

Managing Cystic Fibrosis Care: Frequently Asked Questions

In the beginning:

How do I tell my family?

We can work with you and your family to help you adjust to your CF diagnosis.

- Social workers are available to discuss strategies with you for talking to your family.
- We can arrange a family education meeting with your doctor and social worker for extended family members and other potential caregivers to learn more about Cystic Fibrosis (CF) and the adjustment process.
- Peer mentor support (introduction to other parents who have a child with CF at our CF Center) is available. If you are interested and this has not yet been offered, ask your social worker if they can set it up.
- We recommend the Cystic Fibrosis Foundation (CFF) website, <https://www.cff.org/>, for CF education. Please use the CFF website as your primary source of information on CF as it will have the most up to date materials on the treatment and prognosis of CF.

Should my other children be tested for CF?

Yes, all full siblings should be tested for CF, regardless of symptoms, with sweat testing.

My siblings want to have kids, should they be tested to see if they carry the CF gene?

- CF Carrier screening is an option if they want it.
- Genetic counseling is recommended. This can be requested through their primary doctor or OB/GYN.

My relatives smoke, should I keep them away from my child with CF?

- Yes. Children with CF should not be around smoke. There should be no smoking in your home or car regardless of whether the child is present.
- Discuss how to manage smoking behavior with CF Center social workers.

- The University of Michigan smoking cessation program may be helpful:
 - UM Tobacco Consultation Services
(734) 998-6222
quitsmoking@med.umich.edu

How and when do I give my child enzymes?

Give the prescribed amount of enzymes before food. Mix them with 1 or 2 teaspoons of soft food, such as apple sauce, until they can swallow pills.

Note: Infants with CF begin eating applesauce and other solid foods before an infant without CF would. If your child has trouble taking them, call the nursing office at (734) 764-4123.

When should I call the pediatrician's office as opposed to the CF Center nursing office for my child?

- Call the CF Center at (734) 764-4123 for:
 - Lungs and digestive issues
- We want you to feel comfortable with calling the office if you have any questions. No question is a silly one! The nurse will talk to the physician.
- Call the Primary Care Doctor for:
 - Earache
 - Sore throat
 - Teething
- Please call us after sick pediatric visits so that we can keep track of them.

How can I keep up with appointments and results?

Use the MyUofMHealth app, or the online MyUofMHealth patient portal.

MyUofMHealth allows online access to:

- Notes
- Test results
- Appointments
- Rescheduling
- Refills
- Non-urgent medical questions

What if my child gets a cold?

If your child has discolored nasal drainage, or a cough lasting 2 days or more, call the CF Center nursing office at 734-764-4123.

How do I successfully administer treatments if my child is resisting them?

Methods for successful medication administration are age related.

Here are some of the ways you can help your child:

- Distractions
- Specific toys only given during treatments
- Therapeutic play
- Tablets
- Videos
- Special chair or areas for treatments

Talk to your care team for more information. The more consistent you are with giving treatments routinely from Day 1, the better habits your child will learn. Skipping treatments early shows your child that it is ok to miss treatments.

- As soon as your child is ready, at age 6 – 7 or above, it is a good idea to talk to them about the medications, what they are, what they do and why it is important to take them. If you are having problems with staying on the treatment plan, it is best to call the office right away.

School age:

How do I prepare the school for my child?

- We have resources specific to children with CF in the classroom, including pamphlets for teachers and a letter from this office listing potential accommodations in the school setting.
- You can also find helpful information about talking to your child's school about CF on <http://CFF.org>.
- You will need a note every year for enzymes to be administered at school. Plan ahead, before school starts, and request the form from the CF Center.
 - Forms take 5-7 business days for the clinic to complete them.

How do I prepare my child for school?

- Talk to your child about how their care might differ from other children, like taking enzymes or frequent bathroom breaks. Normalize that everyone is different and has unique needs.
- Pretend play or talk about some situations that might come up. Provide some words to help your child be confident in their responses to questions.
- If there are questions about helping your child during this adjustment period, talk with the CF Center social workers.

Teenage years:

When my child is a teenager, will they have more trouble with sticking to treatments?

We see a developmental pattern in some teenage kids with CF that usually involves them stopping their medication for a period of time. Just as you will learn to cope with your child's illness, your child must also learn to cope with their chronic illness. Usually this is done through the coping mechanism of denial. Many teens think that if they don't take their CF medications, they won't have CF. It is a good idea to assume your teenage will take their medicines, but have a check system in place, such as a pill box. This way you can supervise your child's medication without having to nag. If you have a hard time with this, call the CF office and we will assist you in working through these problems.

My teen is struggling with sharing her CF with their friends. How can I help them?

- Your care team and social workers are available to discuss strategies.
- If you request it, we can arrange Peer mentor support (virtual introductions to other teens who have CF) through Mott or through CFF's Peer Connect Program.

My teen is now a senior, how can I help prepare them for college?

- Social workers are available to discuss strategies with you.
- We can help you create individualized plans, such as using trade schools or community college as a step into university, or to figure out what area of study they will focus on.

- The Cystic Fibrosis Foundation (CFF) website is a great resource that has a section related to managing CF in college. <https://www.cff.org/Life-With-CF/Transitions/Managing-My-CF-in-College/>

Will my child be followed in pediatrics when they are an adult?

No. Anytime between the ages of 18 and 21, the young adult will meet with a CF doctor from the Adult CF Pulmonary Clinic. Please speak with your social worker and doctor when you feel ready to discuss the transition process. It is an individualized process and there is no right or wrong time to make this change.

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