

CF Connection

Summer 2006

University of Florida Pediatric Pulmonary Center

Let's Talk About Tune-Ups!

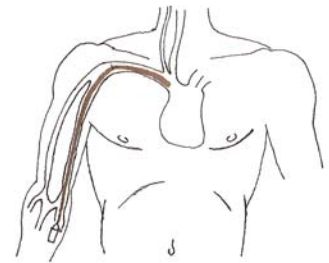
Some of you are well acquainted with the hospitalizations we call "tune-ups," while others of you have not yet had this experience. Here are some things to keep in mind about why you come in for tune-ups and how to handle the experience.

CF lung disease involves an ongoing battle against bacteria, and sometimes fungus or mycobacteria, which make you feel worse at times. You may have more cough, more mucus, change in sputum color to yellow or green, less energy, and/or less appetite. Pulmonary function tests (PFTs) will be down. Our first response is, almost always, to try to treat at home. We usually prescribe an oral antibiotic, an inhaled antibiotic, and more airway clearance. If this doesn't work, the next step is admission into the hospital to get you back to your best.

During your hospital stay, you will get IV antibiotics, airway clearance four times a day, lots of food, and plenty of rest. It takes all four to get your lungs better

and recover lost weight. Let's talk about getting this done because it is a team effort!

If you don't have a port, you will have a PICC line placed. This is a long, flexible tube that enters a vein in the arm and slides all the way up that vein, around the curve of the shoulder, and empties into a



large vessel leading to the heart. PICC lines are great because they allow you to get your medicine without having many IVs placed. They also usually last through a whole tune-up, making it easier to get medication. Blood may be drawn to check that levels of some medicines are high enough to work and not high enough to harm.

(Continued on page 2)

Inside this issue:

CF Vitamins	3
CF Fundraiser—Kickoff to a Cure	3
Check it Out! - New Resources	3
What Does a Social Worker Do?	4
Tips for Healthy Web Surfing	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! Send them to us at the address on page 6 or email to hillajb@peds.ufl.edu.

Let's Talk About Tune-Ups

(Continued from page 1)

Next is the four times a day airway clearance, and you have choices these days. If you have a favorite technique, you can continue doing that in hospital. We can also order a variety of techniques so you can try new things. You can choose from chest physiotherapy (CPT), vest, acapella or flutter, autogenic drainage, or PEP. The respiratory staff can teach you and let you try them all. This is a great idea because you might find a technique that works better than what you had been doing at home.

Food is the next important step in a tune-up. You will have double portions, snacks, and maybe nutrition shakes delivered to your room. You can also seek food elsewhere...lots of places in Gainesville deliver and the staff can help you if you want to order out. Good nutrition is important to help heal your lungs, so eat as much as you can and take your enzymes if they are prescribed.

Rest is the last critical part of a tune-up. Sleep as much as you can while you are in the hospital to help your body heal.

The hospital staff need your help to get you all the care necessary to regain your best possible health. Here's what you can do to make it all work:

- ✓ Be in the room when medicine or treatment is due.
- ✓ Get lots of rest.
- ✓ Eat as much as you can.

- ✓ Disinfect or wash your hands every time you enter or exit your room.
- ✓ Wear a mask when you leave your room or if another person with CF is visiting your room while you are there.
- ✓ Tell one of the pediatric pulmonary staff if you aren't getting the care you should:
 - ⇒ If you don't get four airway clearance therapies every day
 - ⇒ If the airway clearance isn't done well
 - ⇒ If nebulizer kits aren't changed daily
 - ⇒ If you aren't getting double portion meals and snacks
 - ⇒ If you aren't getting nutrition shakes (if you use them)
 - ⇒ If you aren't getting enzymes delivered in time for meals and snacks
 - ⇒ If you aren't getting all your IV medicines
 - ⇒ If anyone breaks sterile technique when doing your PICC meds
 - ⇒ If people aren't handwashing/disinfecting when they enter your room

When all those symptoms that caused you to come in the hospital are gone and pulmonary function tests are back to baseline or your personal best, you can go home! Tune-ups may seem scary but they really are just the best way to keep you healthy.

Cindy Capen, MS, RN



Have You Taken Your Vitamins Today?

Daily vitamins are an important part of caring for cystic fibrosis. You may have been prescribed a special vitamin developed just for people with CF, such as ADEKs® or SourceCF® Softgels. It's important to take these vitamins with food, and also with enzymes (if they are prescribed). Taking them with food helps your body absorb the fat-soluble vitamins A, D, E, and K. Here's why these vitamins are important for you:

Vitamin A is an antioxidant that helps with vision, bone and tooth formation, cell function, and immunity. Vitamin A works in the lining of the lungs to help fight infections.

Vitamin D helps keep bones and teeth strong. People with CF are at increased risk for having

bone problems, so it's important to get enough vitamin D (and calcium) everyday.

Vitamin E is an antioxidant that works in the lining of the lungs to help fight infection. It also helps keep red blood cells healthy.

Vitamin K helps keep bones healthy and also helps blood to clot.

Taking too much of some of these vitamins can cause harm, so it's important to take the vitamins that are prescribed for you. If you have questions about vitamins, talk to us at your next clinic visit or give us a call.

Jennifer Hillan, MSH, RD, LD/N

Tailgate 2006— Kickoff to a Cure

On November 4, the University of Florida will be the site of a culinary football event to benefit the CF Foundation. Guests will tailgate with foods from local restaurants and bid in live and silent auctions while watching the Gators battle Vanderbilt Commodores via TVs in Ben Hill Griffin Stadium's Touch-down Terrace.

For information, tickets, or sponsorship opportunities, contact the CF Foundation Florida Chapter at 904-733-3560 or cedwards@cff.org.

Check it Out!

- ◆ The CF Education Committee has posted several new publications on the www.cff.org website. Learn about hypertonic saline, choosing the right nebulizer, bone health, nutrition and behavior, CF-Related Diabetes, and other topics. Go to www.cff.org, click on "check this out," then "Publications & Videos," then "patient and family education."
- ◆ The CF Foundation will present "Hope for the Future: Update on CF Research" — a virtual patient education day live web cast on September 19, 2006 at 9 PM EST. To pre-register, go to the CF Foundation's Web site, www.cff.org or www.cfwebcast.org. Please use code PT459 when you pre-register.

But What Does a Social Worker *DO*?

You may have wondered why I, or one of my students, often drop by when you are in clinic. What can we offer? This is a common question. People are often unclear about a social worker's role, in part because social workers help in a wide range of ways that do not necessarily seem linked together. Overall, the social worker attempts to improve patients' and families' experiences in the healthcare setting and to enhance health outcomes. Social workers generally provide support to families and advocate for families within and outside of the healthcare system.

One way to think about a social worker's role is to consider the two parts of the word "psychosocial," which is often used to describe the work social workers do. The first part, "psych," relates to social workers' training and skills in the psychological or emotional realm. Social workers can help with concerns about:

- ◆ Adjusting to life with a chronic illness
- ◆ Family concerns or conflicts (such as loss of a job, moving, caring for an adult relative, marital conflict or conflict between parent and child)
- ◆ Relationship problems
- ◆ Grief and loss
- ◆ Depression, anxiety, or difficulty coping
- ◆ Child or teen behavior problems
- ◆ Support through stressful times
- ◆ Anger management
- ◆ Substance abuse
- ◆ Preparing for life as an adult with CF ("Transition" to adulthood)

The "social" in "psychosocial" refers to how social workers can help with "concrete" or "resource-related" issues. These include:

- ◆ Advocacy with schools (for example, writing letters or attending meetings to make sure a child's school environment meets all of his or her educational and medical needs)
- ◆ Providing information about housing or transportation
- ◆ Assistance in communicating with billing offices (for example, with Shands, Medicaid or utility companies)
- ◆ Providing referrals for legal consultation (for example, about guardianship, custody or financial problems)
- ◆ Help obtaining Family Leave or Transition Aid waivers or advocating with an employer
- ◆ Providing information about SSI, Medicaid or private insurance and assisting in problems with these agencies
- ◆ Referrals to community agencies such as vocational rehabilitation, after-school programs, food banks, shelters etc

If I can help you with any of these concerns or others, please let me know! You can call our office or talk with me next time you are in clinic.



Susan Horky, MSW

Tips for “Healthy” Web Surfing

Be a cyberskeptic - Quackery is everywhere on the Web. Anyone can put up a Web page.

- ◆ Beware of claims that one remedy will cure a variety of illnesses, that it is a “breakthrough,” promises quick, dramatic results, or that it relies on a “secret ingredient.” Does it sound too good to be true?
- ◆ Use caution if the site uses a sensational writing style (lots of exclamation points, for example.)
- ◆ Get a second opinion! Check more than one site. Is this the only site making these claims?

Consider the source - Look for recognized authorities and know who is responsible for the content.

- ◆ Look for an “about us” page. Who runs the site? Is it a branch of the federal government, a nonprofit institution, a professional organization, a health system, a commercial organization or an individual?
- ◆ Web sites should have a way to contact the group or Web master. Be careful if the page does not have any contact information, or if you cannot easily find out who runs the site.

Focus on the quality of the information - Who looks at the information before it is put on the Web page?

- ◆ Is there an editorial board? This information may be on the “about us” page.
- ◆ Are the board members experts in the area? For example, a site on CF whose medical advisory board is made up of lawyers and accountants would not be a good source of medical information.
- ◆ How is information approved? Look for “editorial policy” or “selection policy” or “review policy.”

Look for the evidence - Rely on medical research, not opinion or anonymous testimonials.

- ◆ Who wrote the information? Is the name of either an individual or an organization listed?
- ◆ If case histories or testimonials are on the Web site, look for contact information.

Check the date - Look for the latest information – is the information on the site current?

- ◆ Look for dates on documents.
- ◆ Click on a few links on the site. If there are a lot of broken links, the site may not be kept up-to-date.

Beware of bias - What is the purpose of the Web site? Who is paying for or funding the site?

- ◆ Check to see if the site is supported by public funds, donations or by commercial advertising.
- ◆ Look at the information on the page to see where it is coming from.

Protect your privacy - Health information should be confidential. Look for a link saying “Privacy” or “Privacy Policy.” Read this to see if your privacy is really being protected. For example, if the site says “We share information with companies that can provide you with useful products,” then your information is not private.

Talk to your CF Center Team - the best care decisions are those that are made together.



University of Florida Pediatric Pulmonary Center

Family Corner

Hi, my name is Robin and I'm the Parent Advisor for the Pediatric Pulmonary Division of Shands Hospital. I thought I would share some of my background with you. I am married to a great man and have 3 pretty good children, one of whom has CF. He was diagnosed at the age of 5 months; he is 18 yrs old now and that is how long we have been coming to Shands. Over the years I have picked up some "tricks of the trade" for coping and dealing with a child and now a young adult with CF and all of the stuff that goes along with it. I am eager to share advice or help you get in touch with the right people or agencies that might help in a particular situation. I am also getting together a Family Advisory Board to get ideas from parents and families on how to make it easier on the kids and young adults when they go in for hospital stays or to clinic. We all know how stressful they both can be, for us and them. I welcome any tips or advice you all could pass along for others too.



Just to add in closing, I have no degrees or formal training in this—I am just a regular mom. My training has been 18 years of raising a child and now a young man with Cystic Fibrosis, and I have learned there is no question too small or not worth asking when it comes to your child. Please call me at 352-613-2441 or you can email me at jojo424@verizon.net anytime to talk or to join our Advisory group. We will be happy to have you!

Robin Muetzel, Family Resource Partner

The Family Advisory Committee is creating a 2007 calendar called Beautiful Faces, featuring our patients and staff. You should have received a request for pictures and a consent form last month. Please send them in by October 31 to be included in the calendar, which will be mailed out at the end of the year. If you have any questions, please contact Robin at 352-613-2441.

Pediatric Pulmonary Center
University of Florida Health
Science Center
P.O. Box 100296
Gainesville, Florida 32610-0296

Phone: 352-392-4458
Toll Free: 1-888-4UF-SHANDS
Fax: 352-392-4450

Medical Staff:

Terry Spencer, MD,
Division Chief
Terence R. Flotte, MD
Sarah E. Chesrown, MD
Mary H. Wagner, MD
Pamela Schuler, MD
Daniel Torrez, MD
Thomas A. Horsman, MD
Sreekala Prabhakaran, MD
Dawn Baker, ARNP

Pharmacy:

Leslie Hendeles, PharmD

Nursing Staff:

Dawn Baker, ARNP, CPNP
Cindy Capen, MSN, RN
Margaret Humphries, RNS
Lisa Magary, RN, RRT
Rhoda Reed, SRNS

Nutritionists:

Ellen Bowser, MS, RN, RD
Jennifer Hillan, MSH, RD, LD/N

Social Worker:

Susan Horky, LCSW

Office Staff:

Brenda Martin
Tina King
Lisa Harvey
Nita Newell