children, it is possible for a teacher to have a student with CF in their classroom, or at least in their school.

Common issues that arise in the classroom include:

- **Coughing** – Some children with CF have a chronic cough. Coughing is good because it helps the child to clear the lungs of the thick mucus and defend against lung infections. Teachers can help by encouraging coughing and not making the child feel uncomfortable for having to cough in class. Remember, CF is not contagious and a child with CF needs to cough.
- **Restroom breaks** – Because of the digestive symptoms of CF, teachers can help by letting a child with CF leave class at any time to use the restroom. Have a private talk about this with the child to help avoid any embarrassment.
- **Medicines** – Most children with CF need to take medicines at school. The most common medicine is supplemental pancreatic enzymes. Children must take their enzyme pills right before any time that they eat. This includes snacks, lunch and special parties where food is served. Teachers can help by making

To Learn More

- Cystic Fibrosis Clinic
206-987-2024
- Your child's
healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.
- For Deaf and hard of hearing callers:
206-987-2280 (TTY).

sure children take their enzymes with all meals and at the right time.

Other medicines a child might take include antibiotics, breathing treatments or anti-inflammatory medicines. Teachers can also help by working with parents, health professionals and other school staff if other medicines are needed from time to time.

- **Physical education and sports** – Exercise helps people with CF maintain stamina and keep their lungs clear. However, CF may decrease a student's tolerance of physical exertion. Compared to their peers, children and teens with CF may not have the same level of endurance. Teachers can help by working with students on an activity plan that meets their needs for exercise while not overdoing it. Remember, if a child coughs during exertion, it is not harmful. Allow the child enough time to finish coughing and then have them begin exercising again.
- **Absences** – A severe lung infection can cause a child to miss up to 3 consecutive weeks of school. Children often have to be in the hospital to receive antibiotics by IV. Some children are able to receive antibiotic therapy by IV at home with the help of home healthcare services. Teachers can help by sending assignments home and communicating and working with home tutors or teachers in the hospital. They can also work with the child after their hospital stay to come up with a plan for catching up with schoolwork.
- **Peer relationships** – Some children with CF may look smaller and thinner than their peers. They also may not be able to be as physically active, have more school absences, have a chronic cough and take medicines. All of these aspects of having CF differ from healthy peers. Teachers can help by being knowledgeable about CF and working with students, peers, and families to address problems with peer relationships.
- **Academic performance** – Students with CF should be given the same academic program as their peers. They can perform at the same level as other students. Intellectual impairment or other academic problems are not a direct result of having CF. However, in some cases, the impact of a chronic illness – such as fatigue, absences and the effects of decreased lung function over time – can affect a student's academic performance. Teachers can help by working with a student who is feeling ill or fatigued to individualize academic expectations. This is often referred to as an individualized education plan, or IEP. A 504 Plan is a plan that can provide accommodations for absences, etc., without changing academic expectations. Teachers can also assist by giving guidelines and encouragement for school work during times of school absences and hospital stays. Students with CF should be expected to learn and be encouraged to make the most of going to school.

Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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