Back to School Time! Tips to Bolster Your Kid’s Nutrition in the Lunchroom

By Eileen Potter, M.S., R.D., special contributor

From kindergarten through high school, children with CF are challenged to eat a healthy diet during school, with its long hours of homework and an increase in after-school activities. The following tips can help you and your child navigate some common obstacles to eating well while in school.

• **Partner with your school:** Your child spends at least six hours a day in school and eats at least one meal, plus snacks, while there. It’s vital that your school works with you to assure that your child faces no barriers to getting the nutrient-dense foods that children with CF need. You can help educate the school’s staff on CF by providing them with written handouts for teachers — available from your CF care center — and information about the benefits of an individualized education plan (IEP) and the legal protections for students under Section 504 of the Rehabilitation Act of 1973. It also doesn’t hurt to make a few special requests: that your child be given extra time to eat lunch, can easily get enzymes and has access to extra snacks.

• **Plan ahead:** It’s easy to lose focus on eating when life is busy. Running from school to piano lessons or a soccer game may lead to missing dinner. Fuel your child with a robust snack (plus fluids) before exercise, and then replace the calories burned with a healthy evening meal. End the day with a high-calorie snack, with or without a shake.

• **Keep an eye out for bathroom avoidance:** Lots of students avoid using the bathroom at school. This “withholding” behavior can cause problems for anyone with CF because it may lead to constipation, which decreases appetite and causes abdominal pain. Talk to your CF care team if you notice that your child resists the urge to have a bowel movement first thing in the morning. They may recommend a laxative at bedtime to promote good evacuation first thing in the morning.

• **Foster healthy eating habits:** A child who enjoys eating a variety of foods and gets excited about trying new foods is more likely to do well with the demands of the CF diet. Parents and caregivers promote healthy eating by serving as role models for young children. Remember: healthy nutrition isn’t just for the child with CF — it’s a family affair!
My Motivators: Looking to the Future and Remembering the Past

By Joan Finnegan Brooks, special contributor

Staying motivated to do all of our CF treatments can be an ongoing challenge. I’ve been doing aerosol treatments, taking countless pills and “getting pummeled” (à la chest PT) for as long as I can remember. Knowing that I need to complete this regimen day in and day out can seem overwhelming at times and a bit like Groundhog Day — the same daily routine over and over again.

Yet, staying motivated to do treatments is vitally important to maintaining or improving our health, no matter how severe our CF is. I find different things to motivate me and keep my willpower strong. I think about my husband of 23 years and know that if I don’t do everything in my power to stay well, he’ll remind me. We have plans for our future together. If taking my inhalation therapies helps improve my chances of being able to fulfill those plans, I’ll gladly tackle my regimen. Or I think about my nephews and how I want to be healthy enough to dance at their weddings and celebrate life’s other milestones with them.

Remembering the times that I haven’t been well or have been hospitalized is also a great motivator for me. I appreciate every breath that comes easily and every day that is busy and fulfilling. I remind myself of the time before we had any treatments for CF — those of you around my age can remember how bleak our existence was then.

It’s a privilege to even have treatments that can help us manage our CF. If I don’t do my treatments, it’s the same as if I went back in time to those dark days, and that would be crazy.

I’m also motivated by the solemn vow I made to myself many years ago: I would never look back on my life and wish I had taken better care of myself. The only way I know to fulfill that promise is to focus on my actions in the present, and do all my treatments today, tomorrow and the next day.

If you could use additional motivation to take good care of yourself, you have it now in the form of Kalydeco™ — the first drug to treat the underlying cause of CF for people with a specific mutation of the CF gene, called G551D. Kalydeco helps a relatively small group of people with CF, but not me. So why does it motivate me? Because it marks a breakthrough in the CF Foundation’s drug discovery efforts and could eventually lead to additional drugs that will help all people with CF.

When that day comes for me, I want to be healthy enough to benefit from these promising new treatments. Until it does, I will do all I can — day in and day out — to take care of my lungs and safeguard my health. No matter what motivates you to do your treatments, make sure you take a big dose of it every day!

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Meet the CF Services Pharmacy Coordinators!

A CF Services pharmacy coordinator is a partner to the CF community and your direct connection to the pharmacy management team. The pharmacy coordinators work closely with CF care center and CF Foundation chapter staff to assist with pharmacy questions and provide up-to-date information about CF Services.

Pharmacy coordinators provide assistance with transferring your prescriptions, using our auto refill service, getting insurance verification, coverage and reimbursement, and any other questions you have about our services.

You can fill out the online contact form for the coordinator who serves your local area on the CF Services website at www.CFServicesPharmacy.com/ContactUs/rpc. You can also call 1-800-541-4959 and enter the extension for the coordinator for your state.
Understand Your Financial Assistance Options for the Out-of-Pocket Costs of Prescription Drugs

By Maria Thomas, Director, Patient Access Programs, CF Patient Assistance Foundation

As insurers more and more aggressively seek to reduce their expenses, people with CF are shouldering more and more of the costs associated with their prescription drugs. Fortunately, there are programs that can assist with your out-of-pocket costs. But it can be confusing to understand how the various assistance programs work and determine if you qualify for the existing programs.

The Q&A below can help you gain a better understanding of the difference between co-pay cards, co-pay patient assistance foundations and patient assistance programs.

Q: What is the difference between prescription co-pay card programs, co-pay patient assistance foundations and patient assistance programs?

A: All of these programs will reduce your out-of-pocket costs for prescription drugs. However, each type of program has specific guidelines and benefits.

For example, prescription co-pay card programs are usually sponsored by drug manufacturers and are typically available for people with commercial health insurance only. Co-pay assistance foundations, on the other hand, provide help with out-of-pocket costs for both commercially and publicly insured patients. These programs often have eligibility requirements based on household income.

In contrast to the other two programs, patient assistance programs are usually intended for people who do not have health insurance. Patient assistance programs also typically have eligibility requirements based on household income.

Q: If I enroll in a co-pay card program, can I also enroll in a co-pay assistance foundation for help with additional out-of-pocket costs?

A: You may be eligible for assistance from both a co-pay card program and a co-pay assistance foundation. Check with the specific co-pay assistance foundation to determine whether or not you would be eligible.

Q: Are co-pay card programs only for people with low incomes?

A: Most co-pay card programs do not have an income requirement. Once you are enrolled, the co-pay program will pay some or all of the out-of-pocket cost after your insurance has paid its portion. Please note that some co-pay card programs require patients to pay a small amount for each refill. Each program is different, so you need to check with the program to make sure you understand how it works.

Q: Can I enroll in a co-pay foundation if I am covered by Medicaid or Medicare?

A: Actually, most co-pay foundations do provide assistance for people covered by Medicaid or Medicare. You will want to check with each foundation to see if you meet their program requirements.

Q: Do all co-pay programs and patient assistance programs follow the same enrollment process?

A: Each program has its own enrollment process requirements. Please consult with each program to determine how you can enroll and receive assistance.

Q: Is it true that some co-pay foundations will not provide assistance to people who live in Massachusetts?

A: Actually, most co-pay foundations do provide assistance to people who live in Massachusetts. However, check with each foundation to see if you meet their program requirements.

Q: Do all pharmacies automatically enroll their customers in available co-pay programs and patient assistance programs?

A: No; however, some specialty pharmacies ensure that their customers are educated about and receive the information required to enroll in applicable co-pay card programs, co-pay foundations and patient assistance programs. Please check with your pharmacy to determine if it provides this service.

Q: Do I only need to enroll once in a co-pay card program or patient assistance program?

A: Most programs enroll customers for a 12-month period, after which you must apply again for re-enrollment. Please check with each program to determine the terms of enrollment and requirements for re-enrollment.

We hope this helps you better understand the difference between co-pay cards, co-pay patient assistance foundations and patient assistance programs. If you have questions about specific therapies for which you need financial assistance, please contact the CF Patient Assistance Foundation at 1-888-315-4154 or visit www.cfpaf.org. You may also call your dispensing pharmacy for assistance.
How CF Has Changed My Life for the Better

By Matthew Weiner, teen with CF, special contributor

In the last edition of *HomeLine* I said that I am proud to have CF. Now, perhaps I went out on a limb when I said that, but I am. I love it like I love myself, because CF is a part of me — a part of who I am — and no one should ever dislike a part of themselves.

Do I enjoy taking dozens of pills or doing hours of breathing treatments every day? Of course not. CF treatments are mind-numbingly tedious and time-consuming. But, what I do like is that I view the world through a CF lens.

CF has helped me to become a person who looks toward the future while still living in and enjoying the present. As a person with CF, I have to think about how my present actions will impact my future health: “If I forget to take enzymes at dinner, how will I feel in a few hours?” “If I don’t do my nebs, what will happen to my PFTs?”

My physical need to think ahead has also affected my personality. Now, I not only put a lot of brainpower into thinking before I act, but before I speak as well. I also treasure good times, good health, my family and relationships — perhaps more than others my age.

CF has also helped me to be more in-tune with my body because I have trained myself to pay closer attention to how I feel. I didn’t realize this was unusual until a few weeks ago, when I told a friend I thought that I was getting a cold because air wasn’t going all the way into my lungs. My friend, who does not have CF, had no idea what I was talking about. I found this strange because the feeling of being able to breathe deeply is one I know well and really enjoy. I suppose this sensation is something that most people don’t have to think about, so they don’t.

I’m not only conscious of my health, but also optimistic, and I’m always striving to improve myself. For example, I love rowing; and I think that the reason that I enjoy it so much is because I can see myself getting stronger and faster as I row. It is also nice to know that I can succeed at sports while having a lung disability. Some view optimism as a person saying, “It could be worse.” But I think real optimism is asking, “How can I make this situation better?” I like to think that I do the latter.

CF has also spurred me to be a fierce competitor. This extends beyond rowing. Whenever I go in for pulmonary function tests (PFTs), I always try to improve over the previous time. Whenever I hear that my new PFT score is better than the average for healthy individuals, I am proud that my hard work has paid off. I feel like I am proving all of the insensitive people wrong who frightened my parents when I was diagnosed with CF. In a way, I am competing against CF itself.

CF has shaped me in every way. It has made me an optimist, a competitor and a thoughtful, considerate and kind person. It is an important part of my identity and that’s why I am proud to have cystic fibrosis.

Check Out New Resources on the Foundation’s Website!

The CF Foundation has recently added and updated information at www.cff.org about CF genetics, CF infant care, CF-related diabetes (CFRD), lung transplantation and more. Take a look at what’s new:

- **CF Genetics** – This new section provides an overview of the basics of CF genetics and FAQs on CF carrier testing and CFTR-related metabolic syndrome (CRMS). Three new webcasts cover CF genetic counseling and the new CFTR2 database with information on CF mutations.

- **CF Infant Care: First Year of Life** The first of the *Pathways to Lifelong Health* video series features parents of children with CF who share their personal experiences of caring for their baby. Watch these videos online or ask your CF care center for the DVD.

- **CF-Related Diabetes (CFRD)** – Four webcasts are available to help you learn about CFRD screening, diagnosis and treatment. Hear from an adult with CF about how he balances a busy life with managing CFRD.

- **Lung Transplantation** The FAQs on the basics of lung transplantation have been updated. Watch the webcasts to learn more from an adult with CF who had a transplant.

- **MRSA, NTM and ABPA** More and more people with CF have the bacteria methicillin-resistant *Staphylococcus aureus* (MRSA), nontuberculosis mycobacteria (NTM) and allergic bronchopulmonary aspergillosis (ABPA). Watch recent webcasts to learn more from experts on how these might be treated.

- **Bone Health and Vitamin D** – This information has been updated based on the new vitamin D care guidelines and covers bone disease in CF and different ways that it can be prevented with nutrition and exercise.