Spring has sprung...and the time has come to ask ourselves the question…”When is the last time I changed the….?”

Changing or replacing respiratory equipment for the CF patient is very important as to ensure that each patient is receiving his/her medication in the most effective and efficient manner.

Typically, the CF patient will need to replace these specific types of respiratory equipment.

1. Nebulizer
2. Nebulizer tubing
3. Filter for Compressor

The nebulizer and nebulizer tubing should typically be replaced every 6 months and the filter every month.

However, if the equipment appears defective, then it should be replaced immediately.

Your respiratory therapist (RT) can assist you in providing the necessary items for you at the desired time.

Discuss with your RT the best way to keep track of when a piece of equipment should be replaced as it is easy to often forget when was the last time that you replaced a specific item. Some nebulizer kits are packaged with monthly stickers that you can adhere to the top of your compressor, and it serves as a reminder for the next replacement period.

Do not hesitate to ask your respiratory therapist if you have any questions regarding expirations for any equipment needs regarding your nebulizers, compressor, the Vest, or any other types equipment.
CF Advocacy Opportunity for Teens

*** The following announcement is being shared on behalf of a member of the Boomer Esiason Foundation’s Young Professionals Committee

Are you a teen who wants to make a difference for people with cystic fibrosis?

If you are between the ages of 12-18 and know someone who is affected by CF, the Cystic Fibrosis Foundation invites you to attend its Third Annual CF Teen Advocacy Day on Thursday, June 23, 2011.

This event brings teenagers from across the country to Washington D.C., in order to advocate to their elected officials on behalf of friends and relatives with CF.

If you are interested in attending and would like to receive an application, please email 17 year old advocate, Will Barry (wbarry770@yahoo.com) or Eric Chamberlain (echamberlain@cff.org) at the CF Foundation for more information.

May is CF Awareness Month

May is Cystic Fibrosis Awareness Month. It’s a time for volunteers and people living with CF to come together and shine a spotlight on what CF is and the progress being made toward a cure. Take some time this month to help get the word out and encourage the people in your community to become involved, too!

Consider these statistics:

- Approximately 30,000 children and adults have CF in the United States.
- More than 10 million Americans are symptomless carriers of the defective CF gene.
- The disease occurs in one of every 3,500 live births of all Americans and about 1,000 new cases of cystic fibrosis are diagnosed each year.

What You Can Do
As someone who is interested in educating and advocating for increased funding for vital CF research, you can do a lot!

- Participating in Great Strides;
- Becoming an advocate and contacting members of Congress on behalf of people with CF;
- CF Cure Bands; and
- Talking about CF in your social networks (i.e., Facebook, Twitter, etc.)

Together, we can help make “CF” stand for “Cure Found.”
Got Milk?

Dairy Products: Foundation For A Nutrient Rich Diet

Milk, cheese, yogurt and ice cream ..... dairy products are rich in calcium, high quality protein, vitamins A and D, and many other vitamins and minerals. They come in high fat, low fat and even lactose-free versions. You can eat them plain, cook with them, and drink them. There’s something for everyone. (If you have a milk allergy, your nutritionist can help find substitutes for dairy foods.)

Good nutrition is a cornerstone of CF care, right alongside airway clearance and medicines! Nutritional status is linked to pulmonary health. Improving nutrition can reduce the frequency of lung infections and hospital stays. We’re going “Back to Basics” as we better understand just how important good nutrition is when you have CF.

For adults and kids with CF, take advantage of what this food group offers. Here are some suggestions:

"Milk with every meal.” It’s not too late to start, and you’re never too old to start! This simple rule assures 3 cups of milk each day. (Teens and adults can drink 2 large servings instead of 3 smaller servings.)

"Milk with your Happy Meal™.” Set this expectation early. Although fast food restaurants serve lowfat milk, it’s still a better nutrition choice than juice or soda.

Cook more with dairy products. Use milk (not water) when making hot cereals and hot cocoa; add cheese to salads, casseroles and rice dishes; serve ice cream often; choose pudding over Jello™; have cheese sticks instead of pretzels for snack; and have full fat yogurts on hand.

Convenience items help. Milk Chugs™, Hershey’s Milkshakes™ and Gogurt™ are just a few examples of popular portable items.
For many young adults living with CF, leaving home to attend college is a recent, and welcome, development. But campus life opens new questions about disclosure, nutrition, and adherence to treatment.

Amy, a 27-year-old business woman with CF — and two undergraduate degrees (business and international relations) — recently received her Master of Business Administration from the prestigious USC Marshall School of Business. She knows the pitfalls and pleasures of adapting a CF lifestyle to the college campus. She faced juggling commitments, prioritizing treatments and, of course, disclosing CF. Never one to cower before a challenge, however, Amy met the issues head-on, starting with disclosure.

“The summer before I moved into the dorm, I told my roommate about the disease,” remembers the USC Trojan. “I told her that I have some medication treatments to do, but I’d be more than happy to work with her and her schedule so I wouldn’t disturb her too much.”

When it came time to making smart choices about her social life, Amy put the health of her lungs first by avoiding smoke-filled venues and parties. According to data from the Cystic Fibrosis Foundation, the 18- to 24-year-old age group has the highest percentage of exposure to secondhand smoke of any CF age group. To fully protect yourself, you should be in 100 percent smoke-free environments. Amy admits that the commitment to health may lead to some hard choices, not only about avoiding smoke-filled environments, but also about how to divvy up time each day.

“I had to make some decisions,” says the MBA. “When you’re in college you have so many choices: time spent sleeping, time spent studying, time spent out with friends.” While juggling all of this wasn’t easy for Amy, her priorities were clear.

“We all know with CF, getting enough sleep, getting proper nutrition, exercising and complying with medication routines is the key to success - the key to staying healthy and being able to enjoy other aspects of your life,” says Amy. “So making sacrifices for me — not always going out with my friends, or maybe going out with my friends...
but coming home earlier to get the sleep I needed — those trade-offs were essential to my success during my undergraduate experience.”

Amy’s commitment to her health and treatments didn’t happen overnight. Her mom, Susan, can take much of the credit for her daughter’s commitment to health. Susan began making Amy responsible for her own treatments and medication, with parental guidance and supervision, when Amy was barely out of elementary school. As Amy approached college age, Susan, pushed Amy’s transition from pediatric to adult care.

“I purposely started her [transition to adult care] in her senior year of high school, so she could get used to it,” says Susan. She believes that both steps helped her daughter prepare for a smooth transition to life at school.

Wherever you go, whether it’s off to college, or some other life adventure, when you depart from home, experts familiar with transition recommended that you have a relationship with an adult healthcare provider before a medical crisis forces you to find one. Inquire with your current CF center to learn if it has a structured transition program, for instance, where you could meet an adult-oriented pulmonologist in a familiar setting prior to moving out of the house - or the state!²

So, what advice would Amy give to other young adults leaving home and living on their own for the first time?

“What CF has really taught me is sometimes I have to, even if I know people might be a little bit upset with me, I have to put myself first,” acknowledges the graduate. “I have to be very dedicated to my needs. Medication, compliance and exercise, and proper rest, and nutrition are really… the keys to prolonging my life and keeping me healthy and happy and doing the activities I want to be able to do.”

***Article featured from the “Transitions” section of CFvoice. For more information regarding CF patients transitioning from high school to college (ages 18-24), visit the website www.cfvoice.com
The Cystic Fibrosis Scholarship Foundation

The Cystic Fibrosis Scholarship Foundation (CFSF) — a scholarship program for students with CF enrolling in an undergraduate college program or a vocational school in the fall. CFSF was founded by a parent of a young adult with CF and is neither part of nor funded by the Cystic Fibrosis Foundation. Scholarships of $1,000 each are awarded and may be used for tuition, books, and room and board, for up to one year of study. Students may reapply the following year for an additional award, but are not guaranteed future awards. Awards are sent directly to the institution that the student is attending. Scholarships are awarded based on a combination of financial need, academic achievement, and leadership. For application forms, deadlines and other information, visit www.cfscholarship.org or call (847) 328-0127.

CFCareForward Scholarship

CFCareForward Scholarship — Applicants include U.S. citizens with CF who are enrolled or awaiting acceptance from an accredited institution in the fall. Awards are based on applicants’ creativity, academic excellence, community involvement and ability to serve as a positive role model for the CF community. This year 40 $2,500 CFCareForward Scholarships will be awarded to students with cystic fibrosis. And to celebrate the 19th year of the CFCareForward Scholarship, two Thriving Student Achievers will be selected for an award of $19,000 in place of the standard $2,500 award. The application and additional information about the scholarship can be found at www.CFCareForwardScholarship.com/apply.

The Elizabeth Nash Foundation Scholarship Program

The Elizabeth Nash Foundation Scholarship Program awards scholarships to assist persons with CF to pursue undergraduate and graduate degrees. Scholarships are awarded on the basis of demonstrated need and accomplishment, both academic and other. Grants are made each year to people with CF who exhibit clear academic goals and a commitment to participate in activities outside the classroom. Grants are made directly to the academic institution to assist in covering the cost of tuition and fees. For application deadlines and more information, visit www.elizabethnashfoundation.org

Other Resources

For other options, contact the George Washington University HEATH Resource Center for a publication entitled, "Creating Options: Financial Aid for Students with Disabilities," which provides contact information and background about financial assistance opportunities. To obtain a copy, please contact:
The George Washington University HEATH Resource Center
2121 K Street, NW, Suite 220
Washington, D.C. 20037
Phone: (202) 973-0904
Fax: (202) 994-3365
E-mail: askheath@gwu.edu
www.heath.gwu.edu

Federal Student Aid Information Center at the U.S. Department of Education provides a publication entitled "The Student Guide" which lists many financial assistance programs:
Federal Student Aid Information Center
P.O. Box 84
Washington, DC 20044-0084
Phone (800) 4-FED-AID (1-800-433-3243)
www.studentaid.ed.gov
The Texas heat is quickly approaching for the summer, and dehydration can turn a fun outing into a potentially dangerous one. Everyone needs lots of fluids during hot weather. Most of us don’t drink enough.

One of the keys to successful hydration is choosing the right drink. For everyday thirst, just about any beverage will do. But for instances of extreme heat and/or prolonged activity, you’ll need a beverage that is quickly absorbed (that is, one that contains less sugar than soda or juice) and contains salt and electrolytes. **Replacing the salt and fluid lost in sweat is critical for those with CF**; juice and soda don’t contain enough sodium (salt) and the high sugar content slows down the rate of absorption.

Commercial sports drinks such as Gatorade™ are convenient but can be costly. Here’s a simple recipe for a sports drink that costs just pennies and can be tailored to your tastes. Let your kids pick out the flavor packets, mix and match, or add some fruit juice (this also adds more potassium). Lemon juice is an optional ingredient and some children enthusiastically recommend it. This homemade recipe may not be the best choice if you are participating in extreme prolonged exercise such as marathons.

**Homemade Sports Drink**
Mix together and chill:
- 32 oz water
- 1/4 cup sugar
- 1/4 tsp salt
- 1/2 packet of unsweetened Koolaid™ or Wyler’s™ powder for flavoring
Optional: 1 tbsp lemon juice or 1/2 cup fruit juice. If using 1/2 cup fruit juice, reduce sugar to 3 Tbsp.
To make 20 oz: Use 2 1/2 Tbsp sugar, a generous 1/8 tsp salt and 1/4-1/3 packet of flavoring powder.

EileenPotter, MS, RD

**Comparison of Nutritional Content:**
16 oz Gatorade™: 28 gm carbohydrate, 220 mg sodium*, 60 mg potassium, 104 cals
16 oz homemade: 26 gm carbohydrate, 288 mg sodium*, 40 mg potassium**, 100 cals
* The typical American diet contains at least 4,000 mg of sodium (salt) daily. This recipe is not “high sodium” but it contains more sodium than most beverages. Individuals with CF should also choose salty foods and use the salt shaker liberally during hot weather to make up for sodium lost in sweat.
**1/2 cup fruit juice adds about 150-250 mg potassium.
Making CF stand for “Cure Found”

Healthcare Reforms Extends Coverage Options for Young Adults with CF

For the growing number of young adults with cystic fibrosis, finding affordable coverage is difficult, as many are unable to work or to work full time and cannot afford individual insurance plans.

But as national health care reform measures go into effect, young adults — including those with CF — will have less need to worry about health insurance as they venture out into the world.

Under the Affordable Care Act, young adults can remain on their parents’ insurance plans until age 26. In the past, many insurers removed adult children from their parents’ policies once they graduated or moved away from home, leaving some with no insurance at all.

According to the Kaiser Family Foundation, staying on a parent’s plan may be the best option for many young adults. The new law requires plans that offer dependent coverage to extend that coverage to adult children until they are 26 — even if they no longer live with their parents, have existing medical conditions or are not listed as dependents on their parents’ tax returns.

The new law also creates other coverage options that offer better protection than previously and could be suitable for young adults with CF who don’t have access to a family plan.