



*Fetal Alcohol Network New Zealand*

## **International FASD Awareness Day 2008**

### **A Kiwi Mum Shares her Experience of Fetal Alcohol Spectrum Disorders**

**Memories of my life.** I was always an odd child. I tried to keep friendships with the popular girls who took me on when I was 6 but soon I was on my own. I remember getting into predicaments, my hair was always a mess and when I got older I had few friendships and no one to play with. I still have nightmares about that. I would get teased about my looks. I was shy and very quiet and had low self esteem.

When I got to high school even the teachers left me alone or remarked about my oddness. I remember being singled out and picked on but never picked for teams. I struggled with maths and typing and always got it wrong. I tried to get out of PE because I was uncoordinated and my time in a dancing class was very short. By the 5<sup>th</sup> form I was so confused about the work I would bunk school and eventually I left without anybody caring/ helping me.

I was smoking and later got into drinking. I would go to parties and I was the one drinking too much. I felt bad about myself and so drinking heavily and one night stands was my social life. I was pregnant at 19 but had an abortion.

I then met 2 sisters who become firm friends - I was 20, they were 16. I found myself pregnant again but this happened at the same time as one of my friend so I was happy and decided to keep the baby. I was about 2 months when I found out. I was concerned about my previous smoking but it never occurred to me that my drinking might have been an issue because I stopped as soon as I knew I was pregnant. To this day I do remember having a little niggle about it but pushed the feeling away, like most people believing it's ok before you know you're pregnant. My baby was a big bonny beautiful clever, bright baby, I loved being a mum. It gave me purpose.

I am now in my 30s but I struggle with the same kinds of issues as my son. I don't have many friends. I still have memory issues but have learned how to deal with it but sometimes it gets me down. I do believe I have got better as I have got older, like I'm catching up. I believe I have FASD too but I have not tried to find out for sure. My mother was only 18 when I was born. Through my knowledge of FASD I am gaining strength to be who I am. But I feel invisible.

**Memories of my son's early life.** When my son Sean (name changed for privacy reasons) was born they put him on my belly and he looked right up into my eyes, I couldn't believe how perfect he was. He did everything he was meant too. My son flipped on his back when he was 4 months old and got around, I had never seen any other kids do that. I would tell him to watch his head near the doors and he would move it away. He crawled at 9 months and walked at 1 year.

When Sean was about 2 he would get upset when I would leave him with his carer. When he was at

preschool they would do individual plans on all the children. From what I can remember his concerns were not being able to use scissors properly and not being quiet. He starting talking early. At 9 months he was saying "what's that?" but as he got a little older people did have a little trouble understanding him at which point he would clam up but generally his vocab was amazing. I would talk to him all the time, sing to him but reading to him was the biggie.

My son had trouble sleeping. This got worse as he got older. He would appear to be asleep but when I would leave the room he would instantly be awake, I would read him endless stories (he's a good reader and loves books for that) to get him to stay in his bed. Of course it wasn't until later that I learned about how FASD children have trouble with not being able to cut out the stimuli. The sleeping trouble escalated and caused me as a single working mum great stress. I was studying to be a pre school teacher and would have no time to study and would be exhausted from working, trying to study and being a single mum. There were times when I did not do the right things and it was a hard time for both of us.

At 3 years Sean developed extreme temper tantrums. He would scream and fight me when he had to get out or go into the car. In kindy I was told Sean wasn't behaving well with other kids or not doing what he was meant to do. His last kindy report stated how he was "too confident at climbing". I thought that was silly. He was a boy. He would climb up the tall trees in the domain and get over fences without being scared of falling like other kids. He had no fear.

**School.** He started school fine and was learning to read well. He did appear to have trouble with his pencil skills (he still does). The new entrant teacher was an older 'school marm' type. Pretty soon she started to inform me about my son's behaviour. She would tell me how he was unable to keep still on the mat and kept annoying the other kids (I still get told this). Then I got a call while at work that he had hidden his lunch. I went to the school and it was in his schoolbag. I think he had hidden it and then snuck it back in his bag. Another time he had kept it in his desk and after a few days it was found stinking.

I was told of this incident and at this point was getting annoyed with this teacher. I told her that I think he did it because he didn't want to eat his lunch. She told me there was something not right with my son (I was livid about that then, but have to admit now that she was right). Remarkably enough the school put my son in a Riding for the Disabled scheme for kids with behavioural problems. He loved this, learned to ride in a few weeks but it wasn't long enough.

Every year after that, his reports were negative. He started to form habits that he couldn't stop (preservation). First it was chewing his school collars then it was an ongoing battle to stop him picking at sores on his face (pimples now). It got to the point that they would get bigger and never heal. It was always when school photo's where to be taken! It progressed to him chewing on his hands (he has scars from that). That has stopped except when he is really tired and stressed. His schoolwork was ok but his writing was messy and he didn't like to draw or colour and flatly refused to play any sports. He was good at making friends but they would tire of him quickly so he would have nobody to play with.

**Big changes.** I met my partner Dan (name changed) who was visiting from Canada when my son was 8 years old and they got along well to start with. Now I know there is a pattern with Sean where it takes him time to react to change. One morning he didn't want to go to the school swimming sports. We

fought with him to go. He refused and then went "off his tree". He would climb up the steep roof of the woodshed, he would kick and punch and say nasty things. I was working and had to leave him home with my partner. It was horrible. Things are still not completely right between them 6 years later.

We took Sean to a local paediatrician and \$100 later we were told he was being nothing more than a PIA - pain in the ass! Dan returned to Canada at the end of his visa and we decided to leave everything behind and go join him there. It was a big exciting adventure as we had never been anywhere.

**Canada.** Our move started out fine. I had planned on staying for 6 months but we returned to NZ with Dan 3 months later as I had become homesick and Sean went from not going to bed to having huge tantrums to going absolutely mental. In hindsight I can understand why he did. Dan's kids were left with us before we had a chance to get used to being in a strange place. It was tough on all of us but on top of this Sean was losing the plot. I now know it could have worked out if I had done things differently.

We settled in the South Island while Dan worked on a dairy farm and Sean went to the local school - but didn't really achieve much. We decided to try Canada again in 2004 so Dan could be with his kids. This time I homeschooled Sean for over a year while we waited for residency in order for him to go to school. I learned the hard way how he could never concentrate, pay attention or write neatly. It was a constant and very stressful battle. How I wish I knew what I know now but I didn't and so I simply tried harder to get him to do his work using force and behaviour modification.

**New school.** Sean was enrolled in a local school and was alright for the first term. Then the phone calls and requests for meetings started because of concern about homework and assignments not done and his behaviour. They suggested that I take him to a doctor to get his hearing and attention checked. The Dr suspected ADHD and referred him to a pediatrician who told me he just needed time to adjust (it had been over a year). Then he got caught shoplifting at the local store and I went hard on him. They wanted him to write a letter of apology which was a great idea. I forced him to and I battled with him for days.

We bought a farm in another province which was the most amazing daunting/ heartbreaking experience I have ever had. Sean first went to the elementary (primary) school and again ok at first then came the phone calls and comments about his socially defiant behavior, homework and work in general. He was suspended from school and I got told more or less he was "one of those kids" by the vice principal.

He brought his english folder home one day - he never normally brought his work home. I was shocked at what I saw. It looked as if a 5 year old had done the work. I couldn't believe the teacher was not concerned about this. I emailed my concerns to his home teacher and said I think he has a learning disability. Her response was that she had a son who has a learning disability and that it took her, a teacher about 2/3 years to get her son tested and that the only thing would be to go private.

I was perplexed as to what to do. I went to the school and watched my son in class to see how he was behaving or not paying attention. It seemed to me he was trying to listen to the teacher while the others around him weren't paying attention. I emailed my concerns to the Vice Principal. Sean's teacher went on the defensive and emailed me saying she didn't appreciate having negative remarks about her class. I responded by saying that I was just trying to point out that my son was trying. That was the beginning of my battle with the school.

**Finding out about FAS.** Meantime I had to find work. I applied to a nanny firm and was set up with a

family with 2 adopted toddlers, one happened to have suspected Fetal Alcohol Syndrome although they believed the mother's cocaine use played a part as well (I don't think so). To help me understand FAS, I got a book out called "Damaged Angels" written by Canadian Bonnie Buxton. This book turned our lives around! That was the realisation that my son may have FASD, making way for new hope.

I looked online and went on the FASlink site and made a connection with people in my area of Canada who gave me the name of a Dr who specialised in FASD. I took my son there and he confirmed my suspicions that Sean fitted the profile of having a Fetal Alcohol Spectrum Disorder. It was a huge new concept and very challenging and I had to go through a number of avenues to finally get to the formal diagnosis.

Looking after the little girl with FAS extended my knowledge further and I could see how she learned things, see how her brain worked and how the deficits affected her behaviour. I then had understanding about the concepts of inhibition and not being able to screen out the extra stimuli such as when getting to sleep. It made me realise why my son had so much difficulty with his sleeping and all the mistakes I made, thinking he was just a hard kid.

She had spatial disorders, was always falling over and had no awareness of the distance and consequences such as falling from the table to the ground. She'd trip off her feet and crash into things because she would just run. I soon learned after she had an awful smack into a small table that the less clutter the better and to get outside more often. The parents took her to a specialist who told them she was fine. I told them to get a second opinion, but I never told the family that at the same time my son was being diagnosed with an FASD. The stigma and the coincidence were just too great at that time.

**Getting an assessment for Sean.** Meanwhile my son was being seen by a mental health psychologist and had seen a neurologist. The psychologist, after questioning my son alerted family services because he told them his step father was mean to him and hit him. This was very stressful and almost unbelievable to me as I was trying to make things better by getting a diagnosis. Things weren't working out with the professionals or the school. The school was trying to blame us and I was trying to get a plan to change the school's behaviour.

At the same time we were trialing medication. It seemed to be suppressing his appetite but increasing his aggression and I decided to stop this despite opposition. I was told to get parenting classes and to encourage him to be more responsible and to learn from consequence. The mental health psychologist believed family life was the cause of his behaviour and never confirmed FASD.

I went against the grain. As I started learning about FASD through reading articles/ books etc and attending workshops and meeting people who were knowledgeable about it, I changed. I lowered my expectations and I let him be a little boy. I became Sean's external brain and told him what to do and made him follow it through or made things simple and made sure he understood. He became less aggressive and his bad moods lessened. He became much more compliant and responded well to my direction. Things weren't working out so well though between me and Dan however, because of the huge stress we were going through and the way he was with my son. I was changing my parenting but he was still the same. I felt resentment.

The school psychologist tested my son after the summer break. The assessment was done and she called me to give me her interpretation. I was not confident. After she called me and told me he was bright in areas of reading etc and that his behaviour was "attention seeking", I felt let down until I read it myself.

To me the assessment clearly showed his deficits and the percentiles as well as his strengths. I took it to the specialist who was surprised at the school psychologist's interpretation. He explained how low the percentiles were in his executive functioning areas of judgement, inhibition, attention, memory and sensory integration etc.

I drove 6 hours one way to visit the specialist's sister who was the only person apart from her brother who specialized in FASD in two provinces of Canada. She was a psychologist and between the 2 of them they gave me a formal diagnosis of FAS. My son has some facial features which were scored.

At the school we did get a behavioural plan done but by then we had made plans to sell the farm and to return to NZ. Also the problem at the school increased with the admin staff who, although they knew Sean had a plan, went over the school psychologist head and kicked him out of school because of the amount of time he spent in the office (the plan consisted of him being in the office for 5 mins to chill out). The vice principal of the senior school didn't care about the fact he was on a plan. On my son's last day I had to take him home without him being able to say goodbye to his friends even though they had planned a morning tea party with Canadian flags. So sad and maddening! His school counselor was livid and met with us to say goodbye and agreed to work on getting the admin to change how they dealt with students who were on special plans.

**Back in NZ.** We stayed with my parents for a while and Sean loved being with his grandparents again. Dan and I reconciled but things are still stressful at home as we're starting over.

Sean was caught stealing and has almost been kicked out of the high school he attends, even though the school claims to support special needs and knows he has FAS. He is now on what they call an Independent Education Plan although I'm not convinced that it really is. It requires a lot more work and team involvement but I'm not getting regular communication, so the frustration continues!

On a positive note I have had a real success with Sean who is finally getting passionate about something – his guitar, singing and drums. These have been supported and extended by his music teacher and our neighbours who have lent him a drum kit. Also the town has allowed him and his friends to busk with lots and lots of encouragement. It's great to see him and a small group of local kids/ teens at a street party totally engrossed in their guitars in the same spot the whole time they are there and I don't have to worry – for now!

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