

To my fellow parents,

“I hate my voice” stuttered and stammered my 10-year-old daughter, Alice.

Tears ensued.

“I hate my voice.”

When she was 2 years old, a developmental pediatrician told me my Alice would never talk. Around that same time, a fresh out of school speech therapist, off the cuff, said she thought my daughter had apraxia. She left me without explanation of what that scary word meant and rather, left me with confusion, fear, and sadness.

Today, at the age of 13, Alice is a “Talker.” As parents of a child with apraxia, that word “Talker” strikes hope in our hearts. We watch our children struggle with the ability to understand everything that is said to them and the inability to command their voices, to respond, to articulate their thoughts and feelings, to raise their hands in class and answer the teacher’s question, or to answer a knock-knock joke. And we as parents wish, dream, pray, sweat, cry, and want so very badly for their voice to just come easy.

My daughter is a Talker because of Dr. Edythe Strand. After 6 years of traditional speech therapy, my daughter had just a few words barely understandable by a stranger. I learned of Dr. Strand from another parent and was lucky enough to take my daughter to several intensive therapy sessions with Dr. Strand and her colleagues at the Mayo Clinic. Dr. Strand armed me with the knowledge and skill to attack Apraxia. More importantly, Dr. Strand gifted Alice with the ability to use her voice.

I could go forever about our story, about Dr. Strand, about the Once Upon a Time Foundation, and the challenges of being a parent of a child with apraxia. I know, God how I know, you do not have that time. To hit the high points:

- Be proactive.
 - If you do not think your SLP understands apraxia, find someone who does. Do not be afraid to hurt a professional’s feelings; they are professionals and should only want the best for your child even if it is not them.
 - Educate your child’s educators about apraxia.
 - I was told Alice had one of the most severe cases of CAS experts had seen. I was told she would not talk. I pushed. I pursued. I did not take no for an answer.
- Be patient.
 - I swear my daughter can say something and 10 minutes later, she cannot say the same words that moments before readily spilled from her mouth. It can be wildly frustrating- for both of us. Everyone take a deep breath (seriously that is a speech therapeutic device for CAS kiddos) and try again. And again. And again. And again. And...

- Extended family members and pretty much everyone you will ever meet may not understand apraxia. They may whisper back jokingly when your child whispers because it is easier than turning on their voice. They may think your child is being stubborn or rude. It is easy to get frustrated with them. Patience for all including (see below) yourself.
- Cut yourself some slack.
 - Being a parent is exhausting. Being a parent of a child with different needs is exhaustion on high. It is hard not to beat yourself up because you forgot to do speech homework or you did not push your child to pronounce a word correctly because it is 8:00 p.m., your other kids have homework, you still have work to do, and the dishes have not been done yet. Be kind to yourself. Your child and their voice need you.
- Engage others.
 - Talk to other parents; the best steps I have taken for Alice in our journey started with information learned from another parent.
 - Educate others so they can support and encourage your child's talking in a productive way.

That day where my daughter declared "I hate my voice" remains clear in my head. Because it was so sad and heartbreaking? Nope.

After a really challenging session with Dr. Strand, Alice hated her voice. After our second session with Dr. Strand that same day, we went to the beach to throw rocks in to the ocean. My daughter, after a much better session and empowered by Dr. Strand, stood at the edge of the ocean and yelled with incomparable joy and gusto "My voice is awesome! My voice is awesome" over and over.

Alice has Apraxia. And her voice is awesome.

Best wishes to you and yours through the journey of CAS,

Kristen