

It's Only Words

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All about my family.

- Married to Richard.
- Alannah, Liam, Jake.
- Sumner.
- 6 Bedroom house.
- 2 Bathrooms.
- Gardener.
- Housekeeper.
- Swimming Pool.
- Holiday Home.



This is all the information that you need to make your first impressions of me.

Facts about my family read well on paper but in reality it is not as it seems. This is actually the view outside my window. My daughter told me if I put her photo up in the slide show that she would be re thinking my Christmas present. So we will skip straight to Liam.

What would some of you say about me now having read that information? (Ask 2/3 people)

My Children - Liam

- Liam, 7 years old.
- Attends Special Unit at Christchurch East School.
- Loves to run, Ben 10 action figure and marmite on toast.
- Has Autistic Spectrum Disorder and an intellectual delay.
- Loves to be in his own world.



My Children - Jake

- Jake, 6 years old.
- Attends van Asch Deaf Education Centre.
- Loves to run, climb, and annoy his brother.
- Is Profoundly Deaf and a full NZSL user.
- Has few friends because of communication issues.



What's True:

We really do live in a 6 bedroom house with 2 bathrooms a gardener and a housekeeper. Richard my husband is employed as a residential house parent at van Asch Deaf Education Centre where as a couple we “parent” teenage girls during the school year.

Our day to day life



We support 4 profoundly Deaf teenage girls fulltime and can have anywhere up to 8 students when the school runs a course, for out-of-region Deaf/hearing impaired students. We also support 4 people with Disabilities in the wider community on a volunteer basis.

I work full time for LifeLinks here in Christchurch as a service coordinator and in the Community Liaison role.

Our day to day life



The “swimming pool” may be a bit of a stretch of the imagination but Jake likes it.

It’s not really a holiday home but is actually our home that we only get to in the holidays. We have chosen the beautiful town of Blackball on the West Coast as our permanent base. We were welcomed into the community with open arms, which was refreshing as our own extended families struggle to accept the children’s disabilities.

So our whole world is in the field of disability. We have had many professionals involved with our family and most of them have been a pleasure to work with. Some however, have shown very little empathy and understanding of what we were going through as a family.

It was very much like being dropped into a new planet without the guide book, and it felt like everyone was talking a different language. Having to learn New Zealand Sign Language has been one of the biggest challenges that I have had to face. The order of the words is not the same as spoke English and because deaf/hearing impaired people miss out on wider contextual conversations their understanding of what is being said is often very different. Sometimes it is simply because no one has explained to them that a word can have several different meanings. The same as dealing with someone on the Autistic Spectrum, the idea that a word can have two meanings is very difficult concept to grasp.

So I live in a house where everyone is either Deaf or on the Autistic Spectrum, I am including Richard in this as he also is a very literal thinker. Myself ...

Life in our house

- Strategic meetings
- Simplified language
- Avoid sayings or using “expressions”
- Avoid sarcasm
- Facial expressions
- Body language

When Richard and I have to talk to all the children it's not a matter of sitting them down and talking to them, we have to have a strategic meeting to think about how we do this and what words to use. The girls are all black and white thinkers so using sayings and/or sarcasm is lost on them. With facial expressions and body language we may be telling a different story. The same goes with the other young people we support in the wider community. Because of this we have had some very funny moments and some that were not so funny, but I would like to share some with you so perhaps you too can jump on my learning curve.

Free range eggs



One of the gentlemen that Richard supports in the community is named David. David has Aspergers, we were taking David for a drive to Oxford one day, and saw a sign that said “Free range eggs”. David became very animated and wanted us to go back. We turned the car around and stopped at the stall and David jumped out of the car and got some eggs and jumped back in the car. I said to David that he had to pay for the eggs and David said “no I don’t they are free. I took the eggs off David and took them back, I got back in the car and started to try and explain the difference between free as in having it for nothing, and free as in animals running free. David was very upset and couldn’t understand why I had taken the eggs off him as they were free. I made the mistake of saying that it was the chickens that were free, meaning running free and the eggs weren’t. David kept insisting that they were free and I kept insisting that it was the chickens that were free, not the eggs. We were almost home by this time when David suddenly had a light bulb moment and said that if it were the chickens that were free why didn’t we get some of them. I had made the situation worse because of my explanation. This went on all the way home and David was very agitated and yelling, when we got him home and explained the situation to his caregiver they asked us why we didn’t just pay for the eggs and let David have them.

What would you have done?

A complete stranger



Our biggest focus for all our children is keeping them safe, and we are constantly telling them about “stranger danger”. Yet come Christmas we suddenly decide not only to have a complete stranger come into our lounge, and down our non-existent chimney. We also let him eat our food and drink. When we see Santa in malls we encourage our children to sit on his knee – a complete stranger.

Liam could not get the concept that Santa came down the chimney, - how was he going to do that as we didn't have a chimney. Explaining to him that Santa can make chimneys as he goes, did not work, so we tried saying that Santa can come through the door - that did not work because Liam had never seen a picture of Santa walking through a door! Obviously I have been lying.

Liam spends every Christmas night sleeping with me as he gets so anxious about this “stranger” coming into our house. Richard and I get up at 5.00am and put the presents outside and hope like heck that no one pinches them.

We celebrate Christmas in our house but Santa stays firmly outside the door.

The tooth fairy



We learnt a lesson with Santa so the tooth fairy also stays out the door. For Deaf and Autistic children trying to explain why adults make these things up for their enjoyment is often lost on them. They understand that we are telling them that these things are real and then they find out we are lying and they want to know why we did that. It may only be words to us, but to them it is like we are breaking a trust.

This car is a lemon



A friend Ricky once came to visit us out at van Asch and was driving a very flash new car. The girls all wanted their photo of them sitting in the car. Richard and I were interpreting between Ricky and the girls. Santana said that she loved the car and would get one when she was older. Ricky said to Santana that his car was certainly beautiful but it was a bit of a lemon.

Santana laughed at him and said the car wasn't a lemon it was a car, why did you call it a lemon? We then went through a very lengthy process to explain to her that it was an expression or saying, and he didn't actually mean that the car was a lemon. Ricky was just saying that there were some things wrong with it. Santana wanted to know why didn't we just say that. Why not indeed. I don't think Ricky will ever call anything a lemon again. He was actually quite shocked that they didn't get that it was just an expression. So we then proceeded to explain that when you are Deaf you often miss out on the big picture stuff. These girls come from families where the parents may not have many signs in their vocabulary so "word power" is weakened.

To explain a concept would be almost impossible for parents to do, they also wouldn't have the signing ability to joke with them so the girls miss out on this. So when you call a car a lemon it better be a lemon. If you come into our house and say it's raining cats and dogs there had better be cats and dogs falling out of the sky.

Funny though because the girls call the van Asch van that we all drive around in "The Loser Cruiser"

Gone to sleep



Pushing up Daisies



Another one of those silly sayings that are only words, but in our house led to a one hour discussion on the fact that it means they have died and were not actually inside the ground pushing up daisies. I would have to explain I have no idea how they would get into the ground and stay there until the daisies grow, and I have no idea why they would want to push them up.

One of the other things that we do a lot in the field of Disability is talk in acronyms.

Acronyms

- AODC
- ITOD
- ESW
- SLT
- O/T
- VADEC

Another thing that we are exposed to a lot by involvement in the disability field is exposure to acronyms.

Can anyone tell me what any of these mean?

What it really says

- Advisor on Deaf Children
- Itinerant Teacher of the Deaf
- Education Support Worker
- Speech Language Therapist
- Occupational Therapist
- van Asch Deaf Education Centre

This is what they stand for.

Providing a mini acronym dictionary or list for clients and families is a project we are working on developing at LifeLinks.

It's how we say it

- “You’re lucky, lots of families have it worse than you”.
- “God didn’t give you any more than you could handle”
- “Your kids look so normal”
- “He’s only Deaf”
- “My kids are worse than yours”
- “I couldn’t possibly look after your kids, they are disabled”

Finally a small list of things that have been said to me, that I found distressing and sometimes just rude. If we think about the way we use our words then perhaps we can make someone’s life just a wee bit easier.

Remember words are like arrows, don’t sling them unless you know where they are going to land.

“Night, night and don’t let
the bed bugs bite.”



Thank you.

