

CF Connection

Fall 2019

University of Florida Pediatric Pulmonary Center

Better to be Safe than Sorry! When to Call Us...

If your child isn't very sick, the best way to contact us is through the MyUFHealth app. If you aren't enrolled in the MyUFHealth app, ask for an enrollment code at your next clinic visit or sign up at <https://mychart.shands.org/mychartprd/>. If your child has symptoms of an exacerbation, **call us** (do not use the MyUFHealth app).

An exacerbation, or worsening of lung disease in CF, is sometimes an all-of-a-sudden event, but often it is a sneaky increase in cough over days or weeks along with a decrease in energy or appetite. Here are some things to watch out for:

- A cough that is suddenly worse can usually be watched for a couple of days. Your child should increase airway clearance to 3-4 times daily. If the increased cough continues, **call us**. Whether it comes on fast or slow, it's important to treat an increased cough so it doesn't get worse. Remember that in CF, it is hard for the lungs to clear secretions and the worse an infection gets, the longer it takes your child to get back to his or her best.
- Be aware of a change in the color of the sputum (mucus/spit) that usually happens with an increased cough. It can go from clear to yellow or green. There could also be blood in the sputum. If you see blood, it may just be streaks in the mucus or it may look like it's

all blood. This is a sign that inflammation has damaged the walls of little blood vessels in the lungs. Don't panic because it's not unusual in CF, but **call us**. If your child is coughing up all blood and it does not stop, **go to your local emergency room**.

- If your child has pain that is sudden, bad, or gets worse with a deep breath or cough, **call us**. Pain is most often due to sore muscles from coughing a lot, but it could be something else. **Call us** and we can help you decide what is causing it.

If your child has any gastrointestinal symptoms, such as changes in bowel movements, we want to know. Please **call us** if your child has more frequent bowel movements, loose or oily BM, liquid BM, or no BM at all. Please also let us know about stomach pains and changes in appetite. The sooner you contact us, the easier the solution.

If you have any general questions about your child's CF care, need a school letter, or need prescription refills, please **send a message** in the MyUFHealth app. We are here to help you!

Call 352-273-8380 with any urgent issues; do NOT use the MyUFHealth app.

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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.

Are You Happy with Your Airway Clearance?

Airway clearance techniques (ACTs) help to loosen mucus so it can be coughed up and out. This is the best way to keep lungs healthy to prevent lung infections! It can also help improve lung function. Daily airway clearance is very important for people with cystic fibrosis and it is the only way to prevent airway destruction.

Coughing moves mucus out of the large airways, but ACTs must be used to move mucus out of the small airways. People with CF should never suppress a cough or try to keep themselves from coughing since coughing is what gets the mucus out.



There are many forms of ACTs so if you or your child doesn't like what you are doing right now, there may be something else that works better. The best type of ACT is the one that your child will be able to fit into his/her daily treatment plan! For more information about ACT, please ask your Respiratory Therapist or CF Care Team. We will be happy to help find a technique that will work for you. You can also visit the Cystic Fibrosis Foundation's website for more info: <https://www.cff.org/Life-With-CF/Treatments-and-Therapies/Airway-Clearance/>.

Nutrition and New CF Medications

The Academy of Nutrition and Dietetics (a professional organization for registered dietitians/nutritionists) gathered a group of experts in CF nutrition to review recent nutrition research and update nutrition guidelines. Most of the new research was related to the CFTR modulation medications (Ivacaftor, Lumacaftor, Tezacaftor). The studies found improved growth and weight gain with the new CFTR modulators, although the results were different depending on the medication.

Suggestions were made to recommend a more individualized diet for people with CF rather than a the traditional "high-fat, high-calorie" **for all**. High-calorie meals can be made more healthy by a diet of foods that are high in nutrients including: vegetables, fruits, whole grains, seafood, eggs, beans, nuts and seeds, dairy products, and

meats and poultry. A combination of 3 meals plus up to 3 snacks per day is recommended. Doses of pancreatic enzymes may need to be adjusted when intake of fat and/or protein changes. It is very important to talk with your CF dietitian if you or your child has nutrition questions or concerns. As new medications are developed and life expectancy continues to increase, dietary recommendations will change to continue to promote growth and healthy weights for everyone with CF.



Flu Shots

It's that time again! The CF Foundation strongly encourages everyone with CF to get the flu shot to decrease the chance of getting the flu. People with CF who get the flu can get a severe lung infection, like pneumonia, which is much worse than a typical exacerbation. Strains of the flu virus are always changing so it's important to get a flu shot every year. Getting the flu shot will NOT give someone the flu, since the viruses in the shot are dead. It's important for family members and others living with people with CF to also get a flu shot since the flu is very contagious. What about the flu vaccine spray? The safety of the flu spray for people with CF has not been established so the CFF does not recommend it.

Fun Stuff!

Pumpkin Overnight Oats - It's finally feeling a little like fall here in Florida! Well, sometimes in the morning at least! Here is a yummy fall recipe that is high in calories and also super-quick to grab in the morning. Or make it for an afternoon snack! Not a pumpkin fan? Try using Nutella instead of pumpkin and add berries instead of the spices.

2 tablespoons whole-fat plain Greek yogurt
 1/2 cup whole-fat milk
 1/2 cup rolled oats (NOT quick oats)
 1/4 cup pumpkin puree
 1 tablespoon pure maple syrup
 1/2 teaspoon vanilla extract
 1/2 teaspoon ground cinnamon
 2 teaspoons chia seeds (optional)

Optional toppings:

chocolate chips (70 calories/tbsp)
 sunflower seeds (47 calories/tbsp)
 chopped walnuts/pecans (45 calories/tbsp)
 shredded coconut (28 calories/tbsp)
 raisins (26 calories/tbsp)

Mix all ingredients and store overnight (at least 5 hours) in covered container. Enjoy cold or warm your pumpkin oats in microwave. Add extra toppings right before eating and enjoy!!! (1 serving = 370 calories before toppings)

CF Health Insurance Survey - The CF Foundation wants to hear from you! Access to care, health insurance coverage, and cost can be challenging for people with cystic fibrosis. Please take a 15-minute survey and tell CFF about your experience with health insurance. You can find the survey on <http://www.cff.org> or click this link https://cfhis.sjc1.qualtrics.com/jfe/form/SV_2csIF8ejwH5dlqJ.

CF Lifestyle Foundation - The CFLF provides grants to help people with CF live active and healthy lives through recreation. Grants can be used to pay for a variety of activities, such as gym memberships, yoga classes, summer camps, martial art lessons, swimming lessons, horseback riding lessons, golf fees, and much more! Grants may be up to \$500 per year. For more details, visit <https://www.cflf.org/>.



University of Florida Pediatric Pulmonary Center

Family Corner

Family Advisory Council

The UF CF Center wants your help to make life better for our patients with CF. Consider joining our Family Advisory Council! For more details, contact any member of your child's CF team.



Make the most of your visit to the doctor with these handy tips:

Before you or a loved one go to the doctor (or other health care provider)

- Confirm your appointment time.
- Make transport arrangements.
- Don't arrive stressed – give yourself time to get there and to get inside the building.
- If possible, bring someone with you – for moral support and to help remember and understand what the provider says.
- If English is the main language spoken at your doctor's office and you speak another language, ask for an interpreter before you go to the appointment.
- Think about what you want from the visit.

When you are at the office

Ask questions. Here are some tips to get you started:

- "Can you repeat that?"
- "Let me repeat what you just said so that I know I understand."
- "Can you write that down for me?"
- "I need to write that down."
- "Will the clinic follow up with me or should I contact the clinic directly?"
- "How will I get my child's test results?"
- "If I have questions after I leave today, what number can I call?"

For more helpful information, check out the UF Pediatric Pulmonary Center Patient and Family-Centered Toolbox: <https://pulmonary.pediatrics.med.ufl.edu/patient-family-centered-toolbox/>

Pediatric Pulmonary Center
University of Florida
Health Science Center
P.O. Box 100296
Gainesville, Florida 32610-0296

Phone: 352-273-8380
Toll Free: 1-800-749-7424
Fax: 352-294-8098

Physicians & Nurse Practitioners:

Silvia Delgado-Villalta, MD
Mary H. Wagner, MD
Dima Ezmigna, MD
Sreekala Prabhakaran, MD
Carmen Leon, MD
Raymond Veras, MD
Mohammed Al-Humiari, MD
Joseph Russo, MD
Dawn Baker, ARNP
Brittany Knight, ARNP
Alyssa Henry, PA

Nurses:

Alicia Hardy, RN
Tay Gandy, LPN
Ticea Cannon, LPN

Nutritionists:

Ellen Bowser, MS, RN, RD
Jennifer Hillan, MSH, RD, LD/N

Social Workers:

Susan Horky, LCSW
Tatianna Pulcini LCSW

Clinical Psychologist:

David Fedele, PhD

Pharmacist:

Kalen Manasco, PhD

Respiratory Care:

Shands/UF Pediatric Respiratory
Care Team

Family Partner:

Angela Miney—aminey@peds.ufl.edu

Office Staff:

Laura Monday
Lisa Harvey
Chris Gates
Kate Ryland