

# Willow's Story

## Part 2

By Sallyanne McShane

(Part 1. of Willow's story was published in the May 2013 PEPTalk edition, where Sallyanne (Willow's Mum) shares her personal journey on a quest to ensure that Willow is enabled to reach her full potential in life. Back copies can be sourced from the ACD Head office).

### A big part of my journey with Willow has been communication...

I started signing with Willow when she was nine months old, but it didn't seem to be sinking in. I got nothing back from her, nothing at all. I remember writing back when she was two, that "woohoo!" she signed 'biscuit'.

So we just kept giving her biscuits, and she then learned that the sign "more" could get her more of anything. Suddenly it just all clicked. By 2.5 she had over 500 signs. It was just amazing!! But she still only had a couple of vowel type noises.

Our Developmental Pediatrician was on the same page as me: Turners Syndrome just didn't cover all the different things going on with her; so many theories were thrown around. It didn't matter so much about the diagnoses; I just wanted to start helping my baby: first to be healthy; second to communicate and then to help her start to move and develop. Slowly, over these last few years the diagnoses have rolled out and provided the full picture of Willow's complex medical needs.

Just before turning three she said her first word: "Mummy." Bless her; it was the best reward I could ever have asked for after all those countless hours of therapy. However things weren't progressing very fast and we still had no idea why she couldn't talk. We started to look at other ways of communicating. A year ago when Willow was three and a half, we got a new speech therapist, who changed our lives by introducing us to the world of AAC (Augmentative & Alternative Communication) devices.

To start with I was very much, "my child doesn't need this she is starting to speak!" Yes, only seven words, but it was starting. We trialed a few different systems and found the L.A.M.P. (Language Acquisition through Motor Planning) system worked wonderfully with Willow and we started trialing a Vantage Lite device with the help of the Communication Access Team at St Giles, with great success. I noticed that a few weeks into the trial Willow had gained a lot of new words, especially words we were working on with her "talker".

At first, we got a lot of pressure from people who didn't understand why we were using the AAC device, and people often said it will stop her talking. I worried, "what if they were right?" I just didn't know! It felt like I was being thrust into a whole different world, part of it was that it was a very physical sign when out and about that my child was "different", that my child was "disabled." I wasn't ready to accept that yet. So, after a couple of weeks there I was handing back the device saying "we don't need it she is starting to talk"...

And do you know what happened then? Her progression in speech not only stopped it started going backwards! I realised, it was the talker that was helping her to speak! So back to the CAT (Communication Access Team) I went, a little embarrassed, but more importantly, with a new determination and the confidence that this was the right thing to be doing. So from then we jumped in with both feet and it has been a wonderful journey!

Willow is taking to it so well and everything we are learning on it comes through in her verbal communication. We put "- ing" words in the talker and quickly she started using "- ing" words in her speech. We started using plurals, adding "s" onto words, and lo and behold she starts to use plurals in her verbal language! The beautiful thing is it's not fluid or easy for her - you can actually see her pause and then think of adding that 's' onto 'dog' when she sees two dogs.



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In November last year on Willow's fourth birthday, she had an MRI. It showed "significant" grey matter heterotopia in her left frontal lobe and even more in her right, plus other patches in other areas of her brain. This means these are areas where there are actually no neurons, therefore no brain activity.

Willow was then classified as having a "speech disorder"; seeing as her brain is missing some of the areas where speech comes from. Again, now I knew I had made the right decision to use the AAC device and L.A.M.P as we don't know how her speech will improve or what gaps she will have as she grows. Her "talker" will give her the ability to talk at the same level as any adult if she needs it when she reaches that age.

Just after getting this diagnosis and being told that seizures are a major part of this condition Willow began to have many seizures on an almost daily basis. The seizures leave her with speech that is unintelligible even to me, who understands 90% of what she says. I believe the motor planning (new skills) she has learned to use her talker must be in another area of her brain; as she can still use this device even when her speech and walking have been effected

by a seizure. To me this is just simply, priceless. Now, some people may read this and think that all this is sad and tragic, but not us. Willow inspires us every single day. She is a cheeky, funny, loving and happy little girl who brightens our day and anyone's who is lucky



enough to cross her path. My immediate family's world has dramatically changed for the better since Willow came into our lives and we have met the most amazing people. I have also encouraged my older daughters to turn their worry about Willow into something positive and they have done this and more. They are now avid fundraisers for many different causes and the best big sisters anyone could dream of having. I wouldn't have things any other way and am so excited about watching all my girls' blossom on their way to becoming amazing young ladies.

#### What is LAMP?

Language Acquisition through Motor Planning (LAMP) is a therapeutic approach based on neurological and motor learning principles. The goal is to give individuals who are nonverbal or have limited verbal abilities a method of independently and spontaneously expressing themselves in any setting.

LAMP focuses on giving the individual independent access to vocabulary on voice output AAC devices that use consistent motor plans for accessing vocabulary. Teaching of the vocabulary happens across environments, with multisensory input to enhance meaning, with the child's interests and desires determining the vocabulary to be taught.

The LAMP approach was developed by utilizing motor learning principles along with the Unity<sup>®</sup> language system for the treatment of nonverbal individuals who use an augmentative device to communicate.

When LAMP strategies were used with nonverbal children with autism, they were found to increase the ability of the children to communicate spontaneously in any environment using unique combinations of words to express themselves.

It was often noted that as communication skills improved, social engagement increased, problematic behaviors declined, and some individuals exhibited increased verbal speech.

#### Why LAMP?

Individuals with dysfunction in motor planning and sensory processing are addressed with this approach. The LAMP approach continues to be enriched with the emergence of new information in neurology and motor learning and through the successes and struggles shared by parents, therapists, and emerging communicators.

As a result of intervention using the LAMP approach, it is hoped that the individual will gain the ability to independently and spontaneously communicate whatever they want to say. Learning a language takes many years for the neurologically typical individual. LAMP is not a cure. LAMP is a method for providing an individual with a language system that can progress from first words to fluent communication.

Many individuals using the LAMP approach have demonstrated success with some becoming very communicative and some increasing the amount of their verbal speech.

#### Turner syndrome (TS)

Turner syndrome (TS) is a chromosomal condition that describes girls and women with common features that are caused by complete or partial absence of the second sex chromosome. The syndrome is named after Dr. Henry Turner, who was among the first to describe its features in the 1930's. TS occurs in approximately 1 of every 2,500 female births and in as many as 10% of all miscarriages.

Diagnosis is made through a test called a karyotype, which is usually performed on cells in the amniotic fluid before birth and on cells in the blood after birth.

Turner vs Turner's? The clinical term is Turner syndrome with the "S" uncanceled. Since it is the last name of a person "Turner" is capitalized but syndrome is not. Since the syndrome does not "belong" to Dr. Henry Turner there is no need to add the S to Turner. You will find a few variations of the name as

well; Ullrich-Turner syndrome and gonadal dysgenesis. The most common feature of Turner syndrome is short stature. TS individuals are on average of normal overall intelligence with the same variance as the general population. They do, however, often have difficulty with spatial-temporal processing (imagining objects in relation to each other), nonverbal memory and attention. This may cause problems with math, sense of direction, manual dexterity and social skills. New and better ways to compensate for these problems, which currently fall under the general category of nonverbal learning disabilities, are being researched.

Several medical problems occur more frequently in individuals with Turner syndrome than in the general population. It is important that TS individuals are screened regularly to see if any of these problems exist. Most of these conditions can be managed successfully with good medical care.