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CF Care at Nemours
Nemours Children’s Hospital | Your child. Our promise.

Celebrating May as Mental Health Awareness Month
Starting this year, the Cystic Fibrosis Foundation recommends that all accredited cystic fibrosis (CF) centers screen every CF patient ages 12 and up as well as offer screenings to parent caregivers for anxiety and depression on an annual basis and additionally as needed.

Why Is This Important in CF?
We all experience some anxious or depressed feelings at times. When these feelings are persistent and intense, they can get in the way of our daily activities and have a negative impact on quality of life, health outcomes and adherence. Parents who are experiencing mental health problems tend to have a harder time getting treatments done, their children’s outcomes tend to be poorer, and their teenagers are more likely to experience these struggles as well.

In 2013, the Cystic Fibrosis Foundation and the European Cystic Fibrosis Society (ECFS) brought together an expert committee of psychologists, psychiatrists and clinical social workers to develop clinical care recommendations for anxiety and depression in individuals with CF and parent caregivers. Their recommendations were based on the findings of the TIDES study (The International Depression Epidemiological Study) conducted in Europe and the United States over a three-year period. This study found that teens and adults with CF were two to three times more likely to experience feelings of anxiety and depression compared with the general community; they also found that children are twice as likely to experience mental health issues if their parent is anxious or depressed.

What Will This Look Like in My CF Clinic?
- At least annually, you and/or your child will be asked to complete two simple screening tools called the Patient Health Questionnaire (PHQ 9) and the Generalized Anxiety Disorder Screener (GAD 7). The questionnaires consist of nine and seven questions and should take no more than three to five minutes total to complete.
- Our CF team social worker Amanda Montgomery, LCSW, will share the screening tool results with you and/or your child. If there are concerns based on the screening tools, she will work with you to find the best solution to address those concerns.
- Our team will track these results as part of your child’s medical record, as this will allow us to measure trends over time, just like we do with FEV1 and BMI scores.

By identifying symptoms of anxiety and depression early and by providing education, information or linkage to helpful services, we hope that we can optimize the health and quality of life for you and your child. We are very glad to answer any questions or provide further information about these new guidelines. Please do not hesitate to contact us, as we value your input.

“There is no health without mental health.”
- David Satcher, MD, PhD, Former Surgeon General (1999)
May is Also CF Awareness Month

Across the country, volunteers, people with cystic fibrosis and their families will be spreading awareness about the disease and highlighting the progress the CF Foundation has made in the search for a cure.

How all of us can help increase awareness about CF:

- You can check out the CF Awareness Toolkit which offers tips, tools and language that can help you spread the word.
- Another great way to help promote CF awareness is to join or support one of the many Great Strides walks across Central Florida and Brevard County.

Have You Heard About COMPASS?

As part of its commitment to helping people with CF live better today and at every stage of life, the Cystic Fibrosis Foundation offers assistance through COMPASS™. For many people with cystic fibrosis and their families, financial burdens and insurance hassles are as much a part of living with the disease as nebulizers and vests. COMPASS is a personalized service that helps work through insurance, financial, legal and other issues. It’s free, confidential and available to everyone, including family members and CF care providers.

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Life with CF can be hard, time-consuming and expensive. A recent study by the CF Foundation showed that 80 percent of adults with CF worry about having the financial support they need to live with the disease. Nearly 75 percent worry about getting or keeping their health insurance. Plus, understanding and dealing with insurance requirements can take many hours out of a day that is already full trying to manage therapies and other aspects of life with CF.

People reach out to COMPASS for help with everyday concerns, and they often need more support during times of change, such as receiving an initial diagnosis, aging out of a parent’s health insurance or going on disability.

A dedicated CF Foundation COMPASS case manager is ready to work one-on-one with anyone who needs help. Contact them Monday through Friday from 8:30 a.m. to 5:30 p.m., EST, by phone at (844) COMPASS or (844) 266-7277 or by email any time at compass@cff.org. You can also learn more about COMPASS at cff.org/compass.

Link to the Cystic Fibrosis Foundation Compass Brochure for more information: https://www.cff.org/Living-with-CF/Navigating-Insurance/Finding-Support/Compass-Brochure/
What Is MyNemours?

MyNemours is online access to your child’s health records with 24/7 access to scheduling of appointments, care team communications and health record access.

By signing up for MyNemours, you will be able to:

- Communicate with your medical care team for nonurgent matters.
- Schedule appointments.
- Request prescription refills.
- Download health summaries.
- Easily link to Online Bill Pay.
- Access trusted health information from KidsHealth.org.
- Review and graph test results.
- Print school excuses and immunization records.
- View growth charts and past appointment summaries.

Information on MyNemours can be found at any of the Nemours registration desks. Our registration specialists can assist you with any questions you may have.

For more information, please visit Nemours.org/mynemours or for assistance, call our help line at (877) 696-3668 or email MyNemours@nemours.org.

What Parents Are Saying About REACT (Re-Education in Airway Clearance Techniques)

“Our family jumped at the opportunity to take advantage of REACT. It can be overwhelming managing our children’s CF. It can be very easy to administer medication in the wrong order. Reinforcing the importance of cleaning the nebulizer and infection control was something my teenage daughter needed to hear.” — T.A., CF Parent

“Very informative, we learned not to mix some of the nebulizer medication, which makes them more effective.” — J.H., CF Parent

The aim of the program is to:
- increase lung function by 10 percent from current baseline.
- improve the number of patient’s adherent to airway clearance by 50 percent.
- increase the percentage of appropriately working nebulizer compressors to 100 percent.

If you have a home email address, please let the registration specialist know during check-in and they can add the information to your child’s medical record. We can use this information to send you our latest CF newsletter or inform you of important recalls or safety issues related to CF care.

We Want to Hear From You!

“This newsletter is AMAZING! It looks great and it’s packed with useful stuff. Know what else I’d love to see in it? A spotlight on different CF families. They can share about their kid, how they organize life, how they organize meds, important things/tips that they have learned along the way. I’m always wondering how others do it!” — L.C., CF Parent

What a great idea, L.C.! Send us your favorite tips or strategies that help you and your family feel more successful in managing daily life with CF. Look out — you may be highlighted in an upcoming newsletter!