

UT Le Bonheur Pediatric Specialists

Name: _____

DOB: _____

Date: _____

Cystic Fibrosis School Letter

To Whom It May Concern:

The student is a ____ - year-old who has a chronic health condition known as cystic fibrosis, which inhibits breathing and digestion. Cystic fibrosis (CF) is a genetically transmitted life-shortening disease for which there is no cure. It is NOT contagious. Individuals with this disease experience complications resulting from the production of thick secretions in their lungs and pancreas. The thick mucus in the student's lungs limits their ability to breathe. The thick mucus in the student's pancreas limits their ability to digest food.

Bacterial infections in the lungs of people with CF cause exacerbations of the disease, which may require intravenous antibiotic treatment. These medicines may be administered in the hospital or sometimes in the home setting. Each exacerbation causes further irreversible damage to the lung tissue and contributes to the progression of the disease. To avoid these complications, people with CF require multiple sessions of daily airway clearance therapy, treatment with inhaled and oral medications and increased nutritional intake. Exacerbations and hospitalizations are unpredictable-a patient may have several hospitalizations in one year or may go several years without being hospitalized.

The student will need to eat 3 meals and 3 snacks during the day to increase their nutritional intake. A high calorie, high protein diet is recommended for people with CF. To further increase the student's dietary intake, they also receive feedings throughout each night by gastrostomy tube. As the student's nutritional condition improves they will be better able to fight infections and have more energy available to perform the work of breathing. In addition, the student will need to take digestive enzyme pills just prior to eating a meal or a snack. Because it is so important to be well-nourished, it is necessary to have time to take the enzymes AND to eat. One without the other will not support a healthy lifestyle for this young student.

The student's medical regimen includes numerous medications, some of which must be administered while at school. Their enzymes, Creon 24000, are to be taken 4 capsules before meals and 3 capsules before snacks. They may occasionally need 2 puffs of Albuterol Inhaler for coughing, wheezing or difficulty breathing.



Socialization is also important and any person with cystic fibrosis should not be isolated or ostracized. The student should be encouraged to exercise and to eat with their classmates and friends and should be provided the opportunity to do so. On the other hand, because of the digestive challenges of cystic fibrosis, extra bathroom privileges must be allowed. It can be very embarrassing to share a bathroom with friends when they experience digestive difficulties. Every effort is made to gain control of the digestive problems of CF; however, there can often be breakthrough issues. We would appreciate your assistance in supporting the student as they cope with this very serious diagnosis.

The Cystic Fibrosis Foundation recommends that patients with CF be seen by a physician specifically trained in the care of CF at least every 3 months, more often when exacerbations occur. Most of these visits are brief monitoring visits. One visit per year is for an in-depth evaluation which may include lab work, X-Rays, pulmonary function testing and assessments by nutrition, social work, nursing, medicine, respiratory therapy and physical therapy. Of course, the student will not be attending school on these days. If there is work that they need to make up, we are hopeful that you will provide the opportunity for them to do so without penalty.

As you can see, there are a number of life changes that occur when a person is diagnosed with cystic fibrosis. Please feel free to call me at (901) 287-5222 if you have questions or concerns.

Sincerely,

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