Wise Advice  
from Others on Coping with a Chronic Illness  
Kamala London, PhD, Mom to 5 Year Old with EE

When my son was diagnosed with EE at age 14 months, my journey of learning about and coping with EE began. First, I will mention that, at times, I have really struggled with my son’s health issues (such as failure to thrive, multiple food trial failures, eventual formula-only diet, repeated failed biopsies). People react very differently when confronted with adversity. Some people immediately stand up to the challenge, ready to fight. For all of us, though, learning that your child may have chronic health issues requires adjustment to a way of life you weren’t expecting. Each new milestone (e.g., birthday parties, starting preschool with shared food) required me to yet again face the challenges and sometimes pain of dealing with EE. Fortunately for us, my son (now age 5) is doing wonderfully with his current treatment, and I think I’ve also begun to cope much better with the disorder.

I have had a sizable number of people, sometimes strangers, make insensitive (and let’s just say “unhelpful”) comments along the way (e.g., “Wow, your 2-year-old is the size of my 6-month-old;” “Isn’t your 3-year-old a little too old for a bottle” and so on). However a few people have given me advice that has helped me cope with the challenges of having a child with an EGID. I am writing this column because I’d like to share some of it with you.

1. **Things will get better.**  
During the walk for Eos Disorders at the 2007 Salt Lake City APFED conference, I was asking one of the APFED officers how her son handled going to school and eating only one food. She told me she has asked her son that question, and he said he is too busy talking to be bothered by it. She also told me “Things will get better.” (The way things had been going for us, I really didn’t believe her. But they have!)

2. **Let your son decide on when you should be stressed and worried.**  
Also in 2007, I was talking to a 21 year old with Maple Syrup Urine Disorder (a genetic disorder somewhat similar to PKU, where her body cannot metabolize protein, who was reliant mostly on a formula for nutrition). I expressed to her how upset and worried I constantly was over my son and whether he will be able to eat food some day. I was impressed with how mature this young woman was- she reminded me that it was my son, and not me, who had EE and that he seemed to be quite happy and fine at this time with not eating. “Let your son tell you when you should be worried,” she told me. What an epiphany!
3. **Your son is growing up. You’re missing it.**  
   My son had just turned 2 and was doing so many new things! At some point my mom pointed out to me that I’d become so obsessed with trying to get calories into him and worrying about his future with food that I had stopped enjoying him and watching what a wonderful little guy he was. These years were going to go by, with or without EE. I realized this is it - I need to enjoy our time in the present!

4. **I love my son for exactly who he is and I don’t want to change him.**  
   I had coffee with a father of a boy who had a very rare genetic disorder that resulted in a variety of cognitive and physical difficulties for his son. He told me he loved his son for exactly who he was and to wish his disorder away would be wishing that his son was a different person.

5. **My goal as a parent is to help my child grow to be best he can possibly be.**  
   My good friend and neighbor’s 6-year-old son has autism and is non-verbal. A couple years ago, I called her asking her how she copes – she told me she keeps a note in one of her bedroom drawers to pull out as a reminder: My goal as a mom is to help my child be the best he can be. That’s really the bottom line, isn’t it?

   From my perspective, I can definitely say that dealing with EE has made us tougher and has taught us to appreciate life and health more. The comments I have shared in this column have genuinely affected me and have helped me cope. I hope you find them useful too.

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Address: P.O. Box 29545, Atlanta, GA 30359 • Phone: 713 493.7749 • Email: mail@apfed.org • Website: www.apfed.org