

## **My child cannot eat: Joshua's story**

### **What is a feeding disorder?**

The CNN video ([http://www.kennedykrieger.org/video/cnn\\_feeding.wmv](http://www.kennedykrieger.org/video/cnn_feeding.wmv))

explains feeding disorders and treatments at Johns Hopkins' Kennedy Krieger Institute's behavioral feeding clinic in Baltimore, Maryland.

### **First clues**

My son Joshua was born weighing 7 pounds and measuring 21 inches. My pregnancy was normal and Joshua seemed healthy. He did not have problems breastfeeding or transitioning to a bottle at seven months of age. He did not have acid reflux. I had no reason to think he might not be able to eat. I had never heard of a feeding disorder that prevents a child from eating and neither had my family or friends.

When Joshua was four months old, I started offering him baby food. First I tried rice cereal. He refused it, turning his head away every time I offered it. I tried cereal again a few weeks later, same story. Then I tried sweet potatoes, bananas, and other fruits and vegetables. Initially, he would try the food, but then he would gag on it and throw up. At eight months, he still gagged and threw up on baby food. I asked Joshua's pediatrician about his food refusal, gagging, and throwing up. He said to give it some time and emphasized that not all children develop at the same pace. He recommended offering baby food about once a day and warned me to never force Joshua to eat. He stressed that eating should be a pleasant, not stressful experience for Joshua, which turned out to be really good advice.

With hindsight, there were some clues of Joshua's feeding disorder and sensory problems. Joshua never mouthed toys like most children do. I could have put quarters and nails on the floor and he would have never considered putting them in his mouth. Being a new mom, I did not realize how normal mouthing toys was for babies and how important it was for their oral motor and sensory development. Joshua also had difficulty drinking from a sippy cup. He coughed after almost every sip. Brushing Joshua's teeth was very challenging because he did not like the feeling of a toothbrush. Joshua did not want anything in his mouth. He also hated getting messy. When I applied sunscreen, he screamed and cried profusely.

At ten months old, Joshua was eating some Gerber #1 baby food (bananas and sweet potatoes). At one year, he was eating some Gerber #2 baby food (fruits and vegetables), prepared Gerber baby cereal, and Yo-baby whole milk yogurt. I frequently used the yogurt to mask baby food flavors and textures. During this period, he gagged or vomited while eating several times a week. It was really stressful because I did not know why he had problems eating. What triggered it? Was it because he did not want to eat? Was it because he could not eat? Joshua's father and I frequently offered the food on our plates to him, but he always refused. Just before he turned one year old, I remember putting a small piece of a banana in the palm of his hand and he started gagging. From that moment on, I knew something was wrong.

### **Our first referral: ECI**

We moved to the Dallas/Fort Worth area from West Texas just before Joshua's one year wellness check up. Looking back that was the luckiest new job offer we could have ever gotten. The resources in Dallas/Fort Worth for pediatric issues are vastly superior. At Joshua's one year wellness check up, his new doctor was concerned about the composition of his diet and his inability to eat. He called it a "texture aversion" and referred Joshua to Early Childhood Intervention (ECI) ([www.dars.state.tx.us/ecis/index.shtml](http://www.dars.state.tx.us/ecis/index.shtml)). ECI is a Texas program, funded by the federal government to help children from birth to three years old with developmental delays. I remember being so happy that there was help for whatever condition Joshua was suffering from.

We had to wait three months before meeting ECI's service coordinator and occupational therapist (OTR). It was a long three months watching Joshua struggle with food. ECI conducted an evaluation and confirmed that Joshua had an oral texture aversion. He was also orally defensive and tactile discriminate. In laymen's terms that means he did not like texture in his mouth and he refused to touch many things with his hands. Oral texture aversion, oral defensiveness, and tactile discrimination are part of the grouping called a sensory processing disorder. I also learned from the OTR's evaluation that Joshua's big cheeks were not naturally cute and chubby like I thought, but rather the result of being undertoned. Since he did not use his mouth to chew, the muscles had not developed. A speech delay was also likely and he was at risk of his remaining baby teeth not coming in. Furthermore, his limited diet posed a risk to his growth.

When Joshua was fifteen months old, the ECI OTR started coming to our house every other week to work with him. I quickly discovered that the therapist's job was to train me to conduct the therapy. The goal was to desensitize Joshua's mouth and hands. Her exercises were fairly odd. For instance, one day she brought a large container filled with a mix of pinto beans and toys. Joshua did not take the toys out of the container; instead he ran away. Eventually, I had my own containers of dry beans and rice, for him to practice touching different textures. The OTR also brought funny looking brushes to stroke Joshua's tongue and the inside of his cheeks. Joshua wanted nothing to do with it. Soon, when the OTR came to our house with her "interesting toys," he wanted nothing to do with her. I asked ECI what other resources they had to address the behavior issues Joshua was exhibiting. An ECI child psychologist came to see us. The psychologist was not familiar with Joshua's condition. He also advised that we make meal time a pleasant experience and never force Joshua to eat.

After three months of ECI's home based therapy, I knew we needed to try something else. At Joshua's 18- month wellness check up, I told his doctor that he had not made any progress in terms of eating. I liked the OTR, but Joshua was not responding to her. I thought we might be more successful on neutral turf (not at home). The pediatrician was also concerned about Joshua's delay in speech (he could only say five words). He referred us to Cook Children's Hospital ([www.cookchildrens.org](http://www.cookchildrens.org)) for an occupational and speech therapy evaluation. Due to his feeding problems, Joshua was on the most critical list. Still, we waited for two months to get an appointment. In the meantime, I

started sending Joshua to a two day a week Parent's Day Out program (PDO). Our ECI service coordinator thought it would be great way for Joshua to see other children eat. We hoped that peer pressure would help Joshua overcome his food aversion. The PDO program helped. The first couple of weeks Joshua stayed away from the snacks (crackers, cookies, etc.) offered. Then, he started holding the snacks in his hand, a big step forward.

### **Learning about eating from friends**

Joshua's friends, their mothers, and his teachers played a key role in helping him overcome his feeding disorder. The first food Joshua put in his mouth was a sugar cookie. One day Joshua's best buddy was having a grand time eating red heart-shaped sugar cookies and Joshua thought he better try one, too. Almost all of our friends and family became "therapists" when they visited. Some played with rice or beans, others licked sugar off cookies, ate crumbs by the spoonful, put colored sugar on their cereal, showed Joshua how to chew with their mouths open, etc. I remember the day I had a group of Joshua's friends over for finger painting and playing with cool whip. My friends asked me if I was crazy to invite a bunch of children to cause a big mess in our house. I thought that desperation sometimes looks like craziness.

### **Our second referral: Cook Children's**

Joshua was 20 months old when Cook Children's evaluation confirmed his oral texture aversion, oral defensiveness, and tactile discrimination diagnoses. They recommended occupational therapy twice a week, instead of ECI's once every other week schedule.

The new OTR's own son had had a severe sensory processing disorder. She was great to talk to because she gave me hope. She knew what it was like to be a parent of a child struggling with these issues. She promised me that in the worst case scenario Joshua would be able to tell us at some point what the problem was and overcome it cognitively. She told me that we were lucky because often children with sensory issues suffer from autism or Down syndrome. Still, she indicated that training the sensory system would take a long time.

Joshua liked the occupational therapy gym at Cook Children's. In addition to the sensory games with rice, beans, and other things, the gym had slides, swings, and lots of balls. He was more accepting of sensory games and other therapy strategies there than he ever was with ECI's home based approach.

### **Gaining perspective**

Pediatric rehabilitation clinics treat many kids with serious medical problems. After our first therapy appointment, I was overcome with emotion. The twice a week visits removed any denials I harbored about my child's challenges. More importantly, they led me to recognize and appreciate everything that Joshua had going for him. Compared to the other children's issues that prevented them from playing, walking, and interacting with others, Joshua's inability to eat appeared to be a much smaller problem. Joshua's issues did not prevent him from having fun, showing love, or enjoying his life.

The waiting room is its own therapy group for parents. Your child may have different issues, but you can relate. Having witnessed some of their struggles, I have tremendous respect and admiration for the parents of children with severe developmental challenges.

### **Too much coughing**

When Joshua was 22 months old, I expressed my concern to the OTR about his constant coughing after drinking. I told her that switching him from a bottle to sippy cup at 15 months had been extremely difficult. The OTR asked if Joshua had ever undergone a radiology study called the modified barium swallow. She asked me to estimate how much coughing he was doing over a four day period. My home study indicated that he was coughing 70% of the time after taking a sip. The results worried the OTR. She thought Joshua might have a physical problem, too. The OTR gave my results to a speech therapist who recommended a modified barium swallow study. The earliest appointment we could get was in two months. In the meantime, the OTR recommended that I stop introducing new foods to Joshua. She also limited her oral therapy efforts and concentrated on helping Joshua overcome his tactile issues (i.e. messy hand aversion).

### **The first modified barium swallow study**

A modified barium swallow study is very interesting to watch. It is conducted in a radiology suite with video fluoroscopy. It is a video X-ray of the patient eating or drinking. Joshua's study indicated that he was aspirating on thin liquids. Furthermore, Joshua had likely experienced or was experiencing pain and discomfort while trying to

eat and drink. No wonder he was so scared of food. He had to eat, but doing so involved pain, fear, and anxiety.

The speech therapist prescribed Joshua drink only nectar consistency liquids. Thin liquids put him at an increased risk of respiratory disease. She recommended a product called Thick-it ([www.thickitretail.com](http://www.thickitretail.com)) to increase the thickness of his liquids. I immediately included Thick-it in Joshua's drinks. He refused them. Then, I tried gently scaling up the Thick-it to the prescribed amount. He still refused them. In fact, Joshua started drinking his bath water because he preferred it over Thick-it drinks. I talked to his therapist and pediatrician about his refusal of Thick-it. They said to keep trying and could not advise me any further. Eventually, his father and I decided to abandon the Thick-it effort. We decided that Joshua had enough difficulty with food and that Thick-it was only causing more anguish. Many months later Joshua almost entirely stopped coughing after drinking.

### **Gray teeth from baby cereal**

A two year old can eat a lot of baby food. In addition to 8-10 containers of Gerber #2 baby food a day (4 fruits, 2 veggies, 2 meats), Joshua ate two large bowls of baby cereal. Baby cereal is fortified with iron. Because he ate so much of it, his teeth turned gray. We had to make frequent visits to the pediatric dentist to take the iron stains off. Neither Joshua's pediatrician, nor his pediatric dentist, nor his therapists had ever seen a child's teeth turn gray from baby cereal. I checked everywhere in the Dallas/Fort Worth area for non-iron fortified baby cereal. I even called the Gerber Company. Non-iron fortified

baby cereal does not exist in the U.S. because children are more likely to suffer from the opposite problem, iron insufficiency.

### **Two years old and still not eating**

Joshua had been in therapy for months but there was still no change in his diet. His progress was limited to his increased willingness to touch things with his hands. The good news from the doctor was that Joshua was still tracking along his growth curve. At two years of age, it is common for children like Joshua to fall into the “fail to thrive” category. The doctor said that Joshua may be five or six years old before there was appreciable change in what he was able to eat. I thought three or four years was much too long to wait so I asked him about the few behavioral feeding clinics I had read about on the internet. Joshua’s pediatrician referred us to Baylor’s Our Children’s House (Baylor OCH), ([www.baylorhealth.com](http://www.baylorhealth.com)). Baylor OCH is a children’s rehabilitation hospital and has the only behavioral feeding clinic in Texas. There are only ten behavioral feeding clinics in the United States. The earliest appointment we could get for an evaluation was in five months. We continued occupational and speech therapy at Cook Children’s and waited.

### **New therapists at Cook Children’s**

While we waited for Baylor OCH, our Cook Children’s therapists were transferred and we got new therapists. I was happy with the initial ones, but the new ones were even better. They were more aggressive and really likeable. I found it easier to communicate with them and I better understood my role in the process. We added one appointment a

week dedicated to feeding which was tremendously helpful. Our new speech therapist taught Joshua how to chew. It started with having him touch food with his tongue. Then she taught him to put food in his mouth and spit it right back out. Then, he learned to use his teeth to make crunching noises. Eventually, he took a bite and then spit it out. All of this sounds easy unless the child is terrified of putting food in his mouth. The new OTR connected much better with Joshua. He was more engaged in the therapy and looked forward to seeing her every week.

### **Things that worked for Joshua**

According to the Cook Children's speech therapist, there are many ways to address a feeding disorder. She said that you must figure out what works for the individual child. Three things that really helped Joshua were: honey, TV time with the toothbrush, and Gerber biter biscuits in his stroller. The day Joshua figured out how much he liked honey was a big day. His OTR told me to "ride the wave" on honey and put honey on everything. I put honey on cheese, meat, fruit, carrots, green beans, bread, crackers, cookies, and many other foods. Joshua only licked the honey off and that was fine. It was an important first step. Honey made food and all of those therapy brushes acceptable. In the morning, I gave Joshua his toothbrush and turned on his favorite television show, Nick Jr.'s Backyardigans. He happily chewed on his toothbrush while watching TV. A half hour of playing with a toothbrush in his mouth was a lot of therapy time. The toothbrush gave him something safe to practice chewing (he chewed nothing else) and stimulated his mouth. TV distracted him from the feeling of the toothbrush. Joshua was similarly distracted in his stroller. I gave him Gerber biter biscuits on our

family walks. He would never spend a half hour mouthing a cookie, but in a stroller on a long walk, there was nothing else for him to do. His initial approach was to suck on the biscuit. Then he started using his teeth to put pressure on it, just holding it with his teeth. Week by week, he got better at mouthing biter biscuits. Though he did not take a single bite, one day he finally consumed a biter biscuit.

### **Joshua's first table food**

Joshua was 29 months old when he finally learned to chew. Frito-Lay's Natural Cheetos White Cheddar Puffs was his breakthrough food. He had spent months licking Cheetos before he took that first bite. At first he could not eat more than a bite or two. But every day he got a little better and more confident. After a few weeks, he expanded his chewing skills into graham crackers, goldfish, and sugar cookies. It was so exciting. Joshua's PDO teachers were excited, too. They told me that he seemed so much happier at school, especially during snack time. His Dad and I breathed a heavy sigh of relief. We knew he still had a long way to go, but now he could eat crunchy food and pureed food without gagging or throwing up.

Three weeks before our admission to Baylor OCH, we went to Germany to visit my husband's family. Joshua completely refused German baby food. For several days, he only ate milk, orange juice, graham crackers, and cookies. After a week, he tried toasted bread with honey and liked it. His grandparents patiently sat with him as it took almost two hours for him to eat two pieces of toast each morning. From a nutritional point of view adding bread did not improve his diet, but it was progress in terms of chewing and

texture. When we returned home, he ate baby food again, but I replaced baby cereal with bread.

Feeding and sensory disorders are easily misunderstood. When our family and friends saw Joshua eating graham crackers, they thought the problem was solved. It was great that Joshua could chew and swallow graham crackers, but he was far away from being able to manage multiple textures. Every time Joshua took a bite he had to manage his oral hypersensitivity. Joshua's experience was likely similar to how people feel when they are tickled. It feels fine at first, but after awhile it starts to hurt. Moreover, he was terrified of food. Our experience in Germany showed that Joshua was willing to go hungry for a long time before trying anything new.

### **Baylor OCH feeding evaluation**

During Joshua's feeding evaluation at Baylor OCH, I was interviewed by six different pediatric specialists (two behavioral psychologists, two nutritionists, a speech pathologist, and an occupation therapist). They tried to understand how Joshua developed his feeding disorder and how difficult he would be to work with. I immediately got the feeling that they understood Joshua's condition and knew exactly what to. After the almost 4 hour evaluation, they recommended that Joshua participate in their intensive day program for four weeks. The day program is Monday through Friday, from 8 a.m. to 5p.m., and comprises six appointments a day.

## **Baylor Our Children's House feeding disorder program**

Baylor OCH called the week before his admission and asked me to keep a three day food diary for Joshua. They also inquired about his favorite foods, toys, and TV shows. They told me that our insurance company authorized the treatment. That was good news because the bill for his evaluation was \$1,800.

After struggling for awhile, it is a special feeling when you are finally with the right people to help you. From the first day in Baylor OCH's feeding program, I knew we were in good hands. It was obvious that the therapists and psychologists had a strategy, worked very closely as a team, and had lots of experience. They knew exactly how to handle Joshua. They were gentle, yet firm with him. Despite all of the things that that made Joshua uncomfortable, he appeared to feel safe with them.

Joshua was one of seven patients in the feeding program. Baylor OCH serves seven to eight feeding disorder patients a month and the waiting lines are long. I felt lucky to be there. The children's ages were two and half to eight years old and many of them had feeding tubes. Joshua two and half years old and did not have a feeding tube. We were all scheduled to spend the month there. Each child ate four meals and had one occupational and one speech therapy per day. After talking to the other parents and more extensively with the therapists, it became obvious to me that Joshua would not have simply grown out his feeding disorder. Joshua and children like him need professional help.

The first day, I fed Joshua the way I always did. Then, the therapists and psychologists took over. They worked a rotation, each of them feeding him once a day. The daily program was: breakfast, occupational therapy, a break, speech therapy, lunch, a two hour break for a nap, a meal, an hour and half break, and another meal. The first few days were exhausting for Joshua. The new schedule, new therapists, new toys, new children, and taking a nap in a hospital bed was a lot of stimulation. After he got used to it, he began to enjoy his new routine. My role for the first week was to make sure he was ready for each appointment and to be with him during break times.

During the first week, the therapists introduced Carnation Instant Breakfast in whole milk, then soups (cream of chicken, tomato, cheddar cheese), yogurt (Dannon La Crème), applesauce (berry flavored), cubed cheese and finally blended ravioli. I was amazed. To see your child go from eating pureed baby food to cubed cheese and blended ravioli in a few days is nothing short of a miracle.

I also met with the pediatric nutritionist. She answered my nutrition questions and told me about the merits of Carnation Instant Breakfast. Pediasure and Carnation Instant Breakfast have a broader spectrum of vitamins than other liquid pediatric vitamin supplements (i.e Polyvisol). Therefore, it was better choice for Joshua until he could use chewable vitamins like Flintstones Complete.

The second week, I started to observe the therapists. I stood outside the rooms looking through the window and listening via a monitor. I noticed the consistency of their

language, behavior, food organization, eating environment, and reward system. Joshua understood the "take a bite" reward system. He knew that in order to play or watch videos during mealtime he had to take his bites. Each bite meant continued access to the mountain of toys and Elmo videos. Naturally, Joshua tested the system. He refused taking his bites initially but soon accepted the system, felt comfortable in the environment, and enjoyed all the new toys and videos.

The following is the technique (in laymen's terms) I was trained to implement:

1.) *Timing*

Every meal is timed for 25 minutes. When the timer goes off, the meal is over.

Neither the parent, nor the child controls the end of the meal. It is important from a behavioral aspect to have a neutral ending to the meal.

2.) *Environment*

Joshua ate in the same chair and in the same room for every meal. Every time he sat down to eat, the food was prepared. The psychologists told me that consistency helps children feel safe. The predictability of the technique mitigates their fear of food.

3.) *Organizing food*

Food order = 2+1+1 (2 bites of highest calorie or most nutritious food is offered first, then 1 bite of the second food, then 1 drink).

No bites or drinks are skipped. The feeder holds the bite in front of the child saying “take a bite” in a neutral tone until the child eats or until the 25 minute timer goes off. Only one new food is introduced per meal.

#### 4.) *Behavior management*

If the child does not take a bite, the video is paused or the toy is removed until the child takes the bite. The video or toy provides an incentive as well as a distraction, helping the child to manage their food anxiety and oral sensitivities. The feeder’s language is always the same and very specific to the action of eating (i.e. "take a bite", "take a drink", "good bite", "good drink"). After the child takes a bite, the feeder’s neutral tone and expression becomes very positive. No matter what the child's behavior (throwing up, gagging, coughing, etc.), the feeder’s behavior remains calm. That is not always easy to do, especially after your child has thrown up as Joshua did several times. Throwing up does not end the meal. The child must continue until the timer goes off.

During the last half of the program, I was trained to implement the technique. The therapists sat in the room as I fed Joshua. They critiqued my language, behavior, and implementation of the reward system. Joshua was eating so well that they wanted to expand the diversity of his diet as much as possible. In the final days, Joshua tried lots of new foods. I even went to McDonalds to get his first Happy Meal so we could try it in the clinical setting. The Happy Meal was a little too ambitious but we wanted to see how far Joshua would go. Still, Joshua was eating pea size bites of carrots, peas, cheese, pastas, soups, yogurt, bananas, avocado, chicken nuggets, bread, and crackers.

We finished Baylor's program with enough solid foods to create a balanced diet for Joshua, several recommendations for therapy practice at home, strategies for applying sunscreen, and a child who was proud of his new skills. Joshua's dad and I were thrilled about his progress and so were his therapists. Joshua's level of success exceeded that of most children.

### **The second modified barium swallow study**

Despite Joshua's tremendous success, the speech therapist was still concerned about his occasional gagging while eating and coughing after drinking. She recommended another modified barium swallow study. Our Baylor OCH speech therapist conducted Joshua's swallow study at Baylor's main hospital in Dallas. Not surprisingly, the radiology center at Cooks Children's had been more user friendly for a child. Fortunately, Joshua did not aspirate on any of the liquids or foods. However, he did pool the liquids at the back of his mouth before swallowing. Pooling is a risk factor for aspiration and indicated that Joshua still had strength and coordination issues when swallowing.

The speech therapist recommended that Joshua only drink cold liquids. In studies of older people, cold liquids trigger the swallow response better than warm or room temperature liquids. She also instructed me to thicken his liquid to half nectar consistency going forward. I told her about our experience with Thick-it and Joshua's preference for bath water. She was not surprised. She said that Thick-it is difficult to use for a child with sensory issues. She preferred using SimplyThick gel ([www.simplythick.com](http://www.simplythick.com)). I was also

instructed to log every time Joshua coughed or choked while eating. Hopefully, the log would give us more clues as to what triggered Joshua's gag response.

### **At home**

I quickly learned that as long as I fed Joshua using the technique he was happy to eat. The technique is actually self-reinforcing. Still I found it difficult to implement the therapists' litany of recommendations. For 25 minutes, four times a day, Joshua eats his meal per the technique. Then there are the recommendations for sensory play to do twice a day, the brushing technique known as the Wilbarger protocol to do three times a day, chewing practice, keeping the choking log, and so on. It is very time intensive and I skip some of the tasks at times. I try to incorporate therapy into our daily life.

### **Lessons Learned**

*Start early and find the right people to help*

Feeding disorders are so rare that few medical professionals are knowledgeable about them. I got a lot of well intended, yet incorrect advice. I was lucky to have a pediatrician who put us on the referral path when Joshua was just one year old. Many pediatricians do not even address the issue until a child is two years old. I worked with multiple OTRs and speech therapists before I found those specializing in feeding issues. Like everything else in medicine, you should go to the people who handle your problem everyday versus every so often. The lack of institutional knowledge and long waiting times are real problems. The earlier you start the process, the earlier your child will get help.

*While waiting, consult a nutritionist*

I wish I had gotten the advice of a nutritionist much earlier than I did. Baylor's feeding program was supervised by a pediatric nutritionist. Joshua ate a fairly wide range of baby foods, but he was short on fiber and a number of other nutrients. Advice from a pediatric nutritionist would have eased my worries and improved Joshua's diet at an earlier age.

*Therapists and doctors are not always on the same page*

I found on more than one occasion that the therapists and pediatricians contradicted each other. When that happens, it can be very frustrating and confusing. Eventually, you become the expert on your child's issues and you and your spouse have to make the final decisions.

*Try to get moral support from an educated source*

Although Joshua received OTR services from ECI for only a short time, the service coordinator was with us the entire time. It was really nice to spend an hour every month talking and brainstorming with someone educated in child development issues. She was my therapist for all practical purposes. A caregiver needs support in many ways, but it is especially helpful to get it from someone who is familiar with pediatric development issues. They can relate as well as educate. I really appreciate the support we received from ECI.

### **Final thoughts**

If Joshua had been able to eat a couple of items like cheerios or bananas, I doubt that he would have gotten the help he needed. We would have probably concluded that he was a very picky eater. Fortunately, Joshua's all baby food diet and gagging made it clear he needed professional help. There are likely many children who do not get the treatment they need because their problems are not as obvious as Joshua's. I hope other parents can learn from our experience.