
LILY

The Never Ending Story | More Notes

Where we left off

The last time I wrote we were sending out our application for Lily to enter a special school for Apraxia that has a different approach to speech production. Lily was accepted. This is a multi-sensory approach to speech therapy and in so many words it means they are teaching Lily to read, write & speak at the same time. Essentially one



complements the other forming the basis of what Lily needs to learn. The beauty behind the method is that it is teaching other means of communication and not just relying on verbal speech as the only source of expressive language.

Continuing therapy

Lily is now attending her new school for speech therapy on an out-client basis. She is learning to speak with grace at this school. Kelly, her speech pathologist has been wonderful and Lily loves her. Lily also responds to her which is key. At the first few therapy sessions Lily had poor regulation control & had several meltdowns on more than one session. Meltdowns are something that do not occur with Lily. After the therapist learned more about Lily and her personality Lily became less intimidated and more interested in her surroundings & what was being asked of her. Through gentle motivation the therapist coaxed Lily into using her ability to form words into sentences and made the magic happen. With more words came confidence. And with confidence meltdowns were eliminated. Lily has heard her voice. And she knows we are listening.

Currently Lily is learning phonemes and stringing them together to read & speak sounds. Additionally she is learning to write them but more focus is on her speech output. Lily was given her first word just last session. It has taken much learning & memorization to lead up to this point.



Lily is still attending OT at the same small therapy place she used to although we have not been the last two visits because of sickness or the therapist had an appointment. So we would like to go more frequently but insurance is not allowing us this option as of yet. That's a story within itself. We did increase our time to one hour sessions and our last session with Kristine (OT instructor) was an hour long. It was better structured & allowed for more time to actually get activities done. I wish they would have suggested a longer time duration before I did.

We have refrained from going to speech at our old place as of last session with them. It became too much with speech at Lily's new school and honestly Lily was receiving little therapy from it. The therapist was supposed to offer PROMPT speech therapy & never really followed through. More to do with her lack of experience rather than her lack of knowledge she could no longer benefit Lily enough to keep her as a therapist. Lily loved her but she couldn't offer what the school has.

The last geneticist visit

Somewhere in between getting into Lily's new school for her first few therapy appointments we also had an appointment with her geneticist. He agreed again that her variation of the SLITRK4 gene was the cause of her autism. He also decided to take her off carnitine and folic acid and just keep her on a regular dose of children's multi vitamins. So that is what we are doing. I have seen no dramatic effect take place so I am unconcerned. No blood draw was necessary. Her geneticist said she seemed to be doing well & that he wouldn't need to see us for 2-3 years. Wow. This is good news. We learn less but until then there is nothing to know until that information is gathered. That closes this chapter for now.

Retrieving freedom

Lily will be getting her service dog this year by a company called Retrieving Freedom. So far we think it will be a female dog and her name in training is Timber. Oddly enough our other dog is named Sequoia so she suits our family before she even arrives. Originally Lily needed her service dog for regulation problems. Although Lily still has problems



transitioning her speech progression has sided with her regulation/modulation abilities & she transitions with greater ease now. The dog is now for a sense of direction & protection. Lily has a hard time following along in public settings. She might get interested in something & become lost in it as well as her environment. This dog will help give Lily something to walk towards. If the dog has a sense of where it is going so will Lily. Timber will also be trained for search and rescue which makes me feel safe. No one ever wants to use that skill but I am thankful Lily's dog will have it. Lily has taken much more interest to Sequoia now even though he hardly stands still & he gets along well with her with a gentle touch. The passing of our family cat was hard for her and you can tell she is looking for an animal to fill that void. Lily specifically had me draw pictures on the chalkboard after our cat disappeared. (We draw together on the board & I have her tell me what to draw and where to place it) Lily asked me to draw a door. Then a cat and a dog. This doesn't say much to most people. But it represents her animals. Lily sees her cat and dog at the door every morning. I am almost certain this was her language: where is the cat? I miss my cat. Something is missing. It's so simple it's complicated.

Milestones underway

Lily is pedaling her trike without worries. She can mount it, sit on it, and ride it as of recently. One day she just got on it and went. She has also successfully and recently climbed up the playhouse ladder, gone not the house, and down the slide all by herself. It was beautiful. The look on her face was priceless & something I'll never be able to describe & certainly never forget. Lily is still hesitating to pick up a spoon even though the motor planning is there just not automatic. Toilet training is underway but she is understanding & can recite the steps now. She is sitting on the potty but not for prolonged periods of time. She is as defiant as her sister and every average 4 year old little girl. She is typically doing everything her sister did a year and a half behind. Except for sequencing actions and fine motor skills that coordinations skills lack in and those skills improve every day.

Lily is beginning to speak. I can hear her voice. So can she. And she knows it's there. She is speaking spontaneously and repeating sentences after they have been said as if to practice their meaning. If you ask her to say something she will. Most times. She recites her Kaufman cards and asks for them now. She is reciting her DuBard cards with absolute accuracy. Lily is not just learning to speak she is learning to read and write.

Looking for insurance in all the wrong places

We are currently looking into getting more insurance coverage for Lily as she is only getting covered by BCBS for 30 visits combined Occupational therapy & Speech therapy. Now, if you cut that in half you've got 15 visits of each therapy. Really? Lily has Apraxia. I don't think 15 visits will cover it. So we are forced to pay out of pocket those additional therapy costs & juggle which therapy is more important at what time. I imagine this is what most families have to deal with and I am fortunate to have a contact I can speak with that might be able to help our case. Lily has an autism diagnosis. This is the diagnosis that allows for her therapy. But she also has a gene variation. This variation has not been taken into account by our insurance company and frankly we are not sure if it would help our case or hurt it. Lily's gene variation is the cause of her autism. It is also the cause of her Apraxia of speech which has also not been

accounted for. I have read that many insurance companies consider apraxia a developmental disability and not a problem of the CNS. They believe that if left alone it will resolve itself. Not so.



Summary

In a nutshell, Lily is making great progress. She is advancing in speech & occupational therapy. She is getting better at life skills & understanding relationships. She is starting to speak what she has always understood. She still requires help with direction but once motivated can follow through with most ordinary tasks taking a different route than most might but still getting there. Lily isn't getting better. She is better. Better at everything. Lilybird has found her freedom. Lilybird sings. Lilybird speaks.

