School Services

School Guide for Students with Cystic Fibrosis

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is a life threatening, genetic disease, which mainly affects the respiratory and digestive system. In children with CF, the faulty gene causes the body to produce abnormally thick and sticky mucus that can clog the lungs, pancreas and other organs, leading to severe respiratory and digestive problems. Some complications or symptoms that children with CF may have are: respiratory infections, wheezing or shortness of breath, persistent coughing that may produce mucus or phlegm, difficulty digesting food, upset stomach and fatigue. Children with CF may also be smaller than their classmates and have frequent bowel movements. CF is not contagious and affects individuals differently.

How can Cystic Fibrosis affect school Performance?

The most common school concerns for children with CF are:

- Frequent absences due to hospitalization for infections
- Managing the disease at school

How can school assist students with Cystic Fibrosis?

Academic

- Provide the student with a 504 plan to accommodate academic needs, as well as medical needs that they may need assistance with at school
- If academic concerns persist start interventions right away to decide if further action is necessary; consider an IEP (special education program) under the category of "Other Health Impairment" (OHI)
- Create a plan with the family to get students work when they are hospitalized
- Provide after school or before school tutoring for patients to ask questions on any concepts missed if their health permits
- Come up with a consistent way to communicate with child's family (for example weekly e-mails or progress notes, phone conferences or conferences in person)
- For make-up assignments assign a moderate work load, that emphasizes quality versus quantity
- Allow child extra time for long projects or reports when needed
- Provide a second set of text books due to fatigue

Social/ Emotional

- Conduct a staff in-service for those involved with the Child
- Assess the student to see if he/she is a candidate for counseling if they become withdrawn, or have difficulty with peers or adults.
- Untreated social issues or unresolved questions about the child's health may cause some acting out behavior. If this occurs come up with a plan to address patient's behavior as soon as possible.
- Child may benefit from social skills group with school counselor

Physical

- Give the child a laminated bathroom pass to use as often as needed (due to malabsorption issues and possible vomiting due to coughing)
- Allow the child use of the nurse's office bathroom for privacy if they request
- Allow the child to have water or Gatorade at his/her desk
- Allow child extra portions at meal times and sufficient time to eat meals due to their need for larger portions
- Make sure the child has an opportunity for a snack if needed
- School nurse may need to administer pancreatic enzymes, if child is mature then he/she may carry and take them at the appropriate times
- School nurse or counselor may need to work with the student on issues with body image and weight management or maintenance if concerns arise
- Coughing is encouraged for people with CF to clear their lungs of infection causing mucus. Persistent coughing may be interpreted by others as infectious or contagious and result in isolation from peers. School nurse or counselor may need to address this with peers to help the student feel more comfortable
- Child may participate in PE with rest breaks as needed. Aerobic exercise is encouraged

Students with CF should function comparable to their same-age peers. They should not be limited and should be encouraged to pursue their academic, career and life goals.

Resources
Cystic Fibrosis Foundation
www.cff.org
Cystic Fibrosis in the Classroom, Cystic Fibrosis Research, Inc. The Cystic Fibrosis Center at Children's Medical Center Dallas
www.cfri.org

School Services Department
Children's Health
Children's Medical Center
Dallas Campus: 214-456-7733
Plano Campus: 469-303-4670

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