

## Parenting resources

Helpful parenting resources include:

Parenting Children with Health Issues by Foster Cline, MD, and Lisa Greene.

Teleclass: Winning with CF: Tools, Tips and Tactics for Raising Healthier Kids.

“Parenting the Defiant Child” by Dr. Alan Kazdin. Best behavior book on the planet! Its all about positive reinforcement. Helps parents reframe how they think about a child’s behavior. Another tool is commenting on a child’s effort not their ability. For example, the word “smart” is not helpful for kids. When your child accomplishes a task comment on the effort (ex they got an A on a test – respond with “wow you studied so hard for that test- great work!”)

### Q: What are 504 Plans and Individualized Education Plans (IEPs)?

Public schools that receive federal funding are required to provide education and services to children with disabilities under federal laws such as the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973. Individualized Education Plans (IEP) exist within the Individuals with Disabilities Education Act (IDEA), and the Rehabilitation Act of 1973 contains Section 504 Plans. Both IEP’s and 504 Plans can be very useful in helping your child with CF get the assistance that they need to be successful at school.

IEP’s and 504 Plans are slightly different from one another, but some schools and school districts might treat them interchangeably. You will want to check with your school to see which one they will accept for your child with CF. IEPs are used for adjusting a child’s required work load to fit more reasonably with their capabilities given a health condition that has affected their learning abilities. Even though CF does not affect your child’s cognitive abilities, their ability to learn can be affected if they have to miss a lot of school due to hospitalizations or sick days. The workload adjustments that an IEP covers can include less work assigned, extended deadlines, note-taking assistance, extra time for tests, etc. IEPs also can be used for advanced planning of hospitalizations to determine how children will get tutored during their absence from school.

Some schools require 504 Plans instead of IEPs because CF does not affect a child’s cognitive abilities. 504 Plans differ from IEPs in that they address the physical aspects of your child navigating school each day. With CF, your child might need to do CF treatments or take medicines while at school. A little extra time getting to classes might be required, or they might need to use the bathroom more often than other children. To reach calorie goals, they might need to have snacks and water available to them throughout the day, or to have different high calorie choices at the school cafeteria. There may be days where they need to remain inside when the air quality is poor. All of these things, if addressed ahead of time in a 504 Plan, can help you advocate for the needs of your child.








To initiate your child’s IEP or 504 Plan, you will need to make a request to the school in writing. Your CF social work team care team can help you identify some things that would be helpful to your child to request. A meeting will be scheduled with the school team and you and your child. Together with the school team, a plan will be developed to assure your child has accommodations in place so he/she can succeed at school. Your IEP or your 504 Plan will need to be renewed and revised each year. More information about IEP and 504 Plan can be found here: <https://www.cff.org/Life-With-CF/Caring-for-a-Child-With-CF/Working-With-Your-Childs-School/Individualized-Education-504-Plans/>

Private schools that do not receive federal funding are not obligated to follow the IDEA or the Rehabilitation Act of 1973. If you are interested in a private school, you will want to see that they are willing and able to meet your child's needs before agreeing to attend.

Q: What can I do about constipation? Bristol stool chart

Many people with CF experience constipation as part of their illness. The lack of fluid in the intestines, from CFTR dysfunction, can lead to hard-to-move stool (constipation). Another reason that people with CF are at increased risk for constipation is that even with the help of enzymes, some food will make it through that is undigested. This bulkier food can clog the intestine.

Your CF care team will ask you to characterize your child's stool at every visit. For this, they use the Bristol Stool Chart which has types 1-7 of stool, with 1 being the hardest and most compact and 7 being the loosest and most watery.

THE BRISTOL STOOL FORM SCALE (for children)		
choose your <b>POO!</b>		
type 1		looks like: <b>rabbit droppings</b> Separate hard lumps, like nuts (hard to pass)
type 2		looks like: <b>bunch of grapes</b> Sausage-shaped but lumpy
type 3		looks like: <b>corn on cob</b> Like a sausage but with cracks on its surface
type 4		looks like: <b>sausage</b> Like a sausage or snake, smooth and soft
type 5		looks like: <b>chicken nuggets</b> Soft blobs with clear-cut edges (passed easily)
type 6		looks like: <b>porridge</b> Fluffy pieces with ragged edges, a mushy stool
type 7		looks like: <b>gravy</b> Watery, no solid pieces ENTIRELY LIQUID

If your child struggles with constipation, increased water consumption and fiber content in their diet will help to soften their stools over the long term. Exercising can help get smooth muscles in the abdomen moving and will help push stool along. Often fluid and fiber are not enough, and additional therapies are needed. Polyethylene glycol (MiraLAX) is a medicine that treats constipation by drawing water into the stool. If you are concerned that your child may be constipated, contact your CF care team and they can help you decide on a treatment.

**Q: What should I do if my child does not want to eat lunch at school?**

If your child comes home every day with a largely untouched lunch box, you'll want to find out why they aren't eating. Lunch times for elementary schools in the U.S. average about 25 minutes. This includes the time to get your food, get to your table, eat, and clean up your eating area. If your child requires enzymes with meals/snacks, ask if your child can be dismissed from class a few minutes early to go to the health office to take the enzymes. If your child eats the lunch provided by the school, it will be helpful if they can go to the front of the line to get their food, so they will have enough time to eat their lunch. Additionally, lunch is one of the only times throughout the day where kids can talk to each other freely. It's a very social time, and sometimes children forget to eat amidst all of the chatting that's going on amongst their friends. Have a discussion with your child about the importance of eating their lunch so that they can have the energy to play and laugh with their friends the rest of the day. If issues with meals persist at school, consider requesting a 504 Plan for accommodations for your child. The CF social workers can help with this.

You'll also want to make sure that the containers you use for packing the lunch are able to be opened by your child. Ask your child to open and close the containers in front of you so you know that this is not what stands in the way of them eating their lunch. Pack the foods in a form that is easy to eat for the child. For example, instead of a whole apple, slice the apple beforehand so that it is more accessible to the child. For younger children, some parents find that more food gets eaten if they cut it into fun and interesting shapes.

Involving your child in the lunch planning, grocery shopping, and preparation of food helps to increase interest. The more interested and excited a child is in what is in their lunch box, the more likely they are to eat it.

**Q: What should I do if they only give low-fat milk at school when my child with CF requires a high calorie diet?**

We know that children with CF need extra calories to help them grow . This requires a high calorie diet that adds extra fats, protein, and carbohydrates wherever possible. If you are concerned that the food prepared at school is not meeting your child's requirements, bring your concerns to the school. They may be able to modify the menu to make it more suited to the diet of a child with CF. Ask your CF clinic about filling out a modified meal accommodation form for the school to validate your nutrition requests. If modifying the meal plan is not possible for your school, you may need to send in the high-calorie foods yourself.

Milk is a good example where a school might not be able to provide what your child needs. Children with CF need to drink whole milk because it has more fat and calories in it than other reduced-fat milk options. We can request whole milk for your child if it is not a current option at your child's school, ask the dietician at your next clinic visit.

### Q: Is it safe for my child to participate in overnight camps and sleepovers?

Like most children, your child with CF will likely be interested in an overnight camp at some point. Children with CF should be encouraged to attend the camp of their choice, but camps that are just for people with CF are not safe. People with CF have bacteria that they can pass from person to person. Activities or camps that bring many people with CF together put them at risk for getting new bacteria in their lungs which may lead to infections. Even if a bacteria your child has does not seem to be causing problems, it may be troublesome for another child with CF and vice-versa. If another child with CF is going to be at a non CF-specific camp, you will want to work with the camp staff to make sure they follow similar guidelines to those that are followed by a school that has more than one child with CF. These guidelines are discussed in the following question in this document, “What if there is another child with CF at my school?”

You will have to plan ahead to make sure that CF treatments and medications are continued while your child is away from home. Sleepovers, field trips, and meals outside of the home are all fun things and your child should be able to participate in them. Just make sure that your child has the materials they would normally need during that time to manage their CF.

### Q: What if there is another child with CF at my school?

There are some germs that are harmful specifically to people with CF. This may create a challenge when two children with CF attend the same school, because they could pass the germs to one another. There are special guidelines in place to keep children with CF that attend the same school healthy. A lot of the following guidelines involve preventing students with CF from sharing common spaces.

- Students with CF should not be in the same classroom.
  - o If they have to use the same room at different times, they should use different stations or desks.
- The school should schedule things like lunch, gym class, and recess so that the students with CF participate in them at different times.
- Each person with CF should have their own water bottle that they use, rather than using communal water fountains.
  - o If possible, they should be assigned different water fountains to drink from.
- They should report to different rooms to see the nurse or receive medications.
- They should have different restrooms assigned to them.
- Because socialization is so important for a normal school life and development, they should be allowed to attend activities that include the entire school, such as pep rallies and assemblies.
  - o At these events, the students with CF should be seated as far away from each other as possible.

### Q: Can my child keep enzymes and take them on her own?

If your child is pancreatic insufficient, enzymes will need to be taken at snack and lunch times. Preschool age children and elementary age children usually have to go to the health office or teacher to take their enzymes. You will need to work with your school to learn what the school’s policy is on students taking medicine. Some schools allow middle and high school students to carry medicines with them – if this is the case, you can include the enzymes in their lunch bag so that they are easily accessible when your child needs to take them. All schools, including preschools, require documentation from the physician stating the name

and dose of the medication to be given at school. Most schools have a form from the school district, these can most easily be handled at your clinic visit during your summer visit before school starts. If the enzyme dose is adjusted during the school year, a new form will need to be filled out with the new dose.

### Q: What about sports?

Being active is an important aspect in the health and development of all children, including those with CF. Exercise has the special benefit of strengthening muscles in the chest that can help your child breathe better. Exercise also can lead to coughing, which helps children with CF clear their airways of mucus.

Any physical activity that your child is interested in should be encouraged, whether that's their physical education class, a sport or another extracurricular activity. It's important to understand that your child with CF might get worn out more quickly than other children. This doesn't apply to all kids with CF though. Ask the CF team if this is something you should be concerned about. If this does happen, kids should be encouraged to take a break and rejoin the activity when they have energy. It's important to communicate this with teachers and coaches to ensure that they know your child's possible limitations. It's also important to remember that people with CF lose more salt in their sweat than others. To counteract this salt loss, salty foods may need to be eaten before or after physical activity. All of these accommodations can be requested in a 504 Plan at school. The CF clinic social workers can help with this. This is also important to remember for family outings and vacations too.

If you are unsure about a new activity that your child is starting, talk to your CF care team. They can help give you some suggestions of how to keep your child safe while they're exploring the new-found interest.

### Q: How will I know if my child is anxious or depressed?

Symptoms of depression can present in a variety of ways. The most common symptom of depression in children (and adults) is *irritability* in addition to sad mood. Despite popular media portrayals of overwhelming sadness, the most regularly described symptom of depression in youth is a chronic irritable mood. The following observed behaviors in addition to recent changes in your child's functioning (lower grades in school, recent change/decrease in hygiene, dropping out of activities, etc.) would warrant a consultation with a mental health provider and your CF team. Symptoms to look for are:

- Loss of enjoyment in activities, especially activities they used to love
- Less social engagement with friends or family members or isolating for increasing amounts of time
- Difficulty separating from caregivers
- Expressing feelings related to worthlessness or hopelessness such as "This is never going to get better," "This always happens to me," "I wish this would all just go away," or comments expressing not wanting to be a bother or a burden to others
- *Play themes* centering around sadness, death, things never changing, hopelessness or guilt
- Expressing guilt, such as feeling that negative events are "their fault" or that they "always mess things up"
- Changes in sleeping and eating patterns
- Recent difficulties with attention and concentration
- Increased thoughts of wanting to go to sleep and never wake up, death, or "wanting it all to go away"
- Decreased energy or moving more slowly than usual

Anxiety symptoms are also highly varied. There are many types of anxiety that can impact children and adults alike. Most children and teens report anxiety surrounding everyday worries, social situations, and separating from parents. While there are several anxiety symptoms that can be observed (panic attack, skin flushing, etc.) the majority of anxiety symptoms are less obvious. As with all mental health symptoms the following observed behaviors in addition to recent changes in your child's functioning (lower grades in school, recent change/decrease in hygiene, dropping out of activities, etc.) would warrant a consultation with a mental health provider and your CF team. Symptoms to look for are:

- Recent increase in physical symptoms that have no medical correlation or cause
- Increased embarrassment in situation that used to be more comfortable
- Avoiding specific places, situations or crowds
- Difficulty separating from caregivers
- Checking in with parent more frequently about past and future events, such as "Did I do that okay?" or frequently asking about upcoming plans or plan changes
- Increased fears or phobias not observed before
- Restlessness or increased irritability
- Easily exhausted or tired at times that are not associated with physical activity
- Child appears preoccupied more than usual and often "goes blank" or "zones out"
- Changes in sleeping and eating patterns
- Muscle tension
- Child appearing shyer than before

Mental health issues for kids and adults have been worsened by the COVID-19 pandemic and are likely to persist even as things "return to normal". Please reach out to the CF team or your primary care doctor if you have any of the symptoms listed above.