University of Auckland Presentation

Haere Mai
I would like to thank Alcohol Healthwatch for inviting me to New Zealand.

I am here to speak to you as a member of the rffada and as the biological mother of two boys with Fetal Alcohol Spectrum Disorder (FASD).

Today is FASDAY, the 7th year that the world is reminded that it takes nine months to grow a healthy baby before birth and drinking alcohol during pregnancy can interfere with that process.

It is with gratitude that I am here giving my presentation when only a few years ago I felt certain my future lay as a gutter drunk. Now I have my name down in your flyer as a guest speaker AND an author.

Before I start telling you how I came to be here today, I would like to dedicate this presentation to those FASD workers all over the world who are driven by a passion borne of fear for the people currently affected by this condition and an unquenchable desire to prevent more affected births. I also wish that before too many more FASDAYs pass that every man, woman and child in New Zealand and Australia knows that there is no known safe level of alcohol consumption during pregnancy.

I began writing Alcohol and Pregnancy – A Mother's Responsible Disturbance because being an incurable optimist it is my usual approach to ferret out the good that comes from any bad that occurs in my life. However this time, even after knowing about FASD for a couple of years, I was unable to find any good that had come from knowing my sons had been affected. I concluded that the only way I could alter that was to write a book about our experiences in the hope that other people would benefit in some small way.

I would like to make it clear that I will be talking about Fetal Alcohol Spectrum Disorder (FASD) not just Fetal Alcohol Syndrome. FASD is the umbrella term for a range of disabilities caused by prenatal alcohol exposure and FAS – fetal alcohol syndrome is the most severe diagnosis. A diagnosis of FAS is based on three features - pre and post natal growth deficiency; a distinct pattern of cranio-facial malformation; and brain and central nervous system dysfunction. This only occurs early in pregnancy and can be caused by either sustained heavy drinking or just one binge at this critical time in fetal development.

On the other parts of the continuum lie the more subtle neurodevelopmental effects that lead to behaviour disorders and impaired social and emotional functioning in the child and these can be just as devastating to the individual.

Contrary to common belief 96% of women in Canada whose children have been diagnosed with FASD are social drinkers and only 4% are alcoholic women. There is no reason why this would be different in New Zealand. Warning labels on bottles of alcohol could have a huge impact on this group.

As I said I have two sons, Mick who is 24 years old and Seth who will be 21 next month.

At the time of Seth's birth in 1984 I didn't believe I was alcoholic. I drank no more or less than the many people my age I saw every Friday and Saturday night.

I certainly had no reason to think that I had delivered other than beautiful, normal, healthy children regardless of what we used to call Seth's "behavioural idiosyncrasies". I definitely didn't connect Mick's first crippling 20 months of low birth weight, poor sucking reflex, failure to thrive, restlessness and continual crying with drinking alcohol during my pregnancy with him.

At that stage for reasons probably related to the disease of alcoholism and the childhood abuse I experienced, I operated only on a very superficial level.

Mick is now 24 years old. He has been preliminarily diagnosed with neurodevelopmental disorder alcohol exposed. As an adult he suffers from temporal lobe epilepsy. However he is able to hold down a job and will live a normal life, regardless of his difficult start. But he will never know what he could have been and what he could have achieved had he not been damaged by alcohol in my womb - and that is difficult for all of us to accept.

Seth atypically for fetal alcohol syndrome was a strong baby, achieved his milestones on time, thrived well and until he was three or four did not evoke comments of inappropriate or untoward behaviour from those closest to him.

But when he went to kindergarten and school, the behaviour that at the time we thought was "cute" and merely identified him as a "live-wire" and a "go-getter" now became inappropriate and unacceptable.

This unfortunate conduct continued on through to primary and secondary school.

By thirteen years of age, he had become sexually active, used drugs and alcohol, was suspended from school, and was diagnosed with ADHD.

Underneath, though, I knew he was a sad, frightened little boy. I could see that the things he did confused him just as much as they confused us and it seemed that the harder he tried, the more his behaviour deteriorated.

Because we didn't know the true nature of his condition, we weren't able to put any strategies in place to assist him at school. Had we known, there would have been many approaches that would have helped him – not the least would have been an awareness by his teacher that he had a disability. Until we discovered fetal alcohol syndrome, he experienced a series of set backs that would have brought the strongest of us to our knees. He lost jobs, endured criticism, experienced rejection and fought frustration. He was laughed at, bullied, beaten up, cruelly dealt with by teachers and later in employment, called 'idiot' by his bosses and had jokes played on him by his workmates.

Even his parents despaired and began to wonder whether he would be better off experiencing the natural justice of living and managing his life independently.

If he didn't want to go to school in the morning he wouldn't. I could wake him up, I could put his school clothes out, I could cajole, scream, cry, yell, bribe, threaten and plead – all to no avail.

My heart would break when he came home with tears in his eyes and yet another letter from the Principal. He never knew why he kept getting into trouble. Because he could not link cause and effect, all the trips to the office for punishment meant nothing to him because he could never understand why he was there.

Seth is an extraordinarily sensitive soul and this ripped him apart to the point that suicide became a regular option for him. I knew about none of his earlier attempts – running out in front of cars on the way home from school, cutting himself with a knife, attempting to hang himself until my husband and I found a noose and ladder hanging from a beam in our shed.

The events that I have described are only the tip of the iceberg for Seth. His life is littered with unhappy experiences but thankfully because we are a close family and he is now a little older, his life has also had some very happy times and I hope he will continue to have them.

Seth currently has a partner and they live in the flat attached to our house. They are a happy couple and I am extremely pleased he has found someone who loves him as much as I do however I am concerned about their future as Hayley also seems to have some of the symptoms of FASD.

Seth unfortunately suffers from most of the secondary disabilities associated with FASD because of the frustration he suffered while trying to live up to the expectations of the people around him. Had he been diagnosed prior to age 6 and the strategies that I spoke about earlier put into place he may not have developed these disabilities.

There are many behaviours that have been difficult for us not the least his suicidal tendencies, his inability to manage money, and his anger and violence.

Early on he developed depression and anxiety but he steadfastly refused to take any medication at that stage or indeed go to the doctors. After many months of frustration I found the only way I could be reasonably sure that he would attend doctors' appointments was to tell him I would purchase a pack of cigarettes after the appointment as long as he went, cooperated and was polite. Before I discovered this strategy, I felt cornered and can not tell you how scared I was for him.

In the past I had felt guilty about bribing him but these days I will defend this approach for the greater good that it gave him. Successfully parenting a child with FASD is terribly difficult and I measure it in minutes. It is accepted with the proviso that a success this time in this situation may not be a success next time with the same situation. It was also crucial for me to forget about brilliant theories of "tough love", "natural justice", and "taking responsibility for actions" scenarios.

Taking into consideration the last paragraph, I found the only way I could get Seth to go to the doctors was to bribe him and the only thing that I could successfully bribe him with was a packet of cigarettes. I needed to get him to the doctors after a suicide attempt and the only way other than requesting assistance from the police was this method.

It worked and it probably saved his life – at least for the time being. He now has a diagnosis of schizophrenia so his mental health, while currently stable, is fragile and based on the regularity with which he takes his medication.

Another unfortunate aspect of FASD is that taking medication is problematic in the extreme. There is absolutely no way that I have found to ensure that Seth takes his medication regularly without his dad or I giving it to him personally. I know it would seem to others that he is just being a difficult teenager but it is more than that – he has an irreparable brain injury which unfortunately is invisible. Neither of them now look other than completely normal. It is only when the person is young that the facial features are visible and then if you don't know what you are looking at you may not see it.

In a study on primates undertaken by Dr Sterling Clarren in the United States, he found that the only way for a child to have the distinct facial features of FAS is if the mother drinks on the 20th day of her pregnancy. If the mother does not drink on the 20th day, the child will **not** have the features, and therefore will **not** get a diagnosis of FAS, but will still sustain permanent brain damage.

As you know, this condition can be caused by social drinking or binge drinking prior to knowledge of the pregnancy. It is not restricted to the Indigenous population or alcoholic women like me, but it's easier to identify in alcoholic women.

Seth has the facial features that could have been seen when he was younger but as we were not aware of the condition, we did not know what we were looking at. In some of the photos behind me his facial features are very obvious if you know about them ---- if only we had.

Because we did not recognize this, as I said earlier he developed the secondary disabilities usually associated with FASD and described by Dr Streissguth in the United States which from our experience are much more destructive than the primary characteristics.

Along with his compromised mental health, Seth is addicted to marijuana and also has a predisposition for alcoholism because he drinks in a way that is very familiar to me but hard to explain. There is an excitement that seems to permeate every movement he makes when he decides to have a drink as though it is not just a drink but food for his soul. I am frightened for him but powerless at the moment.

There are many people like Seth in our society and it is unlikely they will seek help for substance abuse independently. It is more likely that when they do see a professional about their addiction, it will have been court directed or someone or they will have been taken by someone else.

Seth knows that giving up drugs is the thing he must do before he considers having a baby (this of course is another huge problem for people with FASD which I will speak about later). He says he wants to give up drugs eventually but unfortunately in many cases surrendering an addiction requires the ability to understand abstract concepts such as a Higher Power or the 12 steps of Alcoholics Anonymous. These strategies are very successful for some but for the person with FASD, unless they have a very patient and experienced sponsor who is willing to provide assistance on a daily basis and be prepared to sponsor a person who will no doubt become very dependent on him or her, it is unlikely to be successful.

He has tried several times but of course like most alcoholics or addicts, it often takes many many trials before the person is even partially successful. Success measured by 'normal' standards for this group of people will almost always be well below what is expected. Although Seth has an IQ of 106 which is quite a reasonable IQ, he failed in every subject he ever took throughout the whole of his academic life.

It seems strange that somebody with an average or above average IQ cannot do reasonably well academically or understand abstract concepts, or generalise learning, but that is the case with people with FASD.

Impulsivity, perseveration, and his predisposition for substance abuse, does not augur well in the future for him or his partner, Hayley.

Parenting is another dilemma that the family will face in the future. Of course Seth and Hayley would love children eventually but parenting by people with FASD can cause great concern to the people who love them. I would love to see Seth and Hayley have a child, I would love to have a grandchild and see him or her born healthy and happy and destined for the life that his or her dad should have had, however I have grave fears how either of them would cope.

Seth I believe would have an 'out of sight – out of mind' attitude to the baby. I fear he would become entangled with some activity and forget what he was supposed to be doing with or for the baby. He would never ever knowingly or willingly do anything to jeopardise the safety of the baby but the fact remains that even if he were a perfect father, it would cause me a great deal of anxiety and stress wondering every moment of the day whether or not the baby was being taken care of and was being treated well.

I am also concerned about the possibility of Seth and Hayley not being able to bond with the baby and while I will always be there for our grandchildren, as much as I would like to, I cannot afford to stop work to look after a baby nor could I physically look after a toddler. Looking after Seth and Hayley has drained our resources significantly.

To my absolute horror Seth told me the day I wrote this presentation that he and Hayley are not using contraceptives. I have always made sure that they have some form of prophylactic and the last I knew Hayley had an implant. Apparently awhile ago it was removed by Women's Health and nothing was prescribed in its place. He and Hayley had not thought to mention this to me. When Seth saw the look of horror on my face he said "Don't worry mum she won't get pregnant." When I asked why not he said "it's been a few months already and she hasn't yet." This is his way of thinking, if it's a good thing "it will happen" if it's a bad thing or an accident "it won't happen." What wonderful optimism, but unhappily -misplaced and naïve.

As a toddler he had a charming personality. In the pictures behind me you can see how cheeky he was but also how pure and bright and innocent.

Many doctors are reluctant to discuss alcohol and pregnancy in the fear that their patient will spend her pregnancy worried about the affects that the few drinks she took prior to seeing the doctor will damage her child. It's a terrible choice to have to make, talking to the mother in order to try and save the child from a preventable condition, or have her worry for the remainder of her pregnancy. I know which one I would have preferred and would now willingly give my life for. You just have to look at the photos behind me and get inside my head for a few minutes to know. The grief of knowing these two beautiful boys have been damaged by my hand is, as I said earlier, often overwhelming. They are so non-judgemental, so forgiving, so philosophical, and I think that hurts me more. But really no matter what attitude the child has, for me the grief will be the same.

The reason that is often given by doctors for not pushing for abstinence in the mother is that it may have the effect of inducing or promoting guilt and suffering in a group of light or social drinking mothers, particularly when there has been a poor pregnancy outcome. Dr. Robert Clayton of San Antonio, retired geneticist and former Director of the Birth Defects Clinic in Santa Rosa, says that he would be able to be more helpful in handling dozens of mothers with that guilt than he currently is able to deal with one child with alcohol related spectrum disorder.

It is probable that no two mothers will react in the same way even as there are predictable symptoms of FASD each individual will have his or her own idiosyncratic behaviours, each mother will feel some level of grief but the rest is very individual.
The one thing that has meant more to us as a family than anything else is having a diagnosis. Without that we probably still wouldn't know what was wrong with Seth and may have implemented a natural justice style of process for him.

Even though when we first found out it was a difficult time, it was also the time from which we were able to start helping our sons with strategies that had been successfully implemented by experts overseas instead of making things worse by developing and implementing our own unsuccessful strategies.

It was the moment from which Seth in particular stopped blaming himself for all the things that had gone wrong in his life and started believing that he was not the "loser" he thought he was.

He has brought drugs into the house, had episodes of drug dealing, been involved in street fights and required hospitalisation stays for injuries obtained during these fights. Even now, getting drunk at a party is a concern to me because even with his medication he can still become very angry if someone provokes him sufficiently, and then in combination with his impulsivity, and lack of awareness about consequences, the situation can become volatile.

Hayley says at the moment that living with him isn't too bad – there are a few things that she finds difficult to cope with - the problems with money, his drug use, and his anger. These days his anger is not expressed as often as it used to be but it is still there and Hayley dislikes anger and raised voices. Naturally Seth's anger must be very hard for her to manage.

At the moment she is his official carer but I wonder if either of them truly realise how much I do for them and how much they need me – perhaps not. I can only hope that I will be around long enough for them to mature and be able to cope with life independently or at least with the resources and strategies I can put in place for them. It would be so much easier if there were specific facilities for people with FASD and case workers specifically trained and experienced in dealing with people with this condition, but to my knowledge there are none in Australia at the present time.

I shouldn't ignore the impact this has had on my husband and our relationship.

Don said in my first book, "I find it very hard sometimes to comprehend that my two boys who look so "normal" have a condition that cannot be cured. Right from when they were young I had an idea in my mind as to what I hoped they would be and what they were going to grow up into, with, I suppose the normal aspirations that a father has for his children. Then when they were a bit older I realised that they were not quite what they could be. I got the feeling that something was wrong but I didn't quite know what it was.

I suppose since the boys have been diagnosed at least now I can start to understand more about why or what was happening earlier on."

We all know that diagnosis is crucial but with a diagnosis comes the need for the support services not just for babies and children but for adults to be able to live their lives as well as they possibly can.

Oh God I can't tell you how I feel about what might happen to them. Don and I can only do so much. But this year with the Salvation Army in Australia raising awareness about FASD during national alcohol week and FASday and the many speaking opportunities I have had this week in New Zealand, I am heartened.

All behaviour is explainable even though we may not at first understand why someone behaved in a certain way and many people ask why I drank during my pregnancies when I stopped smoking, took folic acid and other vitamins. It isn't a question I can answer. I don't know why I continued to drink.

I didn't think it would cause any problems and I was an alcoholic – they are the only reasons I can give – they are not excuses. Combining the two with pregnancy has deprived my boys of the lives they were meant to live. So while my behaviour may not be understood at least I have had the chance to explain it through my two books.

The reason for writing my second book was that I wanted to offer the same opportunity to other people affected directly or indirectly by this condition so that the variety of behaviours which we see and cannot explain can perhaps evoke some measure of understanding in the general population.
By reading their stories it is my fervent hope that it will discourage snap judgments about the most recently publicised arsonist, shoplifter or bully who doesn't show remorse.

I hope it might encourage more thought or discussion about whether undiagnosed FASD might have hindered his or her ability to see the connection between cause and consequence and that instead of making the decision with a fully functioning brain their decision making has been compromised by a brain injury.

Each of the chapters in my second book tells the story of a birth mother or father, an adoptive mother or father, or a person with FASD. I have also added stories of professionals struggling to help people with the signs and symptoms of FASD without the services they need to truly make a difference.

It hasn't been easy to compile. There are no treatment centres for people with FASD, no diagnostic clinics, no specific support services for the affected person or their families in Australia – no place where people connected with this condition are likely to congregate.

I hope that by sharing these journeys through life others will gain comfort and benefit from their experiences.

So thank you for inviting me to present to you this morning because by doing this you are guaranteeing that my family's experiences can now be their contribution to others.

Thank you

Anne Russell

Elizabeth (Anne) Russell