



# Complex Child E-Magazine

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## Mismanagement of Care Leads to Heartache by Shannon Gonsalves

In many of life's experiences, the saying "Hindsight is 20:20" is very true. However, you don't expect this to be true when it comes to the health care system or in the management of your child's care. Every day, parents place their trust in doctors, believing in their education and years of experience. When undertreatment of a sick child occurs, it can be as dangerous as overtreating a healthy child.

### **Red Flags That Were Missed or Ignored by Doctors Over and Over**

Our son Caleb was born premature. Although he came home from the NICU (Neonatal Intensive Care Unit) eating on his own and appearing to be a typical healthy baby, there were clues that this wasn't the case. Slowly but surely, those differences became more and more obvious. He didn't have the strength or coordination to nurse, so I pumped breast milk into bottles for him. Even so, he would choke and vomit when fed from a bottle. When he managed to finish a bottle, he would spontaneously vomit that meal about half the time. What stayed down was a tiny amount and a much smaller volume than he should have been consuming. Our son cried in pain for hours on end, but nobody called it a symptom. Instead, it was merely colic.

When Caleb was six months old, our pediatrician sent us to the ER. Caleb wouldn't eat or drink at all and was consistently losing weight. We had been forcing meals on him by dribbling milk from syringes in his cheek every five to ten minutes all day long, which worked to barely maintain hydration until he learned that he could just spit it out. After being tentatively diagnosed with GERD (Gastroesophageal Reflux Disease) and esophagitis, we were sent home with a prescription for Prevacid, a referral to the GI clinic, and directions to continue forcing nutrition with syringes until the medication gave him enough relief to begin eating again on his own.

Little did we know that it would take many weeks for relief to begin.

In the meantime, his doctor ordered an upper GI test. This showed massive reflux immediately upon swallowing, which put him into distress on the table. Testing was ended, and we were again to hope that this magic medication would eventually do the trick. A feeding tube was discussed as a possibility, because at this point he had gone from the tenth percentile in weight down to the third percentile. But Caleb continued to just scrape by, barely meeting the doctor's requirements at each appointment to avoid an

NG tube, a feeding tube through the nose. The ongoing fight to feed him and watch him lose weight continued on until he was 17 months old.

At this point, he was in negative percentiles for weight, losing percentiles in height and testing as developmentally delayed. We agreed to the NG tube. We felt like the biggest failures at parenting, because we were repeatedly told that other than reflux, he was a typical baby.

### **Reality Check**

During his inpatient stay to receive training for the NG tube, we were finally assigned a dietician. She was the best part of our GI experience and worked mostly with patients who were very thin. The GI was never overly concerned about Caleb's thin appearance and often shrugged us off, despite Caleb being at the 97<sup>th</sup> percentile in height but negative percentiles in weight at this point.

Following the GI's lead, we were questioning if Caleb really needed this tube. The dietician kindly told us that she mostly cares for thin children and Caleb was one of the thinner kids she'd worked with. In that moment, you feel such a strong sense of guilt for not realizing things were this bad. Later, you begin to feel angry at the GI doctor who you placed all your trust in. She was the one who followed his weight and height and refused to look for what we felt was missing.

Throughout all of this, we kept going back to the GI who blew us off time and time again and made us feel like we shouldn't be worried as long as he was on the GERD medication. We were told that many kids vomit daily and no further testing was needed. It was normal for kids to choke on a regular basis after eating or drinking. We believed her when we were told that many kids get constipated to his level and it was not a big deal. His speech would catch up just fine and boys were often like this with language development.

No referral or recommendation was made for helping us figure out how to help him eat until we asked how the NG by itself was going to get him eating again. This prompted a referral for a feeding evaluation and we self-referred him for a speech evaluation at the same time, despite her belief that it was just a "boy" thing. Even with the NG tube, his weight wasn't staying steady and often dropped.

After eight months of NG feeds and no progress on feeding or managing his symptoms, we opted for a surgically placed feeding tube in his stomach (Gastrostomy or G-tube) that his feeding specialist recommended. After his G-tube surgery, his GERD flared up to the point that he was miserable. He ended up back in the hospital two weeks later for pain management of some complications of his G-tube site.

During this stay, the surgeon noted the increase in reflux and changed his medications. His GI doctor was very upset that the surgeon had altered the medications and reduced

them back down again without consulting her. We went in circles between the surgeon and the GI until our surgeon, who was the head of surgery, called the GI at home to set things straight. At our last appointment with her, she was very snippy with us and asked, “What are you doing here?”

We felt like incompetent parents who were overly concerned for their child and we almost gave up.

### **Children Are the Casualties of a Broken System**

After researching his symptoms and learning about motility issues on Parent-2-Parent, an online support site for parents, we went back to our GI to question motility testing. After being shrugged off, we left and finally realized that we needed a second opinion. However, in our hospital, kids cannot go see another GI doctor without both doctors--current and new--giving their permission. This is not an uncommon practice.

To make it even more difficult on parents, our hospital has the only pediatric GI specialists within five hours of our city and is considered the best in our state. They held all the power in our child’s medical care, and we were trapped by their system. Despite the system, we finally realized that it was well past the time when we should have been pushing back.

We became the squeaky wheel.

### **A New Beginning and Hope**

We began to feel some hope. After a battle with the clinic, we finally had permission to see a new GI specialist. Caleb’s old pediatrician was moving away, so we started out with a new pediatrician who was instrumental in arranging some key tests. Caleb had a Gastric Emptying Scan, a Swallow Study and a pH probe, which gave us an even greater understanding into our son’s symptoms.

We learned more in a few months with our new doctors than we had learned in almost three years with our previous GI. For the first time, we were trying to figure out why he vomited so much and why he ended up with aspiration pneumonia repeatedly. Finally, we had hope that we wouldn’t have to live in a hospital every other month.

Over the next few months, changes were made in his care that made a huge impact on his quality of life. We learned a lot about our son that had been missed by his first GI doctor after two and a half years of mismanaged care. Better control of his constipation cut back on some of his pain, vomiting and reflux symptoms, which in turn caused him to begin eating some. Thickening his liquids to protect his airway further reduced his choking and vomiting. Finally, a more elemental formula, Peptamen Jr., cut out almost all of his obvious daily refluxing and more of the vomiting. Sensory Integration therapy and

feeding aversion therapy taught us how to help Caleb at home begin to experience foods in a more positive way.

It was amazing to watch a child we were told was “normal” evolve into a more content, happy, typical little boy. Yes, he still had medical issues, but they felt more manageable. After having five hospital stays in eight months, Caleb went a year before he was admitted into a hospital again.

### **Trust Your Instincts and Squeak if Needed**

Hindsight is 20:20, and we can't go back and fix the obvious mistakes in our son's health care. On an intellectual level, I know that we made the best choices we could with the inaccurate information that we were given. On an emotional level, I feel a tremendous amount of guilt for not trusting our gut instincts and challenging the system earlier.

Over and over, I expressed concern that we were missing something. Over and over, what we were being told just didn't make sense or seem right. In hindsight, I wonder what would have happened if the GI would have listened and made very simple changes. I often wonder if Caleb would have ended up with a feeding tube at all if he had the same tests at six months old that he finally had at three years old.

Hindsight won't help us, but our hope and prayer is that our experience will help others. It is imperative to trust your gut and advocate for your children sooner and not worry about whose toes you are stepping on. You are your child's best advocate!

Don't be afraid to be the squeaky wheel and make demands. I have learned that ignoring my intuitions could be at the peril of my child.