Just In: Yearly Screenings for Depression and Anxiety

Depression and anxiety are common in individuals with CF, affecting 19% and 32% of patients, respectively. Caregivers also suffer from these conditions at a much higher rate than the general population. Because mental health issues are common and impact the daily care and well-being of many CF patients, the CF Foundation convened an expert panel to recommend how best to address them. The UNC Adult CF Clinic will be implementing these recommendations, including regular depression and anxiety screening during regular CF clinic visit beginning in early 2016.

There is no single cause depression for the general population or for people with cystic fibrosis. However, in any complex chronic condition that requires a time consuming treatment regimen and the potential for health to worsen, symptoms of anxiety and depression are more common. Since CF treatments can take up to 2 to 4+ hours per day, it can be difficult to balance both enjoying life and engaging in treatments. Further, people with CF and their families may struggle to cope with the uncertainty of the future. Some level of stress or anxiety is, at times, to be expected as a normal response to a very difficult situation. However, persistent and severe symptoms can greatly reduce a person's



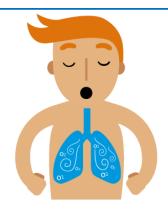
quality of life and makes it much more difficult to adhere to treatment schedules and healthy behaviors. The CF Foundation has implemented new mental health guidelines to ensure that depression and anxiety are adequately addressed. Along with screening questionnaires, education/information, outside referrals, and counseling will be offered as needed.

In the near future, you should expect to be given 2 separate screening forms when you check in for your appointment. These questionnaires are very brief and should take no more than 5 min to complete. Answers to these questions will help us identify those patients who may be struggling with anxiety or depression, which will allow us to offer additional assistance as needed. Our sincere hope is that treating depression and anxiety will lead to a better quality of life and health outcomes.

~Jennifer Pagel, LCSW

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WHY DO I NEED TO COME TO CLINIC SO OFTEN? I FEEL FINE!

As your center for CF care, we are committed to promoting your health so you can enjoy a long and happy life. We aim to provide the highest standard of care and look to the guidelines set by the CF Foundation to ensure that we are meeting those goals. One of the overarching guidelines relates to care, screening and prevention. Research shows that CF centers with the highest

rates of attendance for regularly scheduled visits have the best health outcomes.

The CF Foundation recommends that every patient be seen in clinic at least four times a year. At top performing centers around the nation, 77 percent of patients achieved this goal in 2014. At UNC, only 48 percent of patients were seen at least 4 times - falling short of both the "ten best" center average and the national average of 54 percent.

So why is it so important that we see you this often? Regular clinic visits give your CF care team the opportunity to catch changes in your lung function and nutritional status that may go unnoticed otherwise. These small changes are often symptom-less but can escalate quickly, leading to worsened health over time. Finding these changes early can lessen the treatment required to resolve them, meaning fewer days receiving antibiotics at home or in the hospital, and more days of good health. Regularly scheduled clinic visits, every three months, are essential to promoting your current health and provide us with the opportunity to identify health, medication, and device issues that can undermine your success

If you do not already have a clinic appointment scheduled, call the UNC Pulmonary Clinic at 984-974-5703 to make one. If finances or other barriers are making it difficult for you to come to appointments, please let us know. There may be assistance available for help with transportation or other costs. \sim *Jaimee Watts, RN*



NEED HELP
WITH MEDICALLY
RELATED ITEMS
OR CO-PAYS?

HealthWell Foundation provides assistance with medical costs related to CF that are not covered by your insurance or when the co-pay is not affordable. These include vitamins, nutrition drinks, tube-feed formulas, and medications including hypertonic saline.

- 1. Click on 'Get Assistance Now' tab.
- 2. Click on the 'Application Process' hyperlink
- 3. Click on the 'Let's Get Started' button at the bottom of the page.
- 4. Fill out the application and submit it. You should get an immediate approval confirmation code if you're approved.

HealthWell applications can be completed over the phone & online

Health Well: 800-675-8416 www.healthwellfoundation.org

To qualify, you must have CF, have health insurance, and meet income guidelines up to 500% of poverty.

AIRWAY CLEARANCE DEVICE UPDATE

The techniques and devices used to assist with mucus clearance from your lungs are rapidly changing. Your CF Respiratory Therapy team is dedicated to keeping you informed of treatment options and helping you find the best one for you.

If you have been admitted lately, you may have been introduced to the VibraLung. This device

can be used with albuterol and hypertonic saline and allows you to move into different positions to target different lung areas. The VibraLung uses sound waves transmitted down your wind pipe (trachea) to shear mucus away from your airway walls. There are different settings on the device that allow it to target different lung regions. Currently, this device is also available for home if you have

private insurance, but it not yet covered by Medicaid and Medicare. When this changes, we will let you know.

As some of you are aware, we no longer have the Acapella Duet and Coronet available in the hospital. We have since switched to the Aerobika which also uses vibration and pressure to assist with secretion removal. Albuterol and hypertonic saline may still be inhaled while using

the Aerobika, as was often done with these other devices. When you leave the hospital, please don't forget to bring it with you to use at home!

In other news, the hospital has changed the "vest" machine we use in the hospital. We currently are using the InCourage System by

RespirTech. This device will automatically change the vibration frequency during a treatment each 30 minute treatment session. We will provide disposable supplies for use with this vest system; however, if you already use this system at home, you are welcome to bring your own jacket in. For patients who use the Vest by Hill-Rom, we will keep 2 of their machines for you to use, but will no longer stock jackets and hoses.

Please be aware of this as you pack for your hospitalization. We encourage you to use time spent in the hospital as an opportunity to experiment with alternative forms of airway clearance to find what is most effective for you!

We are here to help with this process.

~Jenn Dane, RT

Image courtesy of westmedinc.com

Introducing the...



Inpatient





What meds should I *
bring from home *
when I am admitted?

Here is a list of a few of the meds that are not available from the UNC inpatient pharmacy

The VibraLung uses sound waves transmitted

down your wind pipe (trachea) to shear mucus

away from your airway walls.

- Kalydeco/Orkambi
- Cayston (with neb setup)
- Any pancreatic enzymes other than Creon
- Any ADEK vitamins other than AquADEK chewables
- Oral contraceptives

Research Study Opportunity!

Early Education about Palliative Care:

Developing a new standard of CF care



We are starting a new study to assess patients' knowledge and opinions about palliative care. People with CF ages 13 years and older and one family member/caregiver per patient will be asked to participate. We will provide basic education about palliative care and issues specific to CF in individual sessions with patients and one of their family members. Participation would include a 20-30 minute session during a routine CF appointment and a brief follow-up survey (3 months later). A member of the research team may ask you to participate at your next clinic visit.

You can contact Dr. Elisabeth Dellon (Elisabeth_Dellon@med.unc.edu) if you are interested.



REMINDER:

FLU VACCINES ARE STILL AVAILABLE IN CLINIC.



Follow us on Facebook!!

UNC Adult Cystic Fibrosis Center



Interested in advocacy?Want your voice to be heard?Join the Patient and Family Advisory Board!

The UNC CF Patient and Family Advisory Board (PFAB) partners with members of the healthcare team to improve the patients' and families' experiences at the University of North Carolina. Its purpose is to promote improved relationships between patients, families, and staff, and thereby improve care and outcomes. It provides an avenue for patients and families to offer input into policy and new program development in CF. The PFAB was responsible for organizing the successful Family Day held at UNC in October. The PFAB meets monthly via teleconference and is open to anyone with CF or their family members. For more information, or to join, contact Kirsten Gebhardt. kirsten@gebhardt.us

N TOUCH

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TO MAKE OR
CHANGE A
CLINIC
APPOINTMENT
PLEASE
CONTACT THE
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