

# CF Connection

Spring 2020

University of Florida Adult Cystic Fibrosis Center

COVID-19  
Special Edition

## We Are Here for You!

During this challenging time, we want you to know that the entire CF team continues working to provide quality care for our CF patients and families. Here is what we are doing:

- We are continuously monitoring the COVID-19 situation and following the recommendations of the Centers for Disease Control and Prevention (CDC), Cystic Fibrosis Foundation (CFF), state and local health departments, and UF Health. Please click on these links for the most updated information:  
CDC: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>  
CFF: <https://www.cff.org/>  
State of Florida: <https://floridahealthcovid19.gov/>  
Alachua County: <http://alachua.floridahealth.gov/>  
UF Health: <https://coronavirus.ufhealth.org/>
- Many of us are working from home and we are having all of our team meetings via Zoom. The staff who are in the office, hospital, and clinics are practicing social distancing and we continue to wear personal protective equipment when we are with patients in the hospital or clinic.

- We are trying to have all regular clinic visits via telemedicine with either a phone call or using Zoom (a video conferencing service). We want you to stay safe at home and not come to clinic. Our office will contact you before your scheduled clinic visit with instructions. All you will need is a smart phone, tablet, or home computer with internet access. If using your smart phone or tablet, please download the Zoom app before your appointment time (you don't need the app if using your computer). Please see page 6 for tips on how to make the most of your telemedicine visit.
- We will continue to admit patients to the hospital as needed but we may be able to treat you at home. **If you have increased cough, fever, shortness of breath, or any other issues, please call our office at 352-273-8740 anytime day or night.** We will either schedule a telemedicine visit for the same day you call (if possible) or give you instructions for coming to the hospital. If you think you have been exposed to COVID-19 but you do not have any symptoms, please call us.

We will all get through this together! Please contact us thru MyUFHealth or call 352-273-8740 if you have any questions.

### Inside this issue:

Tips for You & Your Family	2
Wellness During COVID-19 & Resources	3
Nutrition Resources & Tips	4-5
Family Corner	6

## 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! Please send e-mail to [Jennifer.Hillan@medicine.ufl.edu](mailto:Jennifer.Hillan@medicine.ufl.edu).

## Tips for You and Your Family at Home

- ✓ Stick to a routine. Go to sleep and wake up at a reasonable time, write a schedule that includes time for work as well as self-care.
- ✓ Dress comfortably. Get showered and dressed in comfortable clothes, wash your face, brush your teeth. Put on some bright colors. It is amazing how our dress can impact our mood.
- ✓ Get out at least once a day and try to exercise for at least 30 minutes. Go first thing in the morning, or later in the evening, and try less traveled streets and avenues. Search for free movement classes on YouTube or turn on the music and have a dance party!
- ✓ Reach out to others. Try to do FaceTime, Skype, phone calls, texting, wave to your neighbors. Do it for children as well —they miss their friends, too!
- ✓ Drink plenty of water and eat as well as you can.
- ✓ Develop a self-care toolkit. Keep your favorite things around you: a soft blanket, favorite photos, comfort food, favorite music, paints, or books. Mint gum, Listerine strips, ginger ale, frozen Starburst, and ice packs may help control anxiety. For children, help them create a comfort box (often a shoe-box or bin they can decorate) filled with their favorite things and that they can go to when they feel overwhelmed.
- ✓ Give everyone the benefit of the doubt, forgive generously. Everyone is doing the best they can.
- ✓ Everyone find their own quiet space. It is good to know that even when we are on top of each other, we have our own special place to go to be alone.
- ✓ Limit social media and COVID conversation, especially around children. There is so much information on COVID-19, and it changes minute to minute. Find a few trusted sources and check them a few times a day.
- ✓ Notice the good in the world and help others. Very small acts of kindness make us feel good about ourselves and make all the difference.

### NEW WEEKLY ONLINE DISCUSSION/ SUPPORT GROUP

#### TO COPE WITH COVID-19 STRESS

Thursdays at 5:00 pm PT / 8:00 pm ET

Moderated by psychiatrist Yelizaveta Sher, MD, Adult CF Center at Stanford

CFRI will host an online discussion/support group for members of the CF community. This is an open format via Zoom where people can share their experiences and address the anxiety that COVID-19 is triggering in our community.

To participate, go to <https://zoom.us/j/519241333>

## Wellness During COVID-19

The UF Adult CF Team is here and available to help support you and your family during this time. When you have a moment, we encourage you to review the following resources. We hope that they will be helpful!

### Self-Care Strategies:

- Stress Management: [CF Exchange Stress Management Tip Sheet](#)
- Comprehensive Caregiver Guide: [NCTSN Caregiver Guide to Helping Families Cope with Coronavirus](#)

**Discussing COVID-19 with Children:** Coronavirus can be a confusing topic for children and teenagers. Below are some resources that were specifically developed with kids and families in mind:

- General Parent Strategies: [Cincinnati Children's Steps to Help Ease Kids Fears & Anxieties](#)
- Children: [NPR's Comic Exploring the New Coronavirus](#)
- Teens: [Child Mind Institute's Supporting Teenagers and Young Adults during the Coronavirus Crisis](#)

**FL Blue Emotional Support Helpline:** Free counseling support available 24/7 in English & Spanish - 833-848-1762

## Resources for Uncertain Times

### General Assistance - Need Help? Call 2-1-1

2-1-1 is a free resource referral service provided by United Way that connects area residents to critical health and social services when they need help. From help with a household bill, food assistance, or counseling for suicide prevention, calling United Way's 2-1-1 helpline is open 24 hours a day, 7 days a week, year-round.

Connect in the following ways:

- Dial 2-1-1 (24 hours a day, 7 days a week)
- Text your zip code to 898-211
- Search their [resource database](#) online.



### Employment Resources

Florida Department of Economic Opportunity has initiated two programs to address the work-related impact of COVID-19. For full details visit their website [here](#).

- **Re-Employment Assistance** is temporary wage replacement program caused by COVID-19. FAQs can be found [here](#).
- **Business Recovery** - Offering small businesses emergency interest-free bridge loans. More info can be found [here](#).

### Compass

Cystic Fibrosis Foundation *Compass* is a personalized, one-on-one service that provides people living with cystic fibrosis, their families, and their care teams with a partner in dealing with challenges related to life with CF. Compass remains open during COVID-19 to help you with insurance, financial, legal, and other issues. Call them at **844-COMPASS** (844-266-7277) Monday through Friday, 9 a.m. until 7 p.m. ET, or email [compass@cff.org](mailto:compass@cff.org).

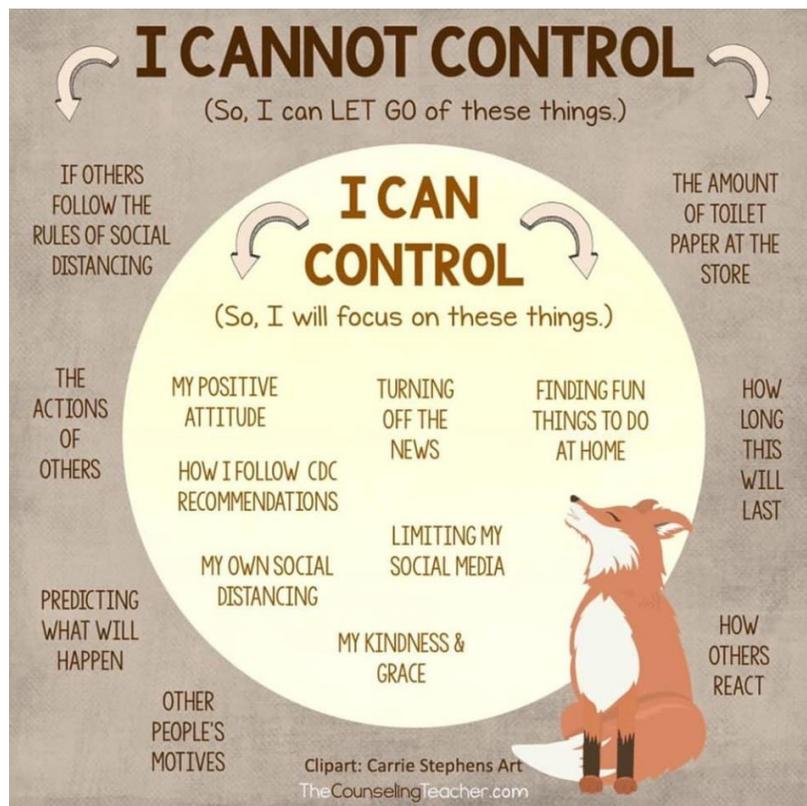
## Nutrition Resources

**Healthwell Foundation COVID-19 Ancillary Costs Grant** can provide up to \$250 to cover costs associated with delivered food, medication, diagnostics, transportation, and telehealth. Family income must fall within 500% of Federal Poverty Level. To see if your family qualifies, click <https://www.needymeds.org/poverty-guidelines-percents/>. For more info about applying, visit <https://www.healthwellfoundation.org/fund/covid-19-fund/> or call 800-675-8416.

**Drive Thru Farmers Market** is available at Working Food, 219 NW 10th Avenue, Gainesville. Participating farms have produce, dairy products, meats, bread, and more. Market days are Wednesday (4-6pm) and Saturday (9-11am) through April 11. Orders must be placed with participating farms two days in advance. Find Working Farm on Facebook or visit [www.workingfood.org](http://www.workingfood.org) for the list of farms, links to online ordering, and updates on the market. For more information, contact Working Food at [www.workingfood.org](http://www.workingfood.org) or 352-260-4458.

**Summer BreakSpot** offers free meals for children under age 18 in the state of Florida. Many schools are offering take-home lunch bags. To find a local site, click <https://summerbreakspot.freshfromflorida.com/> or contact your child's school.

**Academy of Nutrition and Dietetics** offers information about food safety, tips for grocery/meal delivery, tips for grocery shopping, food resources, and more! Click [here](#).



## Eating Healthy During COVID-19

A lot is changing in the world right now with the new public health crisis. Despite the uncertain times ahead, one thing remains constant...we need to eat! When you have cystic fibrosis, it can be even more important to plan nutritious, high-calorie meals with shelf-stable foods (foods that will stay safe to eat for a longer period of time and do not need to be refrigerated).

Here are some high-calorie shelf-stable foods that may or may not need to be refrigerated upon opening. Keeping these items on hand can help ensure you get enough calories through these trying times.



Food Item	Calories	How to Use
<b>Nuts</b> (cashews, almonds, walnuts, etc.)	180 calories per ¼ cup	Excellent as a snack or add to cereal
<b>Nut Butters</b> (peanut butter, almond butter, etc.)	190 calories per 2 tbsp	Add to fruit or mix into oatmeal
<b>Oils</b> (olive, peanut, vegetable, corn)	110 calories per 2 tbsp	Add to pasta, drizzle on vegetables
<b>Creamy Soups</b> (clam chowder, cream of mushroom)	185 calories per 2 tbsp	Eat with buttered crackers
<b>Alfredo Pasta Sauce</b>	90 calories per ¼ cup	Add to your favorite pasta
<b>Cheesy Queso</b> (Tostitos, Velveeta, etc.)	85 calories per ¼ cup	Pour over broccoli
<b>Canned Gravy</b>	120 calories per cup	Pair with dehydrated mashed potatoes
<b>Mayonnaise</b>	180 calories per 2 tbsp	Make tuna or egg salad
<b>Ranch Dressing</b>	100 calories per 2 tbsp	Use as a vegetable or pizza dip
<b>Maple Syrup</b>	100 calories per 2 tbsp	Add to oatmeal or pancakes/waffles
<b>Dried Whole Milk</b>	150 calories per 1 cup	Drink plain, add powder to pasta sauce
<b>Boxed Whole Milk</b>	150 calories per cup	Drink plain or add chocolate syrup

# CF Connection—UF Cystic Fibrosis 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.



**All regular clinic visits will now be telemedicine visits** so you do not need to be seen in person. Make the most of your TELEMEDICINE visit with these handy tips:

#### Before the telemedicine visit

- Our office will call you to confirm your appointment time and then send you instructions for connecting to Zoom through your smartphone, tablet, or home computer.
- Download the Zoom app to your phone or tablet. If you are using a home computer, you do not need the app. Be sure the speakers and camera are working.
- Try to be home in an area with good phone/internet connection. Do not be in a moving car since this may cause a bad connection and also is not be safe!
- If you have them at home, have these items nearby: thermometer, scale, pulse oximeter, and/or a portable PFT machine.
- Connect to the call a few minutes early.
- Think about what you want from the visit and what questions you have.

#### During the visit

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.”
- “I need to write that down.”
- “Will the clinic follow up with me or should I contact the clinic directly?”

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

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