

The Secret

Out of the blue my seven year old son asks me..."Mommy, did you have an aide when you were little?" I stop dead in my tracks and I hesitate for a moment before I respond. "No, but I did have a babysitter. She came to the house every morning to make us breakfast and pack our lunches for school. She made us toast and oatmeal. The oatmeal was too lumpy to eat, and the toast was cold. That's what I remember the most about her, that her breakfasts were awful. Mommy's breakfasts were so much better." While I reminisced about my own childhood, I realized deep down that I was skirting the real question here. My son is asking me - if he is - *different*.

I overheard him having a conversation with his aide this past weekend, he kept asking her if she had a "Wish" when she was little, or did her son Ryan have a "Wish". Most of you all know that Reagan had his wish granted last year from the "Make-A-Wish Foundation" to meet Rascal Flatts! Reagan talks about the experience almost daily.

If you ask Reagan who has Prader-Willi Syndrome he'll say "I have it"; then when you ask him what it is and he'll quietly answer "Ummm...I don't know". That's the gold standard answer these days from him when he can't articulate what's floating around in his brain. He's not blatantly ignoring you, or spacing out, he's simply processing the conversation. You'll notice it when you greet him "Hey, Reagan, how you doing buddy?" ...he looks away, and if you're lucky he'll reply "good". That's called social cues something I learned in Behavioral Therapy. He does not always pick up on these subtle cues. It takes him a bit longer to understand how to greet a person. It's just part of the syndrome and part of his diagnosis of PDD-NOS; which means some of his characteristics are on the Autism Spectrum.

When we drive hours to see a Doctor in Tennessee or in Florida, we tell him it's another check up. "The Dr. just wants to see how you are doing", we tell him. We have a secret, and like most secrets... It's killing me inside to keep it. It's the little white lies that we are taught that are ok to tell.

Only, I know it's only going to be harder for me than it will be for Reagan, because it's going to feel in my heart just like that first initial diagnosis. It's gonna hurt like hell. My husband reminds me that it's easier for us than for him, because we can walk away from it, we don't have PWS. Reagan does, and will for the rest of his life.

So how do I tell this little boy who tries so hard, yet still gets those looks that last just a little bit longer from folks who meet him that don't know about his syndrome. I can almost hear what they might be thinking in their mind...is there something wrong with that boy?

Is Reagan starting to figure it all out? How do I tell him without it crushing his spirit? I don't look at his PWS, I look at Reagan. But every little thing he does is magic to me.

I have raised him much like I have my other four children. I hold him accountable for his actions, I teach him to respect others. I push him to be the best he can be. I build his confidence. I expect a lot from him. PWS or not, I'm his parent. I want the world to be his oyster.

By Diane Seely