

CF Connection

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University of Florida Pediatric Pulmonary Center

An IEP or 504 Plan—Does My Child Need One?

If your child is in school, make sure that he or she has a plan in place for any needed accommodations. These accommodations may include getting treatments at school (for example, enzymes, albuterol, insulin or nutritional supplements, or even g-tube feeds or vest treatments). Accommodations may also include permission to miss school (and not be marked with an unexcused absence) for clinic visits or hospitalizations, make up missed work/tests, have water or sports drinks if exercising in heat, or use the bathroom when needed.

Some schools provide these types of accommodations willingly, with a verbal agreement, after talking with parents. However, often a more formalized plan is needed.

If your child attends a public school, there are laws that mandate that the school make the accommodations necessary for your child to receive the same quality of education that other children receive. Public schools must meet these requirements if they wish to continue receiving federal funding. These accommodations are stated in either a IEP (Individualized Education Plan) or a 504 plan.

When developing an IEP or 504 plan, school professionals

(usually teachers, school nurse, or guidance counselors) meet with parents (and after age 14, the student) to list goals and then to outline the accommodations needed to meet those goals.

Ideally, the school identifies children in need of an IEP or 504 plan. However this does not always occur and sometimes it is up to parents to request a plan. You can make this request verbally or we will be happy to write a letter asking the school to consider your child for an IEP or 504 plan. You should be invited to the IEP or 504 plan meeting and you are welcome to take a friend or other professional for support.



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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to hillajb@peds.ufl.edu.

An IEP or 504 Plan

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It's best to get an IEP or 504 plan in place at the start of the school year. If an IEP or 504 plan is in place, you have something to fall back on if you are having challenges with the school. If you don't have a plan already in place, the school doesn't have to make accommodations. For example, if a teacher won't allow your child a make up test because your child was in the hospital, but this accommodation is in the IEP or 504, you can advocate with the school board. However, if you didn't have this accommodation previously outlined in an IEP or 504, you may not get very far in arguing your child's case. It is also helpful to remember that even though a school may be helpful and responsive one year, this can change the next year if school personnel change. There can also be big changes between elementary school and middle school or between middle school and high school. So it is most helpful to have a plan in place.

Private schools most often are not required to do 504 plans or IEPs. However, it is still a good idea to request a meeting with school personnel to educate them about CF and your child's needs. If you meet with major barriers from the school, the American's With Disabilities Act (ADA) may be helpful to you. The ADA protects people with disabilities from discrimination. If you feel your child is being discriminated against in getting an education, you can contact the US Department of Justice or the US Office of Civil Rights.

If you would like more information about accommodations in school or would like to talk more about your child's situation, please contact Susan Horky.

High-Calorie Ideas

Nutella Porcupine

- 1 medium banana
- ½ oz pretzel sticks (about 25)
- 2 tablespoons Nutella

Spread Nutella evenly over banana.
Stick pretzels in banana for a fun snack.

*Calories:
about 350*



Easy "Nutty" Breakfast

- 2 pancakes or waffles (homemade or cooked from frozen)
- 2 tablespoons peanut butter
- 2 tablespoons pancake syrup
- 1 cup chocolate, whole milk

Spread peanut butter over pancakes or waffles. Top with syrup. (Try Nutella instead of peanut butter if desired.) Serve with chocolate milk.

Calories: about 700

Infection Control: New Guidelines

The CF Foundation published Infection Prevention and Control Guidelines for Cystic Fibrosis: 2013 Update, which you can find in full detail at: <http://www.cff.org/treatments/CFCareGuidelines/InfectionControl/>. Read on to find out what we are doing with this new information...

In clinic: For years we have scheduled our CF clinics so that our patients are not exposed to organisms they have not previously found in their sputum or throat cultures and we will continue to do this. We also ask everyone with CF to get a mask at check-in and to use it when they are not in an exam room. You should use hand disinfectant both coming into the clinic and as you leave. When you leave an exam room, we spray down all the surfaces you might have touched including chairs, exam tables, door handles, and light switches as well as the surfaces touched by the care team. We have started leaving exam rooms unused for 30 minutes to allow time for full air exchange in the room. We also allow that time span in the PFT lab and disinfect surfaces touched in that space. All staff in clinic now wear gowns and gloves so we will not take organisms from one room into another on our clothes. Likewise, we will not transport organisms present in the air (from cough) that land on our clothes.

In the hospital: The infection control policy for individuals with CF has mandated isolation and therefore, private rooms. ALL CF patients will be on "contact" precautions – this means that all personnel entering the room should gown and glove just as we do in clinic. They should gown and glove EVERY TIME THEY ENTER THE ROOM REGARDLESS OF WHETHER THEY ARE COMING IN DIRECT CONTACT WITH THE PATIENT! We know that cough delivers CF germs into the air where they can remain for a length of time. This means that every surface in the room is likely to have whatever germs are growing in that patient's sputum. It also means that just standing in the room can result in those germs landing on clothing where they can be transported throughout the hospital. This message has been shared with all hospital personnel but old habits take time to change, so implementation is still a work in progress. We know that this policy change is really hard on kids in the hospital who have to be cooped up in their rooms but it is SO important. Child Life is helping with activities to keep life fun in the hospital room.

Every year, the Foundation sends a report with data on incidence of various organisms both nationally and for our center at UF. The news for our center is encouraging as we can see that our incidence of pseudomonas has dropped 17% in the past 9 years and we are well below the national average for pseudomonas strains that are resistant to antibiotics. Our rate of burkholderia cepacia has remained low. MRSA, a common community acquired organism, has seen an increased incidence nationally but the numbers in our pediatric population are lower than reported in the previous six years.

We need you to be in charge of quality control in your exam room or hospital room! If someone enters your room without protective clothing, please ask them to go out and get their gown and gloves. Ask if they wiped down their stethoscope! When you check into clinic, please request a mask and look for the hand disinfectant. Please report anyone who refuses to comply or is a repeat offender to your CF coordinator or a patient services representative at 352-234-3210. If you can provide the name of the person and the date of the problem, it helps us make sure we are reeducating the right person and if necessary, notifying a supervisor. This is a very big deal because not all organisms can be removed once acquired and may seriously impact lung health so prevention is really critical. Patients, family, and the whole health care team need to work together with great attention to detail in order to control transmission of organisms.

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Family Corner

Better Together: Partnering with Patients, Families and Healthcare Providers

It's important for caregivers to partner with the healthcare team when in the hospital or at clinic visits. We need to work together to take care of your child. After all, you know your child best! Here are some tips:



Talk about your role. Introduce yourself to staff and let them know how you would like to be a partner.

Observe changes in your child. Ask staff what they would like you to look for and report.

Gather helpful information (current medications, medical history, other health care providers, and insurance) and bring it all to the hospital or clinic visit.

Ensure that you're present, if possible, for in-patient rounds and let staff know how to contact you.

Tell staff if you have any worries.

Help staff understand what treatment options will work best for your child.

Enlist help from staff members when you are making difficult decisions.

Ready yourself for the transition to home by making sure all your questions are answered and you are clear about treatment at home and follow-up clinic appointments.

For more information on being a partner in care, check out the Institute for Patient and Family Centered Care: <http://www.ipfcc.org/advance/topics/guides-for-teams.html>.

If you would be interested in being a Family Advisor at the hospital and would like more information, please contact me at aminey@peds.ufl.edu.

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