

Taking CF to School



Request a Meeting in Writing

During the spring or summer before your child begins school, write a letter to the principal requesting a meeting. Use the following recommended wording: “We request a meeting to discuss educational accommodations for our CF child.” Request that the following people be present:

- Principal
- School nurse
- School counselor
- Nutrition director from the lunchroom
- All classroom and specialty teachers

Make sure you request the meeting BEFORE the first day of school and that you give the principal a way to contact you with the date and time for the meeting.

The Meeting

School Nurse Liaison

You can go to the meeting alone or with a school nurse liaison. The school nurse liaison is a hospital employee who will act as your child’s advocate in educating the school staff about CF and the needs of your child. See your CF clinic social worker for school nurse liaison contact information.

Tips for the meeting

- Be positive and friendly.
- Provide written CF information. The CF clinic can provide you with excellent resources.
- Know that most educators want all students to succeed to the best of their ability.
- Know that CF may be a new topic for your child’s school staff.
- Learn about the legal plans before the meeting. (See below for information about these plans.)

What if the meeting is not going well?

- Don’t sign anything. Reschedule the meeting in order to get more information for educators.
- Send a written request for mediation to the school district superintendent.
- Going to a lawyer should be your last resort. First, try the GA Advocacy Office (404-885-1234).

The Legal Plans

There are two (2) federal plans that you should be aware of – IEP and 504 – and most CF children in public school are covered under one or both. You want to have at least one of these plans for your child. Since you don’t want to start your school meeting with a confrontation, you should not ask for one of these plans at the beginning of the meeting. Ideally, the school staff will suggest setting up the plan. If not, you should request the legal paperwork. A school nurse liaison who knows how to tactfully ask for the plan without offending the school staff will help you immensely. Both plans require a note from your CF doctor. Private schools are not legally required to follow either of these, but they will typically offer accommodations.

Individual Education Plan (IEP)

- Comes from the Individuals with Disabilities Education Act (IDEA) Amendment of 1997.
- Funding statute that allows school districts to provide assistance to children whose disabilities affect their learning.
- Example: the federal government will pay for a homebound teacher when your child needs one.

504 Plan

- Civil Rights law that protects the educational rights of children with disabilities who are “normal classroom” students.
- NO funding from the federal government.

Ideas For What To Include In An IEP Or 504 Plan

General Information

- Give a brief description of cystic fibrosis.
- All teachers should receive a copy of accommodations before school begins.
- Substitute teachers need to receive a copy of accommodations.

Absences and Tardiness

- There may be frequent absences throughout the year, and child may come in late due to morning respiratory treatments. Child should be exempt from school's absence and tardy rules.
- If child is absent for more than 3 consecutive days, he may receive homebound services (1.5 hours for 3 days missed; 3 hours for 5 days missed). Parent contacts the homebound teacher.
- If child is in the hospital, he can go to the hospital's school program if he is healthy enough to attend.
- Child gets an extra set of textbooks in case of extended absences or hospitalizations.
- Audiotapes or videos should be made of missed classes.

Bathroom Breaks

- Child may require more frequent bathroom breaks and for longer periods of time than other students.
- Consider use of a private bathroom.
- Child may sit near door and hand signal to tell teacher when break is needed.
- Child receives a permanent, laminated hall pass for private bathroom use and nurse visits.

Infection Control

- Child needs a water bottle at school. Using water fountains is not acceptable.
- Hand washing is VERY important! Child must also have hand sanitizer in his desk.
- No community sharing of pencils, glue, scissors, etc.

Dehydration

- Child must have unlimited access to water or electrolyte drinks, especially at PE.

Enzymes and High-Caloric Nutrition

- Check with your county on their rules for children delivering their own enzymes. Some start at 4th grade. Otherwise, the child should have easy access to school clinic to take medications.
- Child should have unlimited access to high-caloric food in classroom and cafeteria.
- Child should not get advised on "healthy low-fat diets."

Respiratory Therapy

- Time may be needed during the school day for airway clearance therapy.

Coughing

- Child should never suppress cough or be asked to stop coughing.
- Child may sit near door so he can step into hall if coughing becomes disruptive.
- When necessary, PE teacher should allow increased rest periods for cough.

Other Considerations

- Get a copy of the nutritional guide values from the manager of the cafeteria. This will tell you how much fat is in each cafeteria item, so you can advise your school nurse or child on how many enzymes to take.
- Become best buddies with the school nurse.
- Purchase a spray like Carafree – comes in 4 oz bottle, easy to conceal, clears the smell out of bathroom to avoid teasing from others.
- Ask for the carpeting and vents to be cleaned or replaced.
- Keep an IEP/504 notebook to file all forms and record all phone calls with dates and names.



CF Family Advisory Council

ATLANTA, GEORGIA