

Cystic Fibrosis

An overview for school professionals

Cystic Fibrosis is a genetic disorder that affects mostly the lungs, but also the pancreas, liver, kidneys, and intestines.

What are some common symptoms of cystic fibrosis?

- Very salty-tasting skin
- Persistent coughing, at times with phlegm
- Frequent lung infections including pneumonia or bronchitis
- Wheezing or shortness of breath
- Poor growth or weight gain in spite of a good appetite
- Frequent greasy, bulky stools or difficulty with bowel movements

What type of support plan is appropriate for a student with cystic fibrosis?

Students with CF should have a 504 plan. The diagnosis of **Cystic Fibrosis** gives reasonable cause to bypass the SST process, which will allow you to provide immediate accommodations to the student. All teachers who provide instruction for your student should be made aware of these accommodations.

What accommodations are necessary for a student with CF?

ATTENDANCE: 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.

- full-time and/or intermittent hospital homebound services
NOTE: Please inform parent of homebound procedures. Please provide the name of a contact person during periods when hospital homebound services are needed. Please coordinate a schedule for accessing homebound services that can work around the patient's medical appointments.
- suspension of attendance requirements for absences due to medical appointments and illness, including allowances for student to participate in extra-curricular programs and events without penalty due to absences.
- partial-day attendance, as necessary

ASSIGNMENTS: It is important for teacher and parents to ensure that student receive assignments in a timely manner so student does not get further behind. It may also take the student with CF longer to complete assignments due to fatigue and home healthcare regimens.

- a system for providing advance assignments to the parent or student for absences due to planned medical appointments
- a system for providing make-up assignments in a timely manner when patient is absent due to illness or hospitalization
- modified assignments: Shorten assignments to emphasize mastery and to limit repetition.
- extra time to make up missed assignments

FATIGUE: A student with CF 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.

- morning testing session(s) when student is more alert
- extra time to complete work and tests, including standardized tests
- rest periods during physical activity, including PE class, as needed
- a location provided for student to lie down, as needed
- extra set of books for home and another set kept in his classroom(s) to minimize the need to carry heavy books, and for him to have them available in case of sudden onset of illness

RESTROOM: 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 mal-absorption problems may cause urgent bowel movements.

*****PLEASE! NEVER STOP A STUDENT WITH CF FROM USING THE RESTROOM!*****

- liberal bathroom privileges, including a system for the student to go to the bathroom without having to draw attention to himself. (Example: Give free restroom privileges designated by a hand signal or a permanent restroom pass.)
- extended time in the restroom
- alternative seating to accommodate easy access to classroom exits

NUTRITION AND HYDRATION: Most children with cystic fibrosis cannot absorb proteins and fat without taking pancreatic enzymes with every meal and snack. A child may take several enzymes with each meal to help break down foods, allowing the body to absorb the proper nutrients. If the child forgets or throws away his enzymes, he may have severe stomach cramping, increased flatulence, and loose stools. Children with CF usually consume large meals that are high in protein, fat, salt and calories.

*****PLEASE! 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.*****

- permission to eat snacks at the desk or to leave class and have them in a designated location, as needed
- permission to carry and drink fluids throughout the day
- permission to carry and take his own enzymes, if necessary
- access to hand sanitizer and tissues at all times

The list of accommodations above is not meant to be exhaustive; each student's unique needs will dictate the appropriate accommodations to be listed in his/her 504 plan.