Pulmonary exacerbations often lead to the progressive loss of lung function and gradual lung destruction over time. Their frequency is also associated with worse quality of life and shortened survival. The UNC CF Center has been particularly focused on better ways to treat, detect and prevent these illness episodes as one way of improving the quality and length of the lives of our patients. Almost a year ago, using a grant from the Cystic Fibrosis Foundation, we started new programs to improve our quality of exacerbation care, both inside and outside of the hospital. Here is an update...

In the Clinic
Ideally, we would love to prevent all pulmonary exacerbations! Faithfully adhering to your airway clearance and exercise regimen is extremely important, as is the appropriate prescription and regular use of maintenance medications (e.g. hypertonic saline, Pulmozyme, azithromycin, inhaled antibiotics). However, exposure to respiratory viruses and other events out of your control can still trigger exacerbations. When this happens, our goal is to detect the onset of the illness as soon as possible, so that intensified treatments can be used to try to prevent more serious loss of lung function and illness symptoms. Hopefully, early detection can also save you a trip to the hospital or need to undergo a course of IV antibiotics at home.

So how can we achieve this? We have instituted a home monitoring program that includes the use of a hand-held spirometer and a log book where respiratory symptoms and weight are tracked regularly. Instructions on when and where to call the CF Center is also included. Week to week assessments of your lung function, rather than every 3 months in clinic, certainly allows you and our team to be more aware of your lung health. The regular use of these tools may allow you to keep closer tabs on your disease, and to detect when something is going wrong earlier. These tools will also help you to track your improvement after new therapies are prescribed (e.g. antibiotics). To date, more than 80 adult CF patients have joined this exciting program.

If you would like to participate in this home spirometer program, please let Kathy or your CF doctor know so we can tell you more!

If you already have a spirometer and notebook, be on the lookout for a survey from our group. Your answers to these questions are very important, and are needed for us to learn how this program is helping you, and how it can be improved. Keep up the good work!

In the Hospital
Hospitalization for a pulmonary exacerbation is always a major event in patients’ lives. We strive to make the most out of these hospital stays by giving you well
Important Flu Tips — Seasonal and H1N1

This flu season offers special challenges to the CF community. Supply of the seasonal influenza and H1N1 influenza vaccines has been limited both at UNC and in local communities. This website may help identify places near you that have vaccines in stock:

http://www.flu.gov/whereyoulive/index.html

This year, you should receive 2 separate vaccinations—one for seasonal flu, and one for H1N1 flu. These shots can be given to you on the same day. Remember, patients with cystic fibrosis should get the seasonal and H1N1 flu shots; they should not get the nasal vaccine preparations.

During flu season, please remember these important infection control guidelines:

- Avoid contact with people who are sick with flu or viral illness. Droplets from cough and sneezing spread the influenza virus from person to person.
- It can also be spread by touching a surface with virus on it (like a table or utensils), then touching your nose or mouth.
- Wash hands frequently with soap and water, or with alcohol-based hand sanitizers.
- Contact us immediately (919-966-4131 for the pulmonary fellow on-call) if you experience fever greater than 100.5°, chills, dry cough, body aches, sore throat, fatigue and/or headache. Some people with H1N1 influenza may also experience nausea and diarrhea. Medications are available to help alleviate flu symptoms, but they must be started within 48 hours of the onset of symptoms.

For any questions, please contact Kathy Hohneker, RN at 919-966-7049.

Food Vending Machine

The home spirometers being distributed through our QI program.

As part of UNC Healthcare’s commitment to you, the Nutrition and Food Service department has created a new gray meal ticket tag designed specifically for Cystic Fibrosis patients. Instead of having to wait a week for meal tickets, the gray card may be used starting the day that you are admitted to the hospital until the day that you discharge. It carries a $6.25 balance that reloads each day. You keep the card and can use it as many times a day as you want until meet your daily balance. It is redeemable at any of the 4 hospital cafes: Terrace, Corner, Overlook, and Larry’s Beans as well as the new 6BT vending machines.

UNC recognizes that CF patients have high calorie needs and frequent hospitalizations; promoting access to a variety of foods is important. Remember that nutrition is part of your medical therapy for CF! Here are some tips for getting the most out of your hospital stay:

- Ask for double portions
- Request a written menu if you prefer it to the bedside ordering system
- Drink high calorie nutritional supplements (CIB Plus, Scandishake, etc)
- Order snacks. They are offered three times daily: 10am, 2pm, and with dinner
- Utilize high calorie supplemental meal list
- Use your gray meal card every day (volunteers can help)
- Contact your doctor or nurse if you want to get the CF dietician involved!

CF Patient Assistance

Need Help During the Holidays? Members of the CF/Pulmonary Research and Treatment Center have collected donations to help patients from our clinic who are having a difficult time affording essential items such as food, utilities, clothing and gasoline during the holiday season. Small, one-time awards may be available to assist patients with specific needs. Please contact Jennifer Pagel (Jpagel@unch.unc.edu, 919-966-7873) or Kathy Hohneker (khohekr@med.unc.edu, 919-966-7049) ASAP+ if you would like to request assistance from this fund.

The UNC CF Patient Assistance Trust Fund: This fund was established to provide direct patient assistance to those who are having a difficult time affording food, bill payments, medications, and gasoline. If you are interested in learning more about this fund, please contact Jennifer Pagel (Jpagel@unch.unc.edu, 919-966-7873) or Kathy Hohneker (khohekr@med.unc.edu, 919-966-7049).