



Complex Child E-Magazine

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When the Mouth Won't Work by Keely Schellenberg

Take a minute right now and think about your mouth. What is it doing right now? Where is your tongue? Do you have saliva you need to swallow? Are you picking breakfast leftovers out of your teeth? Are you whistling? Talking? Chewing? Swallowing? Yawning? Licking your lips? Kissing your child?

Your mouth plays a big role, if somewhat under-celebrated most of the time. Think about what it would mean if you couldn't control your tongue. Or throat. Or lips. Think about what all would be affected...how much of your daily life would be completely different.



Brandon's Story

My son Brandon was diagnosed with mitochondrial encephalomyopathy--a form of mitochondrial disease--when he was two years old. At the time, he had trouble walking and wasn't talking due to muscle weakness and uncoordination. He was, however, learning alternative ways to communicate and was showing us that in spite of his issues he was a bright little boy with lots to share.

Brandon was initially diagnosed with an Expressive Speech Delay, meaning he could understand everything and knew what he wanted to say but could not get the words out.

As time went on this was changed to a diagnosis of Apraxia of Speech, a disorder in which the brain and the mouth do not communicate properly and spoken speech is difficult or, as in Brandon's case, impossible. Over time this diagnosis was again amended to Global Developmental Dyspraxia when he developed dysphagia (difficulty swallowing). This diagnosis basically extends speech apraxia to include other areas of development.

In Brandon's case, his brain was not communicating messages properly to his mouth, tongue, throat, and the rest of his body. There is no general term to describe what goes on with Brandon or why he struggles. He is considered to have a movement disorder, a broad classification that can include Parkinsons, dystonia, ataxia, and other similar disorders. Basically, his mitochondrial disease has damaged his basal ganglia, the part of his brain that controls movement throughout the body. In his case, the major casualty is his mouth/throat.

Early Speech Solutions

We tried many therapies for Brandon's speech, including:

- Conventional oral/motor speech therapy: the "mainstream" type you see in public therapy settings
- Vitamin therapy: there are some theories about vitamin E benefiting speech development in children with apraxia
- Vestibular therapy: balance/movement therapy
- PROMPT speech therapy [<http://www.promptinstitute.com/>]: a school of therapy that focuses on physically training the mouth to create shapes and sounds

In our experience, we saw the most drastic improvement with PROMPT speech therapy. After a few short sessions Brandon was actually saying words! It was astounding how fast it was working for him.

Unfortunately, his disease progressed around that time (at age four) and he started to aspirate (choke on his food). This was when his diagnosis was upgraded to Global Developmental Dyspraxia. After a few weeks of sputtering on drinks and choking on foods, Brandon developed aspiration pneumonia, a potentially life-threatening form of pneumonia caused by food entering the lungs. This pneumonia caused a major regression in speech skills that Brandon never did recover.

To date he has no spoken words at all. We have had to focus on sign language, picture symbols and a lot of yes/no games to communicate with him. His patience far exceeds his age.

Solving Eating Problems

Brandon then had a swallow study done which had him swallow different consistencies laced with barium in front of an X-ray machine to see how food was traveling down his throat. This test showed that he could not safely drink thin liquids or eat food that wasn't pureed like baby food. His throat was not protecting his airway the way it was supposed to, and his mouth had very little control over solids, causing food to "fall" down his throat.

To make food safe for him, he was put on a pureed diet. Brandon can only eat food the consistency of oatmeal. We have found several ways to deal with this. On his worst days we make him a slurry of yogurt, with ground up nuts (mixed nuts), a few teaspoons of canola oil or olive oil, and ground flax. Brandon has in the past gone long stretches of time eating nothing but this and thrived on it. When he is doing reasonably well, however, he does like "real" food, and we work our family meals around this. We've discovered that almost anything can be blended and made to be tasty. Brandon will eat blended potato, steak and broccoli quite happily!



We have a few appliances that are indispensable. The one with the most mileage is the Magic Bullet (<http://www.buythebullet.com/>). This will blend food to a puree fast and in just the right quantity, and cleanup is very easy. It's also small enough that we can take it when we go out for dinner, go to family gatherings, or travel.

Another handy appliance has been our solid glass blender. When pureeing big batches for freezing it is good to have a solid blender to stand up to abuse. We would do large batches of pea soup or meat stew in our crock pot, blend it all, and then store it in small freezable plastic cups in single serving sizes to pull out when our meal wasn't particularly tasty blended. Pizza, for example, does not blend well.

School lunches are composed of either leftovers from dinner, yogurt cups, applesauce cups, high calorie pudding cups, etc. We have found that Brandon can eat things like

popcorn curls as they melt quickly, and meltable baby crackers or puffs. It is a lot of trial and error, but we are figuring out what works for him.

As time has gone on, Brandon's swallowing has worsened and on his worst days he can only swallow his nutrition drink, which for Brandon is Nutren Junior. It is becoming clear as time goes on that eventually he will need a gastrostomy feeding tube. For now he is still thriving with the dietary management; however, should he start losing weight at any time or develop further pneumonias, this decision will be on the table. For a child who cannot safely eat, a gastrostomy tube is lifesaving, and most parents who have had to consent to one will tell you afterwards it was the best choice they ever made.

Some children also struggle with choking on saliva. Thankfully, Brandon has not had this problem. Should it become an issue, however, there are medications that can be prescribed to reduce the production of saliva, botox to inhibit the glands, or surgery to remove the salivary glands all together.

Brandon Today

Today Brandon is almost six and does not talk at all, though he is certainly vocal! As he has grown so have our options for communicating with him. He has learned sign language over the years, and knows enough signs to get his basic needs across in a hurry. He has also been learning to use picture symbols (PECS) to communicate and is working toward ultimately being fluent with communication software on a computer or a small handheld device using programs that will literally speak for him.

Brandon's mouth has slowly shut down over the past four years, and we are continually amazed at how much we take for granted with our own mouths. In spite of it, we have learned over time how many ways there are to accommodate most of the problems it causes. Even more, we are continually amazed at Brandon's resilience and ability to compensate for the fact that his mouth simply will not work for him. I'm sure we will continue to learn over the years.

Keely Schellenberg and her husband Dave live in Canada and have two boys, Brandon and Tyler. Brandon has confirmed complex 1 deficiency and Tyler is suspected at this point but not confirmed.