



Cystic Fibrosis in the Classroom



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Editor's Note:

Since the last edition of Cystic Fibrosis in the Classroom was released, new highly effective therapies, referred to as CFTR modulators, have become available to many individuals with cystic fibrosis (CF). These therapies address the underlying issue with specific CF-causing genetic mutations. For those who are eligible to use modulators, the symptoms of cystic fibrosis described in this book may be greatly mitigated.

Unfortunately, cystic fibrosis is a multi-systemic and complex disease. Not all people with cystic fibrosis can use modulators, and people of color are far less likely to benefit from them. Even those who are eligible may still experience many CF-related symptoms and secondary complications.

We hope that by the next edition of this booklet, treatment options have advanced, so that in the near future the majority of information contained in this book is obsolete.

— Siri Vaeth, MSW

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What is Cystic Fibrosis?

Cystic fibrosis (CF) is an inherited progressive disease characterized by an abnormality in the glands that produce sweat and mucus. CF is a genetic disease and is not contagious. Due to improved treatments, the median age of survival for those with CF has increased dramatically. In the 1970s, children were not expected to reach adulthood. Today, there are more adults than children with cystic fibrosis, and many are expected to reach middle age.

Mutations of a specific gene (the CFTR protein) affect the transfer of salts and chlorides into and out of cells that line the organs of many systems. Approximately 40,000 people in the U.S. have been diagnosed with cystic fibrosis. Cystic fibrosis impacts people of every race and ethnicity. While it occurs more often in people of northern European ancestry, CF impacts the Hispanic/Latinx, African American/Black, South Asian, East Asian, and Native American communities. There are many mutations of the CFTR gene, and people of color are more likely to have rare mutations that are not responsive to the newest effective therapies.

Approximately one in 31 people in the U.S. are carriers of a mutated cystic fibrosis gene. For a child to be born with CF, each parent must have passed on one copy of the CF gene. CF carriers – who have only one copy of the mutated gene – are not overtly affected by the disease and usually do not know they are carriers, although it is increasingly understood that there are health risks associated with carrier status.

Visit <https://tinyurl.com/5czzm7au>

Students with CF often follow a rigorous health regimen at home, including respiratory therapy, and multiple medications. They may fatigue easily and are required to see physicians frequently. Many students live with chronic, non-contagious infections. It can be hard to determine when a student needs extra support. This booklet has been written to help teachers, school district representatives and other educators better understand cystic fibrosis, and the CF-related issues they should be aware of in the classroom. In addition, this booklet supports parents to effectively advocate for their children.

While often associated with lung disease, cystic fibrosis affects various organ systems including the following:

- **Respiratory system**
- **Digestive system**
- **Reproductive system**
- **Musculoskeletal system**

Almost all people with cystic fibrosis show some symptoms of the disease.

Often, they live with chronic respiratory and gastrointestinal problems, both of which can range in severity.

Students with mild or moderate CF symptoms usually appear healthy, but this appearance can be misleading.

What Are the Impacts of Cystic Fibrosis?

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 pulmonary and gastrointestinal systems, including the pancreas. CF also typically impacts the sinuses, liver, spleen, reproductive organs, and skeletal system.

Respiratory System

For the majority of people with CF, complications in the respiratory system are the most serious. Advanced lung disease leading to respiratory failure remains the most common cause of death from cystic fibrosis. Thick, sticky secretions interfere with the body's natural process of clearing infectious material from the lungs. The secretions clog the small airways, causing poor air exchange, while preventing the cilia from helping to remove viral, bacterial and other particles from the airways. The lungs then 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.

Gastrointestinal System

Another serious problem often occurs in the gastrointestinal system. Everyone produces enzymes in the pancreas for digesting food. In most people with cystic fibrosis, thickened secretions block the pancreatic duct, and enzymes cannot reach the small intestines to break down food. As a result, nutrients cannot be absorbed, and poorly digested fats and proteins pass through the body. This is called malabsorption.

Poor absorption and resulting poor weight gain can lead to delayed onset of puberty, which can impact children's self esteem. For some children and teens, malabsorption – and associated vitamin D deficiency – sets the stage for musculoskeletal issues, including early diagnosis of osteopenia (a precursor to osteoporosis) and exercise intolerance.

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

- **Chronic cough**
- **Increased sputum production**
- **Shortness of breath or wheezing**
- **Frequent respiratory infections or pneumonia**
- **Chronic sinusitis and/or frequent sinus infections**

You might notice that the student with CF has:

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

Cystic Fibrosis-Related Diabetes (CFRD)

About 2% of children, 19% of adolescents and 40% of college-aged students with CF will develop diabetes. The scarring of the pancreas that occurs due to thick mucus keeps the pancreas from producing sufficient insulin. Frequently, the student with CF will struggle with chronic fatigue and an exacerbation of other pulmonary symptoms before diagnosis. Once CFRD is identified, the student may have special dietary requirements prescribed by their physician, and eventually may need 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 student. 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, visit <https://tinyurl.com/z5j66945>

Other complications from cystic fibrosis may include liver cirrhosis and male infertility. The effects of CF can vary widely from individual to individual. Not all people with CF have the same complications or symptoms, nor do they require the same care.

Cystic Fibrosis Related Diabetes (CFRD):

- *CFRD is currently present in 2% of children and 19% of adolescents*
- *CFRD is different from Type 1 and Type 2 diabetes*
- *CFRD often requires close monitoring and the use of insulin*



How is Cystic Fibrosis Treated?

Medications and Therapies

Medications are often numerous and treatments can be time-consuming. They may vary during the year, depending on whether the student is having an exacerbation (a decline in lung condition, often with a lung infection) or “well” period. They also vary depending on the severity of the student’s CF disease expression. Students may be on anti-inflammatory medications, antibiotics, pancreatic enzyme replacement therapy, CFTR modulator therapy, 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

Daily respiratory medications are aimed at clearing thickened secretions, opening airways, and preventing or controlling respiratory infections. Students with CF may require chest physiotherapy to help remove the thick secretions in their lungs. This is primarily done at home, but sometimes a student may need treatments at school that require the help of a respiratory therapist or nurse. Various inhaled medications are used to open airways either by an inhaler or nebulizer (a small plastic device with a mouthpiece, which, when used with an air compressor, turns medication to a mist for inhalation). A student on oral bronchodilators may become slightly overactive, experience mood swings, irritability, and increased appetite due to steroidal medications.



A school nurse or respiratory therapist may perform clapping on the student’s back, or the student may blow into a tube-like device (e.g. Aerobika®, Acapella® or FLUTTER®) that causes coughing and is designed for mucus clearance. These small hand-held devices are easily carried to school. At home, a student may have a motorized airway clearance system with an inflatable vest that oscillates to help remove secretions. All of these techniques open and help clear the airways, decrease infections and improve air exchange, enabling students to attend class and benefit fully from their educational experience.

CFTR Modulators

These therapies address the underlying issue with specific CF-causing genetic mutations. For those who are eligible to use modulators, the symptoms of cystic fibrosis may be greatly mitigated. There are many mutations of the CFTR protein that cause cystic fibrosis, and not all people with CF can use modulators. Students of color are far less likely to benefit from them. Even those who are eligible may still experience many CF-related symptoms and secondary complications.



Intravenous (IV) Medications

In addition to the daily health regimen, the student with CF may need to receive IV medications. In many cases, a student's parents (or caregiver) can administer IV antibiotic medications at home (instead of entering the hospital), allowing the student to attend school if he or she feels up to it. If a student comes to school with an IV line, school administrators, 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 student. If possible, 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 student's health-care plan.



Hospitalizations

When necessary, the doctor will admit the student to the hospital in order to treat a lung infection or to address other medical issues. Tutorial support must be instituted immediately for the home-bound or hospitalized student (if well enough) to prevent the student from falling behind. Elementary and high school teachers should contact the parents to see what support is needed. This should be specifically addressed in the student's healthcare plan and 504/IEP (see page 15).



Proper Nutrition and Pancreatic Enzymes

Gastrointestinal medications and nutrition are essential to the well-being of a student with cystic fibrosis. Pancreatic enzyme replacement therapy is very common for individuals with CF. Most people with cystic fibrosis cannot absorb proteins and fats without taking several pancreatic enzyme capsules with every meal and snack so as to assist with digestion and nutrient absorption.

Although the teacher or student should monitor medication of any type, these enzymes are not dangerous to others, except in large quantities. For mature school-age children, often the doctor will write a note asking

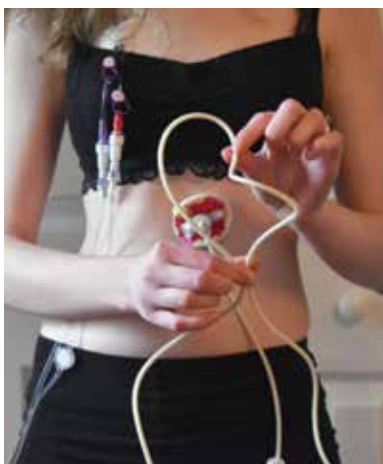
that a student be allowed to self-administer his or her own enzymes. While some school districts will not allow this, many will. Ask the school nurse in your district for the protocols that need to be followed. This can be addressed in the Individual Healthcare Plan or 504/IEP (see page 15). It is important to remember that, as these children grow, they must learn to take their medications themselves.

Allowing the student with CF to self-administer enzymes is a relatively safe way to give him or her a sense of responsibility and independence. Some students want to take their medications privately so as not to be questioned or observed by other students. If students forget or throw away their enzymes, they may have severe stomach cramping, increased flatulence and loose stools. Talk with the student and parents to assist them in finding the most appropriate way for the student to take pancreatic enzymes to ensure adherence.



Gastrostomy Tube

Some students 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, notify the parent or appropriate emergency contact immediately.



Special Diet

Students with CF often consume large meals that are high in protein, fat, salt and calories, and they need daily supplemental vitamins. Your student with CF may need time and encouragement to eat every meal, especially when classmates have finished and are already free to play. Some students require a mid-morning or mid-afternoon snack to help maintain proper nutrition. When teaching your class about proper nutrition, be sensitive to the student with CF who may have a diet that appears unhealthy by most nutritional standards.



Additional Considerations 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 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 student 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, and students 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 student.

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. Special hand signals may be needed to allow for privacy. Please remember: cystic fibrosis is not contagious. A student with CF may have an active cough without having a virus. If you are unsure, check with the parents before sending a student home from school.



Chronic Sinusitis

Some students with CF have chronic sinus infections due to the thickened secretions and the development of sinus polyps. This gives many students with CF a nasal quality to their voices. You may notice that a student has frequent headaches and blows his or her nose regularly. Again, please keep tissues readily available and remember that CF is not contagious.

Restroom Privileges

Due to coughing episodes and frequent digestive problems, students with CF should have unlimited access to the restroom. Coughing may cause them to gag, 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 student's parents. Please, never delay or stop a student with CF from using the restroom.

Exercise

Aerobic exercise is an essential form of therapy for students with CF. They should be encouraged to participate in physical education and sports as much as possible. How much they are able to participate will depend on an individual student's level of disease and how the student feels from day to day. The student 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 cause some embarrassment to the student. A discussion between the student, parents and teacher can help confirm appropriate activity levels.



Dehydration

Students with CF often have a reduced tolerance to heat, especially when exercising, because they 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 a salty snack or take salt tablets during hot weather. It is very important that the student remain hydrated.

Absences

Students with CF frequently miss school. It may be for short periods due to stomachaches 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 fall 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.



COVID-19

At the time of this writing we are still coping with the COVID-19 pandemic. For those with cystic fibrosis, the fear of having COVID is heightened due to potential respiratory complications. While many schools have relaxed their requirements related to mask wearing and testing requirements, students with cystic fibrosis may be more likely to wear their masks. This may be by choice, or because their parents have asked you to ensure that their child wears a mask. Should there be positive cases of COVID at the school, it is possible that the student with cystic fibrosis will prefer to stay home to avoid contracting COVID. If this is recurrent, speak with the parents to discuss strategies to keep the student up-to-date with class work.

Appearance and Self-Esteem

While students with CF generally appear very normal to people unfamiliar with cystic fibrosis, there may be some differences that might embarrass the individual with CF. A student with CF with advancing lung disease may appear barrel-chested. The student may be very self-conscious of the frequent need to cough up and spit out mucus, or blow his or her nose. This embarrassment causes some students to work hard at suppressing their cough. Please remember that coughing is essential for these students and that CF is not contagious.





About 10% of students 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 student may be short in stature, 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.

Many students 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. 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, students, and especially adolescents, may feel uncomfortable changing their clothes in front of their peers.

As with all students, self-esteem is individual, and despite the above-mentioned issues, the student 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.

Class Discussions

The biology class curriculum in middle or high school may include a section on genetic diseases. It is important to notify the biology teacher about the student with CF in their class so that they can be conscientious about how they cover the topic in class.

Tools for Success: IDEA/IEP and Rehabilitation Act/Section 504



Accommodations or services needed for students with disabilities – including CF – that attend public elementary or high schools are provided under the Individuals with Disabilities Education Act (IDEA) or the Rehabilitation Act of 1973. These are national laws that protect qualified individuals from discrimination based on their disabilities. Sometimes parents do not want to set up an Individualized Education Plan (IEP) under IDEA, or a 504 (under the Rehabilitation Act) for a student that currently appears healthy. In the best interest of the student, 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 student suddenly becomes ill, heads into a decline, or needs to be hospitalized, 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.

IDEA and IEPs

The Individuals with Disabilities Education Act (IDEA) mandates that all public schools must provide a free and appropriate education for students with disabilities. Many schools have interpreted this law to provide for students with learning disabilities, but it is also meant to protect students with “Other Health Impairments” (OHI), including cystic fibrosis. Students with CF will qualify for protection

Section 504 mandates that “reasonable accommodations” be provided to qualified individuals with disabilities. The following is a list of potential accommodations for a student with cystic fibrosis:

- **Transportation to and from school**
- **Chest physical therapy in school**
- **Air-conditioned classroom(s)**
- **Exemption from attendance policy**
- **Tube feedings in school or feeding therapy**
- **Student carries and takes own enzymes**
- **Student is moved away from other classmates who are sick**
- **Student is allowed to eat snacks in class**
- **Student does not need to ask permission to use the restroom or get a drink**
- **Handicapped parking**
- **Extra time to complete tests, homework assignments and grading**
- **Modification of workload to accommodate health status, fatigue and absences**
- **Preferential seating**

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under this law so long as their health issues may impact their ability to learn, including if they must regularly miss school to receive medical treatment or attend doctor's appointments. To qualify under this law, you must prove necessity.

The IDEA mandates that qualified students receive an Individualized Education Plan (IEP) that provides accommodations or services for their specific disabilities. This requires an IEP Team, and the specific content of the IEP is mandated by law. Some teachers, school nurses or administrators may not understand that this law encompasses "Other Health Impairments," and unknowingly deny student accommodations/services under IDEA. If this happens, consult Section 504 (see below).

The Rehabilitation Act and Section 504

Section 504 of the Rehabilitation Act of 1973 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 and/or provide services for people with disabilities and cannot discriminate against someone based on the person's disability. The advantage of 504 over IDEA is that it covers students in some environments outside of the public school, but in the majority of cases, IDEA provides the most protections in the school setting. For a fact sheet about your rights under Section 504, visit: <https://tinyurl.com/vu2s6us7>

A listing of health services pertaining to the implementation of IDEA and Section 504 can be found by using the following link:
<https://tinyurl.com/3wtaafbj>

504 Mandates cont. from page 15

- *Physical education adjustments (due to heat intolerance, physical limitations, etc.)*
- *Homework sent home during absence*
- *Home or hospital instruction after 3 days absence*
- *Second set of books at home*
- *Participation in all extracurricular activities (evening, sports, field trips and overnight events included)*
- *Nurse or appropriate medical personnel required in building at all times, including at school-sponsored activities*
- *Self-testing of blood glucose in the classroom*
- *Self-administration of insulin via needle or insulin pump*
- *Training of support personnel in the administration of Glucagon*
- *Helping to wipe down student's desk(s), door handles, water faucets with disinfectant at least once per day*
- *Daily reports of blood sugars to parents requires close monitoring and the use of insulin*

Communication Between the School and the Family

Parent Advocacy in the Classroom

For school-aged children with CF, the parent must still be the ultimate advocate for the student in the classroom. There is a heavy burden on teachers to make accommodations for students with a wide range of health and academic needs, while meeting the requirements of Section 504 or IDEA. 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 student's rights.

Notifying the School about the Student's Diagnosis

There should be a discussion between the parents, a 504 coordinator (or IEP team), teacher(s), and the school nurse as to whom should be informed about the



student's condition and what, if any, accommodations need to be made. The student's parent(s) may wish to consult with the CF social worker prior to the meeting to explore additional considerations. As the student nears ado-

lescence (or starts middle school) the student should be included in the conference. These meetings educate the school 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.

As with any school issue, confidentiality is vital. Some students and parents want to inform everyone about cystic fibrosis, while others prefer total privacy. When school faculty or students are educated about the disease, the student with CF receives more support and understanding. Nonetheless, it is up to the student and parents to determine whether or not to divulge this information, not the school administrators or teachers.

Communication is the single most important tool available to parents and teachers. Teachers need to let parents know when a student is falling behind. Parents need to inform teachers when a student 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, 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 to anticipate the health needs of their student, and the earlier in the year that they do so, the greater the chance that the student will be able to manage his or her class work successfully and also be safe and comfortable in the classroom. Understanding the student's rights, building communication with the teaching staff and outlining any modifications that might be necessary are all important factors in a student's success.

Working Together for a Healthy Environment

Cystic fibrosis (CF) is a genetic disease and for this reason is not contagious. However, there are some "germs" that are contagious and can pose a health risk to those with CF. Several particularly harmful germs can be passed from one person with CF to another person with CF. This is called cross-infection. To minimize these infection risks, good hygiene needs to be practiced in all classrooms. In addition, it is recommended that students with CF who attend the same school should be assigned to different classrooms, if possible. They should not share computers, books, toys, writing instruments or other items. Disinfecting common areas (countertops, desktops, bathrooms, playground equipment, surfaces in the nurse's office, etc.)



after each use will create a healthier environment for all students, especially those with cystic fibrosis.

Preparing for Higher Education



For students with CF who are considering college, it is important to plan in advance for accommodations which can assist in the process, including those related to the SAT's and other standardized testing. The College Board (PSAT/SAT/AP) considers a specific diagnosis of a disability and description of functional limitations (impact on learning resulting from the disability) as fundamental components in determining that you are eligible for accommodations on College Board tests, and what accommodations appropriately meet your individual needs. Students with CF who are seeking an accommodation should complete a Student Eligibility Form at the end of their sophomore year. Planning in advance is key. This form should be available in the high school guidance department. If the 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 866-360-0114, email ssd@info.college-board.org or download the information and form at <https://tinyurl.com/5yzjh7>

Under the ADA, colleges must:

- ***Ensure that qualified applicants and students have access to the college's programs***
- ***Provide reasonable accommodations for the student's documented disabilities***
- ***Demonstrate a good faith effort to provide the student with meaningful access to all available services***

Under the ADA, students must:

- ***Self-identify that they have a disability (following the specific college's stated policies and procedures)***
- ***Provide appropriate documentation of disability***
- ***Request specific accommodation(s)***
- ***Follow the agreed-upon procedures for using accommodations***

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Some of the testing accommodations provided by the College Board include breaks as needed, extended time, multiple days (may/may not include extra time), and testing at a specified time of day. In addition, accommodations may include testing in a small group setting, a private room, or at an alternative test site (with proctor present). Students may request preferential seating, food and drink during testing, and the ability to take medication during the test.

College and Student Obligations under the Americans with Disabilities Act (ADA)

In post-secondary education, IEP's are no longer valid, though special accommodations continue to apply under Section 504. The Americans with Disabilities Act (ADA) provides federal protections against discrimination for college students with cystic fibrosis.

It is better to register with the campus disability office in advance, even if unsure that accommodations will be needed. It is far easier to forego accommodations than to establish them after there have been issues due to illness.



ADA Obligations cont. from page 19

Once accepted to a college, and after sending in the acceptance letter, students should meet with the campus disability office to register and inquire about accommodations and/or services they offer.

Examples of reasonable modifications for higher education include:

- *Provision of specific types of living arrangement, such as a private dorm room, a room with air conditioning, or private bathroom*
- *Decrease in the required number of class hours/units per semester*
- *Modification of class attendance requirements*
- *Modification of physical education requirements*
- *Modification of educational deadlines for assignments, projects or tests due to illness*
- *An established plan to have notes or audio recordings of class available to student if absent due to illness*
- *The opportunity to complete course work after the course ends if student misses part of semester due to illness*
- *Provision of parking/handicapped parking on campus*

Other Suggestions for a Healthy College Transition

- Inquire about housekeeping services and request increased attention if necessary, including vacuums with HEPA filters, and extra care of shared bathrooms.
- Sign up at the campus recreation center to use the exercise facilities.
- Meet with the director of the student health center to find a primary care doctor (preferably one who knows about CF), and schedule an initial meeting.
- Meet the campus pharmacist, as there may be times when a medication must be ordered on short notice and the campus pharmacy is the most convenient location.
- Confirm local pharmacy locations in advance.
- If using a mail-order pharmacy, coordinate orders regarding the time of delivery and mailing address where medications are to be shipped, especially chilled medications that are sent overnight.
- Check on the college's health insurance program and see how it interfaces with any existing coverage.
- At 18, the Health Insurance Portability and Accountability Act (HIPAA) affects parents' ability to have access to their young adults' medical records and participate in their medical decisions. Consider having your son or daughter sign release forms for each health care provider, pharmacy, and insurance carrier, etc. in advance. See <http://tinyurl.com/7wryofz>
- Ask the CF doctor from home to send standing orders for routine procedures such as sputum cultures, spirometry, and blood work, etc. to the primary doctor at school in case a change in health requires an immediate diagnosis.
- Get a recommendation from specialty doctors at home (i.e. endocrinologist, ENT, gastroenterologist, etc.) for an equivalent care provider near the college campus.
- Create a binder or electronic file with copies of the following: 1) a complete list of medications including their dose and frequency; 2) insurance contact information and copies of health insurance cards; 3) names and contact information of all CF-related doctors and nurse practitioners (for local doctors to fax or email test results).



- CF-related diabetes requires special attention: alert the dorm's resident assistant and possibly a neighboring student, and provide them with necessary information in case of an emergency.
- Consider assembling a "med cart" with drawers and trays for the storage of medications, nebulizers and sterilization equipment.
- Make sure the sterilization process for nebulizers, etc. will work easily in a dorm setting.
- Get a small refrigerator for medications that need to stay cold.
- Stock an ample supply of paper towels, hand sanitizer, antibacterial wipes, tissue, etc.
- Consider a reduced course load when scheduling classes. Many students with CF need to devote the time equivalent to one or two class periods per day to respiratory treatments, cleaning equipment, exercise, etc. This way, treatment times are built into the course load and are less likely to be sacrificed due to academic and social pressures.
- Schedule classes around treatment times, if possible.

Going to college is an important step towards becoming independent. Creating a supportive environment is crucial for every student, and developing relationships with key people on campus.

Resources for More Information

Cystic Fibrosis Research Institute (CFRI)

1731 Embarcadero Road, Suite 210, Palo Alto, CA 94303
Toll free 1.855.cfri.now (1.855.237.4669) www.cfri.org

Genetics Education Materials for School Success (GEMSS)

www.gemssforschools.org

Cystic Fibrosis: A Guide for Patient and Family

David M. Orenstein ©2012 (Lippincott Williams & Wilkins)

The Complete IEP Guide:

How to Advocate for Your Special Ed Student

Lawrence M. Siegel ©2011 (Nolo Press)



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Our Mission

*To be a global resource for
the cystic fibrosis community
while pursuing a cure through
research, education, advocacy,
and support.*

Our Vision

*To find a cure for cystic fibrosis
while enhancing quality of life
for the CF community.*



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