



Complex Child E-Magazine

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A Journey through an Intensive Feeding Tube Wean by Daria Mochan

On January 28, 2011 we started reducing calories for a hunger-based, feeding tube wean. I documented the weaning experience and my feelings for an online mothering magazine. This article is excerpted from articles posted on Mamalode.com.

In a few days I will stop feeding my child.

I will do it slowly, dropping meals over a week's time. I will not give in and feed her the way she wants to be fed. She will be upset. She will cry. I will be upset and cry. Our world will be turned upside-down.

In the end, I hope she eats.



Life with a G-Tube

My second daughter was born with a genetic abnormality and has more difficulties and needs than a typical child, one of which is eating. While Gia shows some interest in eating orally, she's had a feeding tube since birth. I am thankful we live in a world where she survived with the aid of medical interventions. Placing a gastrostomy tube (G-tube) was not an easy decision, but a necessary one and perhaps our only choice at the time.

As a result, I spend countless hours analyzing her diet, weight gains and losses, and blenderizing a special diet just for her.

G-tube moms have quite a bit to deal with, and life with a G-tube kiddo is not easy. In our case, I cannot leave Gia with just any babysitter or even family and friends, unless they are trained in G-tube feeding and emergencies. Worries about our kids' health are often intensified by medical professionals analyzing our children's nutrition and frequent weigh-ins. Feeding a tube kid in public can often elicit unwanted stares. Also, the time it takes to prepare the food, clean the equipment and feed our kids can often be several more hours than a non-tube kid. It can be a stressful situation, putting strain on the family, especially if no outside help is provided.

But in the end, we have the same goal as moms of typical eating kids do. And we have the same worries about our special children growing. The only difference is that our children are fed through a hole in the body, rather than through the mouth. It is every mother's natural instinct to feed her child, and we are no different.

However, I cannot deny that I absolutely hate the G-tube. I've spent many hours wishing it away, cursing it as I deal with the medical aspects of having a hole in her body cavity, swearing as I spend half my day feeding her through a tube only to have her vomit it back up. Recently, though, I have made my peace with her G-tube and am thankful to be able to have this option. The tube helped facilitate Gia's growth into a healthy little toddler. In all likelihood, without the aid of a G-tube, she might not be alive today.

She is now 19 months and I believe the time has come. After two previous weaning failures, and meeting with many therapists and medical professionals, we are ready for the next attempt. Gia and I will be traveling to Seattle Children's Hospital for an intensive two-week G-tube weaning program. She will be closely monitored as we drop the amount of calories we give her via the G-tube. We will be surrounded by food, both healthy and unhealthy, in the hopes that she will eat something, anything.

And as I embark on this adventure in weaning, I have every possible emotion you might imagine: scared, nervous, excited, sad, and even a little exhausted and overwhelmed. I have been reflective and hopeful. I have to believe she can do it. I have also felt very guilty for putting her through this ordeal.

And what I've decided is that I have to torture her so I can give her a gift. The gift of tasting family dinners, of nibbling on fresh veggies from our garden, of sharing freshly

baked cookies with her sister, of licking an ice cream cone on a hot summer day, the gift of eating her own birthday cake. Eating will not make Gia a typical child and she still has many obstacles in life, but it is a start. A very tasty start.

Day 10

It's been ten days since I started reducing food via my daughter's G-tube in our third weaning attempt. Under the watchful eyes of the Seattle Children's Hospital medical team, we have been monitoring hydration and slowly reducing Gia's G-tube meals by about 10% a day. We are currently at a 70% reduction of calories, and Gia is still not very interested in eating.



We've had a long and exhausting week of daily hospital appointments. Gia is battling a cold and is congested. She is miserable, but thankfully seems to be more comfortable with our new surroundings. Our lives revolve around food now: touching, smelling, playing, and yes, even tasting all kinds of food.

Although much of Gia's time is spent in a highchair at the hospital, she has the most fun at the baby picnics. The purpose of a baby picnic is actually not to eat. Well, kids CAN eat. The kids can do what they want with the food. But the main purpose of a baby picnic is to allow the kids to be comfortable with food, to handle and explore different tastes, textures, colors, smells in an un-controlling, no-pressure environment. Easy to say, a bit harder for a mom to do, especially when your child doesn't eat orally.

She's played with purees, smashed bananas and avocados, crumbled scones, thrown chips, painted with pudding, kneaded dough, rolled in pasta, poured juice all over herself, smeared peanut butter on me, and even taken a small bite of a cracker. She is extremely focused on feeding us, not so much herself.



However, something is changing.

There is a stirring deep inside, an internal revolution of sorts. She wants me to feed her using the G-tube, but then fusses during the feeding. Watching this struggle has been agonizing. There are times I just want to take a graham cracker and force it in her mouth, so she eats SOMETHING. But I refrain and hope she will follow my lead as I constantly shove food in my mouth instead. I am so tired of thinking about and eating food, yet I cannot escape it.

While Gia battles food demons in her head, her conflict is a reminder for me that the decision to eat is something she alone can make. I can only lead her to food; I cannot make her eat.

Day 13

Thirteen days ago I started reducing my 19-month-old daughter's calories via her gastrostomy feeding. Thirteen days ago I was very nervous about starting this intensive program. I was uneasy about leaving my first-born, almost five-year-old, to take her little sister to Seattle, scared of Gia becoming sick and canceling our third wean attempt, and downright anxious about Gia's eating abilities.

And here we are on the thirteenth day and my mind is more at ease.

A few days ago Gia developed a cold and I thought we would have to cancel the G-tube wean. But the therapist was convinced that Gia would ride it out, and sure enough she did. Slowly, but surely, her interest in food has increased. She only has one tube feeding a day (in the evening) and is only receiving a percentage of her necessary caloric intake through her G-tube. During the day I am giving her water through her tube if she does not drink the required three ounces of fluids needed for hydration. She has been drinking a few ounces of smoothies, juices or purees recently, so I've been subtracting the difference from her necessary fluid intake. It has been at least two ounces of water after each meal.

But not today.

Day thirteen was different.

You know it's a good day when Gia, without hesitation, shovels seven tiny spoonfuls of food in her mouth for breakfast, happily plays with more food at the high-chair, excitedly feeds us, and then finishes up by effortlessly drinking 1.5 ounces of a high-calorie, coconut milk and avocado smoothie.



She was very excited as I carried her down the long hallway to our 11:30 appointment at the hospital, but I don't think anyone expected what followed.

She ended up drinking *four ounces* of pear puree *independently* in about five minutes. She did not gag, choke, or vomit and she hardly spilled any of it. With a tummy full of

four ounces, she still ate a few spoonfuls of guacamole, took a small bit of cracker, nibbled a little on a graham cracker and drank an ounce of her avocado smoothie.

For the first time since her birth, I was told *not* to give her a tube feeding of water. She drank enough ON HER OWN to skip the three ounces of water she needed for proper hydration. Granted, her calorie count wasn't high, but at this point in the program, that isn't the issue.

And with that simple act of not tube feeding the water, I feel we've made it over the hump. It is the first time that I 100% truly believe she is going to do this. She is learning how to eat. *She wants to be an eater.*

Of course I always believed, deep down, she would eventually be an oral eater. But after two unsuccessful tries I had my share of nagging doubts. Perhaps because I didn't want to feel the same disappointment I've felt before and I was trying to protect myself from the failure, hopelessness and the depression that seemed to follow a failed wean.



So today, for the first time ever, I can let it go. *Gia IS an eater.* We are not out of the woods yet and she still has many eating skills to learn. She needs to be able to sustain and gain weight without the use of the G-tube. She needs to stay on path when she is sick. The road is long and bumpy, but we are on it and so happy to have come this far on this journey.

In these thirteen days a door was unlocked that Gia had not previously been given a key. And through it we will take baby steps into a whole new world full of flavor.

Two Months Later

It's been two months since my daughter and I returned from the weaning program at Seattle Children's Hospital. It has been a busy 60 days. Gia has been sick three times, had two ear infections and one surgery. She's lost weight, gained it back and is almost her pre-wean weight. I've tolerated and dismissed doubts and worried opinions from our local medical team. However, during the hour preceding her weekly weigh-in, I've struggled with my own fears. I hold my breath, cross my fingers and hope she is just a little heavier.

It is hard to put in words the emotions I have felt in these two months. But mostly I am still in a state of disbelief. Watching her now, I cannot believe Gia did not eat anything orally for 19 months of her life.

This whole process has been nothing short of amazing. Within a few days of her breakthrough in Seattle, while waiting at the airport to return home, Gia grabbed and ate *a third* of a Starbucks scone! That evening she showed off for Daddy and big-sister Anna by polishing off her puree and then taking little bites of my pizza. The next morning when she nibbled on pancakes, her sister screamed, "Mommy! Gia's eating HUMAN food!"

I've experienced moments of pure joy while watching Gia's very excited reaction to my question, "Are you hungry?" She can hardly contain her enthusiasm as she quickly crawls straight for the high chair. Tears of joy flowed these past two months as not only did my first baby, Anna, turn five, but to have her little sister eat and enjoy the special request "Aardvark and Cinderella" birthday cake was more than I had ever hoped for. My heart continues to melt after each meal when she gives me such a look of satisfaction and pride. *She is doing it.*



What has been most unbelievable is that I have been given a little taste of normal life. With constant doctor and therapy appointments, we are still not a typical family. I have not found that I have more time or less laundry to do, but I don't mind. Feeding Gia orally is far superior to G-tube feeding and I'd much rather be washing clothes with food stains than vomit.



She has not vomited since Seattle, which is beyond belief fantastic. I can treasure Gia's hearty belly laugh without fear of puke. I can enjoy just watching and not stop Anna as she tickles her little sister. I have been able to leave the house without fear of Gia throwing up, and have been thrilled to introduce experiences all toddlers should have like going for a long family walk in the spring, swinging at the park or practicing downward dog while playing with her sister. As a result, Gia's self-confidence and gross motor skills have skyrocketed!

And Holy Cow! She is eating un-mushed GREEN PEAS! Incredible. Mind-boggling. Unreal. Just plain wonderful.

She is so happy and so are we.

Daria Mochan lives in Montana and is mom to two girls and one old dog. Gia is still a fantastic eater, weight gain is slow but they hope to remove the G-tube sometime this summer. You can follow along with Gia's progress and other musings at Daria's blog, [An Unexpected Path](#).