

Cystic Fibrosis in the Classroom



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What Is Cystic Fibrosis and How Do You Get It?

Cystic fibrosis (CF) is the most common genetically inherited chronic disease among Caucasians. On average, it occurs once in every 3,300 live births. It affects more than 25,000 children and adults in the United States, with approximately 850 individuals newly diagnosed each year.*

People are born with CF. On average, 1 in every 29 Caucasians (1 in 29 Ashkenazi Jews, 1 in 32 Native Americans, 1 in 46 Hispanics, 1 in 60 African Americans and 1 in 90 Asian-Americans) carries the gene that causes CF. Carriers do not have any symptoms and do not have CF. For a child to be born with CF, the CF gene must be passed on by both parents. **You cannot catch cystic fibrosis. It is not contagious.**

In the early 1940's, children with CF rarely lived to be toddlers. Today, thanks to recent advances in medical care, the median age of survival (half live longer, half die younger) is 37 years, with many CF patients living well into their 30's, 40's and 50's.



Almost all children with cystic fibrosis show some symptoms of the disease. Typically, they live with mild, moderate, or even severe lung disease and gastrointestinal problems. Children with mild or moderate CF usually appear healthy, but this appearance may be misleading. They may have to follow a fairly rigorous health regimen at home and be required to see physicians frequently. Many children with CF fatigue easily and take a lot of medications to maintain their health.

Many children are used to living with chronic, controlled infections and even their parents may miss signs of a health decline. For these reasons, it can be hard to determine when a child needs extra support. We have written this booklet to help teachers and the school district understand cystic fibrosis and to help parents realize what their child's educational team should be aware of in the classroom.

* <http://www.urmc.rochester.edu/genetics/CysticFibrosis.htm>



How Does Cystic Fibrosis Affect the Child?

When someone has CF, his or her cells are missing an essential protein, so chloride and sodium cannot be properly transported across the cell membrane. Mucus secretions become thicker and stickier. This directly affects the respiratory, pancreatic and gastrointestinal systems. It can also affect the sinuses, liver, spleen and reproductive systems.

Respiratory System

For the majority of people with CF, complications in the respiratory system are the most serious. Respiratory failure is usually the most common cause of death. Thick, sticky secretions interfere with the body's natural process of clearing infectious material from the lungs. The secretions plug up small airways, causing poor air exchange.

With mucus unable to remove viral, bacterial and other particles from the airways, the lungs become a breeding ground for bacterial colonization, a condition where certain bacteria take hold in the lungs and cannot be removed. Colonization leads to repeated pulmonary infections, permanently damaging lung tissue.



The student with CF in your classroom may have the following respiratory symptoms:

- **Chronic coughing**
- **Sputum production (this may occasionally be tinged with blood)**
- **Shortness of breath or wheezing**
- **Pale appearance**
- **Frequent respiratory infections or pneumonia**



Gastrointestinal System

Another serious problem occurs in the gastrointestinal system. Everyone produces enzymes in the pancreas for digesting food. In someone with cystic fibrosis, thickened secretions block the pancreatic duct, and enzymes cannot get to the small intestines to break down food so nutrients can be absorbed. Poorly digested fats and proteins pass through the body. This is called malabsorption.

You might notice that the child with CF has:

- **Excessive appetite**
- **Poor weight gain, small stature, and distended belly**
- **Occasional flatulence and stomach cramping**
- **Foul-smelling, excessive or urgent stools (and the occasional unavoidable accident)**
- **A need for extra restroom privileges or extended time in the restroom**

Other complications from cystic fibrosis may include fatigue, chronic sinusitis, late onset of puberty, CF-related diabetes, liver cirrhosis and male infertility. The effects of CF are very individual. Not all people with CF have the same complications or symptoms, nor do they require the same care.





How Is Cystic Fibrosis Treated?

Medications and Treatments

These are numerous and time-consuming. They may vary during the year, depending on whether the child is having an exacerbation (a worsening of lung condition) or “well” period. They also vary depending on the child and the severity of the cystic fibrosis. A child on oral bronchodilators may become slightly overactive, with a fast heartbeat and trembling hands. Also, given certain steroidal medications and/or a diagnosis of CF-related diabetes mellitus (hyperglycemia or hypoglycemia), a child may experience mood swings, irritability and increased appetite.

Daily respiratory medications are aimed at clearing thickened secretions, opening airways, and preventing or controlling respiratory infections. Children may be on anti-inflammatory medications, antibiotics, steroids and/or bronchodilators. These medications may be given orally, intravenously, through metered dose inhalers or in aerosol form using a small-volume nebulizer.

Airway Clearance Treatments

Children with CF may require chest physiotherapy to help remove the thick secretions in their lungs. This is done at home, but sometimes a child may need treatments at school that may include the help of a respiratory therapist or nurse. Various inhaled medications are used to open airways either by an inhaler or nebulizer (small plastic device with a mouthpiece, which, when used with an air compressor, turns medications to a mist for inhalation). A school nurse may perform clapping on the child’s back, or a child may blow into a tube-like device (acapella or flutter) that causes coughing and is designed for mucus clearance. This small hand-held device is easily carried to school. At home, a child may have a motorized vest that vibrates to help remove secretions. All of these techniques open and help clear the airways, decrease infections and improve air exchange. These maintenance programs enable students to benefit fully from their educational experience.



Intravenous (IV) Medications

In addition to the daily health regimen, the child with CF may need to receive IV medications. In many cases, a child's parents can administer IV antibiotic medications at home, allowing the child to attend school (instead of entering the hospital) if the child feels up to it. If a child comes to school with an IV line, school administration, including the school nurse, should meet with the family to determine who is caring for the line, what potential emergencies might arise, who should be called in an emergency, and what level of activity is appropriate for the child. It is best to have the line checked daily by the school nurse. The administration of IV antibiotics in school should be addressed and incorporated into the child's healthcare plan.

Hospitalizations

When necessary, the doctor will admit the child to the hospital in order to control a lung infection. Tutorial support must be instituted immediately for the homebound or hospitalized child (if he or she is well enough) to prevent the student from falling further behind. Please contact the parents to see what support is needed. This should be specifically addressed in the child's healthcare plan and 504/IEP.





Proper Nutrition

Gastrointestinal medications and nutrition are also essential to the well-being of a child with cystic fibrosis. Most children with cystic fibrosis cannot absorb proteins and fats without taking pancreatic enzymes with every meal and snack. A child may take several enzymes with each meal. These **pancreatic enzymes** help break down food in the intestines, allowing the body to absorb the proper nutrients. Some children want to take their medications privately so as not to be questioned or observed by other students. If the child forgets or throws away his or her enzymes, he or she may have severe stomach cramping, increased flatulence and loose stools. Talk with the child and parents to assist them in finding the most appropriate way to take pancreatic enzymes. Be aware that certain antibiotics may exacerbate problems with loose stools.

Pancreatic Enzymes

Although the teacher or student should monitor medication of any type, these enzymes are not dangerous to others (except in large quantities), and often the doctor will write a note asking that a child who has shown maturity be allowed to self-administer his or her own enzymes. While some school districts will not allow this, many will. Ask the school nurse in your district for the protocols that need to be followed. This can be addressed in the Individual Healthcare Plan or 504/IEP. It is important to remember that, as these children grow, they must learn to take their medications themselves. Allowing the child with CF to self-administer enzymes is a relatively safe way to give the child responsibility and provide a sense of independence and privacy.





Gastrostomy Tube

Some children have a gastrostomy tube to help with severe malnutrition. This is a feeding tube that goes directly through the abdominal wall into the stomach. A plastic button sits on the outside of the abdomen. Supplemental liquid nourishment and certain enzymes can be administered through this button. This is rarely done at school, but if medically necessary, this procedure can only be done by a nurse. In some instances, the tube can become dislodged. If this occurs, contact the parent immediately.



Special Diet

Children with CF usually consume large meals that are high in protein, fat, salt and calories, and they need daily supplemental vitamins. A child torn between eating and playing may want to eat a little and run to the playground. He or she needs time and encouragement to eat every meal. Some children require a mid-morning or mid-afternoon snack to help maintain proper nutrition. When teaching your class about proper nutrition, be sensitive to the CF child who has a diet that may appear unhealthy by most nutritional standards.





Exercise

Another essential form of therapy for children with CF is aerobic exercise. We encourage them to participate in physical education and sports as much as possible. How much they are able to participate will depend on an individual child's level of disease and how the child feels from day to day. The child may lack endurance compared to peers and it may be especially difficult to run laps or participate in very strenuous activities. Exercise may bring on coughing episodes, shortness of breath and wheezing. This may be of some embarrassment to the child. A discussion between the CF student, parents and teacher can help provide appropriate activity levels for the child

The child with CF also has a reduced tolerance to heat, especially when exercising. Children with CF lose an abnormally high amount of salt through their sweat. You may even see salt crystals on their faces after strenuous playing or physical education. This causes an increased risk of dehydration, electrolyte imbalance and even heat prostration. The student with CF should carry water or sports drinks, eat salty snack or take salt tablets during hot weather.





Other Ways Cystic Fibrosis Can Interfere at School

Fatigue and Endurance

A student with cystic fibrosis may fatigue easily. This could be due to chronic infections, early waking for morning respiratory treatments, poor lung function and malnutrition. You may notice reduced endurance in comparison to other students, and long school days can be difficult for some. However, CF does not affect the ability to think. Although this disease does take a lot of time and energy, it in itself has no neurological effects.

If possible, give tests when your CF student is most alert. Provide extra time for tests and makeup work if possible. A child of small stature or one who is recovering from a lung infection may not be strong enough to carry the heavy books now required in middle and high school. Provide for an extra set of textbooks for home.

Coughing

This is another school issue that is occasionally misunderstood. Students with CF frequently have chronic coughs. Coughing is the body's way of clearing secretions. Thickened secretions are harder to clear. Children with CF are encouraged to cough. It helps them clear their airways so that they can breathe more easily. Sometimes they will bring up secretions, which can be embarrassing for the child.

You can help by having tissues available at the student's desk, not bringing attention to the cough and allowing him or her to get a drink of water or go to the restroom if needed. Special hand signals may be needed to allow for privacy.

Please remember: Cystic fibrosis is not contagious. A CF child may have an active cough without having a virus. If you are unsure, check in with the parents before sending a child home.

Chronic Sinusitis

Some children with CF have chronic sinus infections. This gives most children with CF a nasal quality to their voices. You may notice that a child has frequent headaches and blows his or her nose constantly. Again, please keep tissues readily available.



Cystic Fibrosis-Related Diabetes (CFRD)*

About 15% of youngsters with CF, primarily teenagers, will develop diabetes. Frequently the student with CF will struggle with chronic fatigue and an exacerbation of other pulmonary symptoms before diagnosis. Once CFRD is identified, the child will require special dietary needs prescribed by their physician, and eventually may need multiple daily insulin shots or an insulin pump to control sugar levels. Parents and teens will have to negotiate with the school district and the school nurse to determine the manner in which insulin will be administered to the child. Teachers need to be aware of this plan and what to do for the student when blood sugars become too high or too low.

*For more information about CFRD and its treatment, visit:

<http://www.cff.org/UploadedFiles/LivingWithCF/StayingHealthy/Diet/Diabetes/CFRD%20Manual.pdf>

Restroom Privileges

Due to coughing episodes and frequent digestive problems, students with CF will need to have unlimited access to the restroom. Coughing may cause them to gag and vomit, and their malabsorption problems may cause urgent bowel movements. Consider giving free restroom privileges designated by a hand signal or a permanent restroom pass. If use of this becomes excessive, please contact the parents.

Please! Never delay or stop a student with CF from using the restroom.

Absences

Students with CF frequently miss school. It may be for short periods due to stomach aches or extreme fatigue, or for extended periods due to IV therapy and hospitalizations. It is important for the teacher and parents to ensure that the student receives assignments in a timely manner so the student does not get further behind. It may also take the student with CF longer to complete assignments due to fatigue and home health-care regimens. In general, students with CF should be exempt from attendance policies. If you feel you have a student who is abusing this privilege, please check in with the parents. An open line of communication with the parents is the best policy.



Appearance and Self-Esteem

While CF children and teens generally appear very normal to people unfamiliar with cystic fibrosis, there are some differences that might embarrass the individual with CF.

Because of lung disease, a child with CF may appear barrel-chested, and his or her frequent and persistent cough may distract, frighten or annoy peers or teachers. In class, the student knows it is essential to regularly blow the nose and cough up and spit out mucus, but he or she is very conscious of how this must look and sound to others. This embarrassment causes some kids to work hard at suppressing coughing. Please remember that coughing is essential for these children and that CF is not contagious.

About 10% of children with CF have had abdominal surgery as babies* and may have long scars running over their abdomens. As mentioned earlier, the malabsorption of food may cause periods of flatulence, foul-smelling stools and a distended belly. The child may be short in stature, quite thin and occasionally require a gastrostomy tube. With growth problems, puberty can also begin late. Peers may tease CF kids for any of these reasons.

Additionally, children with CF have been trained from a young age to pay attention to diet and weight, as serious health complications can develop if they do not keep their weight up. This may make them more sensitive about their physical appearance than another child who just happened to grow up petite and slender. Boys may have a harder time with this than girls, as culturally it is popular for girls to be thin. For all of these reasons, children, and especially adolescents, may feel uncomfortable changing their clothes in front of their peers.

As with all children, self-esteem is individual, and despite the above issues, the child with CF in your classroom may have very healthy self-esteem. Still it is important to notice when CF issues, which may include questions about the length of life, are interfering with healthy self-esteem. The family should be notified in order to provide extra help and, if necessary, intervention.

**Cystic Fibrosis: A Guide for Patient & Family*, 3rd ed., ©2004 David M. Orenstein, (Lippincott Williams & Wilkins)



Communication Between the School and the Family

Parent Advocacy in the Classroom

Ultimately, the parent must be the advocate for the child in the classroom. There is a heavy burden on teachers in today's society to make accommodations for children with a wide range of health and academic needs. However, they must meet the requirements of Section 504 or IDEA which are Federal laws to protect people with disabilities. This requires more of their resources at a time when many classrooms are crowded, aides are scarce and the school nurse actually serves many schools. It is important for parents to understand the limitations of the system and how to work with them. At the same time, it is appropriate for a parent to advocate for their child's rights. If it is necessary to have a school nurse in the building, this must be incorporated in a 504/IEP plan.

Notifying the School

There should be a discussion with the parents, a 504 coordinator (or IEP team), teachers, the school nurse and the student as to whom should be informed about the child's condition and what, if any, accommodations need to be made. Some students and parents want to inform everyone, while others prefer total privacy. When school faculty or students are educated about the disease, the student with CF receives more support and understanding. Teasing, rejection and student isolation may occur when faculty and peers are unaware of the student's condition. Still, it is up to the student and parents to determine whether or not to divulge this information. As with any school issue, confidentiality is important.





Notifying the School (cont'd)

In some states, a local CF medical center will offer to send its CF coordinator and social worker to meet with the parents, teachers, principal, and the school nurse at the beginning of the school year. At the very least, parents and teachers should meet. As the child nears adolescence (or starts middle school), we encourage you to include the student in the conference. These meetings educate the staff about CF and stress the importance of communication between the school and the family. The staff can identify a contact person for the parents at the school to improve communication flow. Follow-up meetings should be scheduled when new problems arise at school or when there is a major change in degree of illness of the student.

Communication is the single most important tool parents and teachers have. Teachers need to let parents know when a child is falling behind. Parents need to inform teachers when a child is going through a rough period. Eventually, the student should take over a certain amount of the responsibility for regular communication with the teacher. Teachers might be suspicious when the only time they hear of a problem is on the day of a test or when something is due. They will be more understanding if they are regularly notified when a student is feeling fatigued, is not able to keep up, finds the workload too demanding, has been fighting a cold or has had a lot of after-school medical appointments.

The more parents can do (early in the year!) to anticipate the health needs of their child, the greater chance that the child will be able to manage his or her class work successfully and also be safe and comfortable in the classroom. Understanding the child's rights, building communication with the teaching staff and outlining any modifications that might be necessary are all important factors in a child's success.



IDEA and Section 504 - Tools for Success at School

Any accommodations or services* needed for your “special needs” child at school fall under IDEA/Section 504. These are national laws that protect qualified individuals from discrimination based on their disabilities.

The first law is called the Individuals with Disabilities Education Act (IDEA). It says that any public school must provide a free and appropriate education for students with disabilities. Most schools have interpreted this law to provide for students with learning disabilities, and you may know other children who have an Individualized Education Plan (IEP) that provides accommodations/services for their disabilities. But it is also meant to protect children with Other Health Impairments (OHI). A child with CF will qualify for protection under this law so long as his or her health issues may impact his or her ability to learn. For example, CF may impact a child’s ability to learn if the child must regularly miss school to receive medical treatment or attend doctor’s appointments. To qualify under this law, you must prove necessity. Additionally, teachers, school nurses or administrators may not understand that this law encompasses OHI and, unknowingly, deny child accommodations/services under IDEA. If this happens, consult Section 504.

The second law is Section 504 of the Rehabilitation Act of 1973. It offers the same modifications as IDEA, but extends beyond the boundaries of the school campus. In general, fewer teachers and school administrators are familiar with this law. Section 504 says that any agency that receives federal funds must make accommodations/services for people with disabilities and cannot discriminate against someone based on his or her disability. The advantage of 504 over IDEA is that it covers children in some environments outside of the public school, but in most cases IDEA has the most protections in the school setting.

*A listing of health services pertaining to the implementation of IDEA and Section 504 can be found in the following link
<http://www.actioncf.org/healthservices.htm>



The requirements of the law apply to organizations that receive financial assistance from any Federal department or agency. These may include private schools as well as public schools. In any case, parents, teachers, the school nurse and administrators meet to develop a plan that sets out all of the necessary modifications a child needs or may need in the future. Be creative in setting up modifications so that the child can get what he or she needs in order to learn.

Since the Individualized Education Plan/Individual Health Care Plan /Section 504 is a legally binding document, it is imperative that all requests, concerns and changes be placed in writing whether it is by letter or email. Conversation, either in person or by telephone is not legally binding.

This point cannot be stressed enough: **Document with a paper trail!**

Each State has a Department of Education and Office of Special Education to assist you. Contact Early Intervention Services through the State for children from birth to two years old. Services can include speech and physical therapy. Contact your local school district as part of "Child Find" to address the needs of children as young as three years old for pre-school handicapped services.

Use the following link for phone numbers and websites of Department of Education in your State:

<http://www.actioncf.org/school.html>

The following sample list includes a wide variety of accommodations and services that may be considered for a student with CF, depending on his or her needs.

On-Site Accommodations:

- o **Unlimited access to restroom**
- o **Unlimited access to snacks and water**
- o **Isolation from sick classmates**
- o **Self administration of pancreatic enzymes**
- o **Chest Physical Therapy in school**
- o **Exemption from the attendance/tardiness policy**
- o **Tube feedings in school or feeding therapy**
- o **Full-time nurse in building at all times**
- o **Air-conditioned classrooms**
- o **Handicapped parking**
- o **Transportation to and from school**



Educational Accommodations:

- o Extended time for tests, homework assignments and grading**
- o Modification of workload to accommodate health status, fatigue and absences**
- o Preferential seating**
- o Physical Education modifications**
- o Homework sent home after one absence**
- o Home or hospital instruction after three days absence**
- o Second set of textbooks at home**
- o Full participation in extra-curricular activities and field trips**

Under Section 504, a child with a disability can attend school-sponsored activities. The school must provide appropriate medical personnel.

Sometimes parents do not want to set up an IEP (under IDEA) or a 504 for a child that currently appears healthy. In the best interest of your child, it is beneficial to have a plan already in place upon entering elementary school. Although this plan may not be needed immediately, it is critical that it be formulated. When a child suddenly becomes ill, heads into a decline, or needs to be in the hospital, it is a very difficult time to try to put a plan together. Once in place, both IEP and 504 plans are reviewed and modified at least yearly by parents and the school team.



Recent Supreme Court decisions regarding Special Education and assistance for the health impaired child can be found at

<http://www.actioncf.org/supremecourt.htm>



Preparing for Higher Education

College Board Testing (PSAT, SAT, AP & ACT)

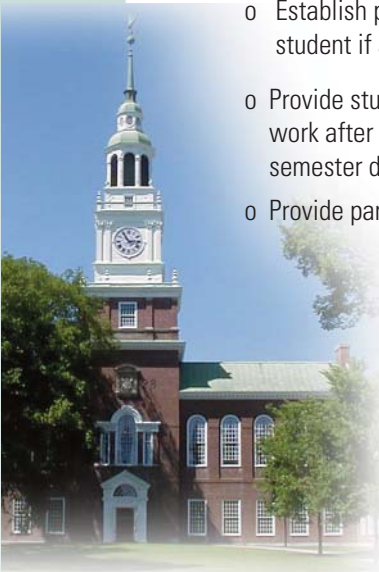
Complete the Student Eligibility Form at the end of your child's sophomore year. This form is available in your school guidance department. If your school did not receive the Instructions and Form, or for further information about specific appropriate accommodations for these tests call the College Board SSD office at (609) 771-7137 or download the information and form at

<http://www.collegeboard.com/ssd/student/index.html>

Thinking Toward the Future

For those attending college, special accommodations continue to apply under Section 504. Here are some you might want to address, once you have been accepted

- o Provide specific type of living accommodations (private dorm, private bathroom, air-conditioning)
- o Decrease number of class hours per semester
- o Modify class attendance requirements
- o Modify physical education requirements
- o Modify deadlines for assignments, projects or tests due to illness
- o Establish plan to have notes of lectures available to student if absent
- o Provide student the opportunity to complete course work after course ended if student misses part of semester due to illness
- o Provide parking/handicapped parking on campus





Resources for More Information

Cystic Fibrosis Research, Inc. (CFRI)

2672 Bayshore Parkway, Suite 520
Mountain View, CA 94043

Voice: 650.404.9975

Fax: 650.404.9981

cfri@cfri.org or www.cfri.org

Action CF

Fair Lawn, NJ

info@actioncf.org or <http://www.actioncf.org>

Cystic Fibrosis: A Guide for Patient and Family, 3rd Ed.,
David M. Orenstein © 2004
(Lippincott Williams & Wilkins)

*The Complete IEP Guide: How to Advocate for Your Special Ed
Child*, Lawrence M. Siegel © 2001 (Nolo Press)
ISBN: 0873376072

Cystic Fibrosis Website Guide © 2007

Available online at www.cfri.org through CFRI at 650.404.9975,
or through Digestive Care, Inc. at
<http://www.digestivecare.com>





Our Mission

Cystic Fibrosis Research, Inc. exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease

Our Vision

As we work to find a cure for cystic fibrosis, CFRI envisions informing, engaging and empowering the CF community to help all who have this challenging disease attain the highest possible quality of life.

CFRI is a nonprofit 501 (c) (3) organization that collaborates with other CF organizations reaching out to the CF community. We have a base of 14,500 subscribers including adults with CF, parents and extended families with children and adults with CF, volunteers, corporations and foundations.

CFRI has a diverse volunteer Board of Directors which includes an adult with CF, parents and relatives of children with CF, and professionals in the business community. We have a volunteer Research Advisory Committee (RAC) of physicians, scientists, and community members who administer, review and offer guidance on funding cystic fibrosis research projects. They administer both the Elizabeth Nash Memorial Post-Doctoral Fellowship and the New Horizons Research Campaign.

CFRI has a general membership that meets semi-annually and makes research funding decisions after reviewing recommendations from the RAC and the Board of Directors. CFRI is driven by several volunteer-based, staff-supported committees dedicated to improving educational resources for the CF community, providing personal support and raising funds for critical cystic fibrosis research.

Our support comes from hundreds of volunteers across the country.

Celebrating 32 years of research, education and support.



Working Together to Give You the Best!

Provided by:

CFRI

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