

Open Letter, From One CF Parent to Another

If you are reading this, you are probably in the midst of discussions regarding your child's weight. I feel for you. I've been there. Supplements are an excellent start, and sometimes supplements are all your child needs to keep his or her weight up. In any event, we, as parents, need to embrace this: there is a direct correlation between body mass index in young children with CF and lung function in later life.

So, with that data firmly in mind, what should you do if supplements are not enough? I can't answer that for you, and neither can your pulmonologist. But I can share my experiences with you.

First, I'd like to tell you about our oldest child with CF. We lived on the west coast when she was little. The doctors treating our daughter at the time did not initially offer us the option of a feeding tube. Instead, we tried supplement after supplement with limited success. We also tried every form of bribery, cajoling, and manipulation we could think of to get our daughter to eat. Every meal became a battle, and every CF visit a failure. Finally, when she was about six, the doctors suggested a feeding tube. It was the first time we had heard of that option, and we were not on board. Ultimately, we decided not to have a g-tube placed. Was it a good decision? I really don't know. She's a young adult now and heading off to college next fall. Her lung function is decent, but not stellar. She had trouble growing during her formative years, and finally topped out at 4'10". Overall, she is happy and doing well, but there are some days when I wonder if we made the best decision on her behalf.

My son is a different story. When he was three months old, his doctors told us he needed a feeding tube. We agreed. That was a hard decision, but it was the right decision. The surgery went off without a hitch, and the feeding tube allowed us to get my son the extra nutrition he needed without the drama that often accompanies meal times. Today, nearly a dozen years later, he is a happy, healthy boy. We removed his feeding tube when he was about 2 ½ - he just didn't need it anymore. He has some scars along his abdomen, and he loves telling a story about how that's where the shark bit him while he was surfing off the California coast.

If I could go back in time, I would give myself this piece of advice: be open to considering options that are best for your child **long term**. Because that's what we want for our kids: a long term. I have three children with CF, and I want to support their dreams. I want to applaud my son as he walks across the stage to pick up his diploma. And I want to help my daughters on their wedding days. And the hard truth is, if I want them to have the best shot at those dreams, I need to make wise choices today. Some of those choices are obvious. Make sure junior takes his medicine. Be diligent about keeping the neb equipment clean. Some choices are not so obvious.

We're a tough breed. We've weathered a hard diagnosis. We battle with insurance companies. We manage well-meaning but often ill-informed friends and family members. We are experts on getting medicines into uncooperative little ones. We multi-task like nobody's business. And we spend many, many sleepless nights worrying about our children. But we need to be more than tough. We need to be wise.

I wish you and your child the very best.