

## **Getting Permission to Love**

Jenn, Harper's Mom

Looking back at the past two years, I don't know that I would change a thing. Isn't it wonderful to be able to say that? No... my husband and I are surely not perfect parents, and every step has been a learning experience for good and for bad. But the whole feeding journey in itself... where we all are as a family, where we began, how far we have come... it has changed who we are and our lives and perspectives for the better. We have all grown so much from the whole of it. I think I would simply want to tell myself from the get go to relax... to slow down, as there's no rush... to appreciate, to respect, and above all to love.

Two years ago our youngest child Harper was just six months old. After struggling every day of his life with horrible reflux pain and continuous vomiting, he finally began to shut down emotionally due to the trauma of the saga. At a mere few months of age his way of dealing with the physical pain and fear he experienced was to nurse enough just to exist, but not enough to grow. Discomfort and struggles at the breast eventually led to completely refused nursings. Day by day we tried and tried to coax him to nurse, but each day was worse than the last. He became thin, pale and weak. I cannot tell you how difficult this time period was for me both as a mom and also as a breastfeeding counselor. Not being able to feed your child or even to comfort him carries the emotional feeling of complete and utter failure. Add to that the sense of hopelessness you reach from not being sure exactly how to help your child and it is a very devastating place to be. Finally after a long-awaited referral to a pediatric gastroenterologist at the age of six months, Harper was started on a feeding pump via nasogastric tube to augment his bare minimum of breast milk intake. The theory at the time was that we would give Harper the additional calories he needed and that in time as his reflux improved due to medications and normal maturation he would begin to eat.

Those early months of tube feeding are a blur. I remember myself pumping at all hours, and agonizing over the feeding pump, and losing sleep counting calories and ounces going in versus ounces thrown up. I remember feeling so incredibly relieved to finally have a way of feeding Harper, but I also know I was very much not at peace with having a tube fed child. And although we were still breastfeeding regularly, this relationship was not as idyllic as I had anticipated. Surely I, regardless of my experience and background in breastfeeding had done something wrong. If I had just tried to nurse a few more

times per day? Or perhaps push to nurse fewer times? A different position? Different environment? What had I done or not done? The Ng tube, although a welcome and needed intervention was still an enemy. How much weight gained until he can and will eat? What's the magic number? How many more ounces? How much more time? The counting and judging and waiting and hurrying we wished on him in the beginning... poor little guy. Such an unhappy time for all of us.

Fast forward two years. Here we are. Yes, the hated Ng tube is gone, but was replaced with a much loved gastrostomy tube a long time ago. Did I say loved? Yes. We love it for it is a part of Harper, and a tool that we can use to help him to be as healthy as possible via nutrition. Notice I said a part of Harper... not the only part, just a small part. But more on that later. So yes... Harper is now almost three and has been tube fed for two years now. So many things have changed. Those early nights of a feeding pump hooked up to an ng tube are distant (and still troubling) memories. Under the guidance of a registered dietician and with the approval of our pediatric gastroenterologist and pediatrician we feed Harper boluses through the day of pureed table foods or soothing teas. Usually he has whatever our family eats for breakfast, lunch and dinner. We offer him whole foods at his place at the dinner table just like his older two brothers. Why shouldn't we? Although Harper does have severe reflux still (so we avoid spicy and acidic foods) he is above all a normal little guy. Harper weaned last month so the breastfeeding is gone completely. But he does take in some liquids... water or juice or miso soup.... by mouth. On a really great day when he is feeling especially daring and confident he'll munch on a chocolate chip cookie or piece of tofu or cantaloupe and swallow a bit. On a not so brave day Harper might chew up and spit out an entire plate of food with the family dinner and swallow nothing. And that's okay too.

So what has happened along the way? When did six months become two and a half years? Where did calories become nourishment? How did feeding go from a medical procedure to special family time? Where did judgment become acceptance and even finally respect? How did we as parents progress from questioning our errors to becoming confident... even proud and appreciative... of our journey? When did love become truly unconditional?

As time went on Marsha helped us to realize all of these things. Her "Get Permission" approach to feeding is so simple, really. It's about loving, of course, but also respecting your child as an individual. These little people who end up needing gastrostomy tubes are not

purposefully complicating things. They arrived in this position not by choice. If they found it so easy to eat then they would already. Period. There is no mind game here, or willfulness, or manipulation by them. The unavoidable and traumatic experiences (reflux pain, daily vomiting, Ng tubes and NICU stays) that led them to this point are ones that most of us would recoil from as well. If we could only put ourselves in their shoes and try to see their perspectives we might approach things differently. We are not feeding a g tube... we are nourishing a child. Yes... the route by which the food goes in might be different than the kid next door but the message is just as positive: I love you. I want you to grow, to thrive and to feel well. I want you to know that I understand where you are coming from. I am so proud of you. I am here for you unconditionally. We will... (we will!) get through this together, and when you are ready.

The "Get Permission" approach for feeding is child-led and anything but passive. Harper acts as the guide for our journey. He shows us with gestures, expressions and even words what he is ready (and not ready) for. What are his forward-moving cues in this active approach? Harper seeks out food experiences. He helps to select the foods at the family table that will be on his plate. Interestingly enough he asks for a bit of everything that is available at the table. After he helps to dish food onto his own plate, Harper talks with us as we cut his food into manageable pieces. For any given food item there are several sizes of pieces. Small mouse bites are so that he can easily discern and manage morsels in his mouth. More typically-sized toddler pieces are there so that he can chew larger pieces of food for that oomph of sensory pleasure, although he usually spits them back onto his plate. We always have large, hand-size pieces somewhere on the plate so he can pick up food and bite sections off to munch on, as that's a whole other food experience. Finally at every meal there is some sort of soup, smoothie, or puree for Harper to enjoy. Although he is most certainly not limited to this consistency with regards to foods to taste, he is most comfortable with actually swallowing significant quantities of this type. He also builds more confidence with these shakes and realizes that the ounce he swallowed into his belly actually does help to satiate that hunger feeling. As Harper drinks more liquids and progresses from touching, then tasting, then chewing, and finally swallowing foods, he is actively participating in food experiences. At all times he is the one to choose bites and self-regulate... we are not spoon-feeding, directing, or pressuring.

As parents we also take a very active role in this approach. We present a variety of foods at meals that are nutritious, exciting, and varied. We

make sure that the foods are presented in a number of sizes and ways on his plate. We support him with the opportunities with food to explore, to build confidence, and gradually to learn to love... yes, to love... to eat. There is no bite counting, or our mandating that he try anything. It is our responsibility to make meals and time with food fun, light-hearted and emotionally uplifting. In addition, we put a considerable amount of thought into the meal schedule for when he is tube fed throughout the day. The blended foods Harper gets in his tube are similar to what anyone might eat for that particular time of day. For example, for breakfast he might start the day with a granola, yogurt, and mango parfait as that is a wonderfully yummy and healthy way to start a day. We are most recently tweaking bolus times to fall behind the meals he shares with family, as that way we can most appropriately help him to find hunger at a given mealtime and respond to his body's cues well. My husband, Harper and I are not the only ones involved in this active get permission approach either. It is very much family-mediated.

Harper's two older brothers (although only four and six years old) are integral to his progress. They model how delicious the foods are and they are the first to try new foods and encourage his venturing out into uncharted territory as well. This past weekend as my four year-old talked with squid legs literally hanging out of his mouth, Harper broke down and demanded a piece as well and loved it. How's that for real world adaptability?

As a family we also talk quite a bit about how full or empty our tummies feel, how crunchy or wet or sticky or delicious a particular food is, and so on. We also are vocal with recognizing little things... what a great job you did on that soup, or looks like that broccoli was really yummy to you, etc. Every second of every day Harper knows how proud of him we are for who he is and how far he has come. We celebrate small victories and rejoice in what he can do every day. He might have a day where he throws up and feels awful or a day when he swallows something... on both days Harper knows how wonderful he is to us.

As he builds confidence and remains supported and happy he becomes more able to try new things with food, and he builds even more food skills. As he does so he understands all along that eating is fun. Food is happiness. There are only good things here. He is building for a lifetime of comfort with and around food. When he finally becomes completely orally fed... and he will when he is ready.... he will have the

psychological foundation as well as physical skill set to have a beautiful, stress-free life with food.

How has this change in direction affected us emotionally? Obviously Harper is a much healthier and happier person as a result of our child-focused, "Get Permission" approach, but how do we as parents fare? This is pure joy. At the beginning we were overanalyzing, pushing and rushing. We were unhappy, pressed, miserable and always looking ahead to the better day. The grass was much greener over yonder. Now so much has changed. In following Harper's lead we are completely at peace with where we are as parents, where Harper is as an individual and where we are as a family. There is no race to be oral. He will eat when he is ready. Our only job is to love, to respect, to support and to help. How much easier can that be? No longer do we judge ourselves or him. We offer unconditional love and do not pressure Harper... this is such a happier place to be. We are content... no, blissful! in the here and now.

A hugely significant caveat of our mind frame change with this child-centered approach is that we now see Harper as a child who happens to have a tube, not the child with the tube. As I mentioned earlier, the button is a part of him but it is not who he is. Harper is a child who can do so many things. He can sing, dance and plays a mean game of hide and seek. He loves to run, to talk and to ride his big wheel. He has an adorable baby-talk southern drawl and the best laugh ever. He gets into wicked spit fights with his two older brothers and can actually (is this a good thing?) hold his own. He's an amazing snuggle bug and a merciless bed-cover-stealer. He loves orange kitties and chopsticks and the moon on a clear night. And yes (but only as an afterthought!) he also happens to have a G- ube. And you know what? I wouldn't change a thing about him, either.

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