Auckland Presentation

Thank you for inviting me to speak here. It is an honour and a privilege as well as a great fear of mine to speak in front of professionals because my qualifications come from life not a University. I hope I will do justice to the confidence you've placed in me. I encourage you to ask questions at the end of my presentation and please do not let any questions remain unasked in an effort to spare my feelings. I am sometimes nervous but always grateful for the opportunity to turn my family's pain into something positive.

I am here as the biological mother of two children with fetal alcohol spectrum disorder.

A visual presentation will be running in the background while I speak.

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. Warning labels on bottles of alcohol could have a huge impact on this group.

Teenagers with FASD are likely to be the people you see in the newspaper who light fires, are expelled from school for behavioural problems, who bully and are bullied, who use drugs and alcohol and who are constantly AWOL either from school or work. In Canada they are also estimated as being 70% of prison inmates.

How does this condition and consequently these symptoms impact on the individual and their family?
At the time (about three years ago) I had not been able to find anything positive about my sons' disabilities and it has always been my practice to ferret out the 'good' things that hide behind the 'bad' so I began to write a book. It is called Alcohol and Pregnancy – A Mother's Responsible Disturbance and was released last week. By writing this book I was able to find the 'good' that would come from my sons' condition.

I called it "A Mother's Responsible Disturbance" because I understand that it could cause a disturbance amongst families but I believe that it was the only 'responsible' thing to do. I also believe, like the writers of the movie 'National Treasure' that 'when there is something wrong those who have the ability to take action have the responsibility to take action.'

In this book my sons are called Mick and Seth - for the sake of consistency, during this presentation I will continue to call them by those names.

Mick is 24 and was diagnosed around 12 months ago with Neurodevelopmental disorder – alcohol exposed – one of the lesser points on the continuum. Seth who will be 21 next month has full fetal alcohol syndrome. They were both preliminarily diagnosed by Dr Sterling Clarren an expert in FASD in North America.

When my eldest son Mick was a baby he suffered from low birth weight, failure to thrive, poor sucking reflex, was very late with all his milestones and he cried almost continuously for months. When he was six months old the paediatrician diagnosed him as possibly retarded and told me I would need to wait another six months before he could give me a definitive diagnosis. I did everything I could think of to stimulate him physically and mentally and when he was 12 months of age we returned nervously to the paediatrician and to my tears of gratitude, he declared Mick to be “normal”.

No reasons were given to me for his belief that Mick could be retarded, but if he had questioned me I would have said I had been drinking.

The only time any doctor mentioned alcohol to me was when I was eight and a half months pregnant with Mick and my obstetrician referred me for an amniocentesis. I found it quite a traumatic procedure hoping that he would avoid hurting my baby with the needle used to extract the amniotic fluid. He could see I was distressed after the procedure so he advised me to “go to the pub and have a few drinks” to relax and also to stave off an early labour sometimes brought on by this particular procedure. Being an alcoholic I took this to mean that alcohol would not harm my baby and I think subconsciously this gave me permission to continue to drink during my pregnancy with Seth.

Since then Mick has not had any problems of this nature through providence and the fact that I did not use alcohol as freely as I did with Seth, it seems he can live a normal life.

He can budget; he has a full time job which he has had for a number of years; he can be relied upon to attend appointments, take medication and respond to letters; and he doesn’t use drugs and only uses alcohol socially. He does have Temporal Lobe Epilepsy with which he was diagnosed at 10 years of age but as long as he takes his medication, it doesn’t make a huge difference in the way he lives his life.

When Seth was born it was obvious he was everything that Mick was not. Apart from the unfortunate miscalculation on the part of the anesthetist who didn’t give me enough anesthetic to stop the pain of the caesarian, his birth was normal. He thrived, his birth weight was good, he met and exceeded his milestones and it was only when he reached 12 years of age that I started to have niggling little doubts about him. When he was diagnosed with ADHD at 13 I felt secure in the belief that we had found the problem. After the medication stopped working my fears re-surfaced. When it was obvious he was using drugs and alcohol at 13 I didn’t know what to think. I couldn’t imagine why he was doing the things he was doing. He was overbearing, argumentative and clumsy. My heart broke when I saw him use a scooter that he had bought on holiday - his clumsiness and immaturity drawing only heated and angry comments from the people he accidentally bumped into.

I can’t tell you how often I felt so much pity and anguish for him that I didn’t know how I was going to get past it. I learned that I had to stop feeling this level of pity and fear for him or I would not cope in the long term and this would not benefit anyone. But it was hard. He never excelled in anything, he never won anything, he never received so much as a “Trying Hard” ribbon, when all he *ever* did was try hard. But it was never recognised because Seth’s “trying hard” was like everyone else’s “stuffing up”. I knew how hard he was trying, Don, my husband knew, Seth knew, but no one else did. If we had known about this condition when he was at school, much of this damaging frustration and disappointment he experienced could have been avoided and perhaps he could have grown up feeling good about himself instead of feeling like a failure and a loser. My heart aches just to think about how he must have suffered.

By the time we had a correct diagnosis when he was almost seventeen he had amassed many of the secondary disabilities from the frustrations of his primary condition.

He has:

- Schizophrenia and suicidal tendencies
- Very poor academic performance and early school dropout
- Trouble with the police - at this stage this is by no means extreme although it has taken great dedication and a lot of money to avoid
- Drug and alcohol addiction
- Huge problems with employment to the extent he can only work 3 days a week and then requires an on the job support worker with him
- Is currently on Disability Support Pension where I trust he will remain for the rest of his life

He also has trouble:

- linking the linear effect of cause and consequence
- generalizing rules
- violent and aggressive behaviour when not on medication
- with Central Auditory Processing Disorder although this has not been formally diagnosed
- and as a young child he suffered from hyperactivity and was diagnosed with ADHD.

The diagnosis of ADHD is a mistake made most commonly because many of the symptoms of FASD can be similar to the symptoms of ADHD. Many times this diagnosis is made because it will not cause undue guilt or anxiety in the mother as would most certainly a diagnosis of FASD.

The problems that I feel will impact Seth the most severely throughout his life is his complete lack of ability to responsibly take his medication, manage money, attend appointments, action mail and see to requests by government agencies or departments. Even though he is on the disability support pension it still doesn’t preclude him from attending appointments with our welfare agency Centrelink. Without assistance he will not fulfil these obligations.

Even though his fiancé Hayley is his carer, over the years they have been together, and from information she has gradually divulged it appears she could have been affected by alcohol prenatally as well. She doesn’t seem to be able to remember to take medication or attend appointments or to budget so I can’t assume just yet she will be able to be Seth’s “external brain” when I can no longer fulfil these duties.

The trait of not taking medication is common amongst people with FASD and now that it is more important than ever for Seth that he take his medication and I can’t rely on either he or Hayley - I have to remind him every night. Unfortunately it is not merely a matter of saying “Don’t forget your tablet Seth”, I have to go into his flat every night and say “take your medication Seth.” His usual response is

"I'll take it later." The nightly dance then shifts to "Seth, I'll get the tablet out for you." He says "Its OK I'll do it later." I walk to the tablets, get one out and hand it to him. He holds it in his fist and looks at me. I say "Take it Seth!" He says "I need water." And so I get the water and watch him take it. This happens every night and if I forget or I'm away and Don doesn't do it, he doesn't take his medication. It sounds like pure nastiness doesn't it? It is hard even for me to believe but it's not.

When he doesn't take it, he becomes angry, violent, aggressive and paranoid. He doesn't like himself like that nor does Hayley and I am sure he can see that the medication makes him better but still we go through this production every night.

He has gotten into some dreadful situations through not taking his medication. He has ruined furniture, cut his wrist and tendon by punching a window, deliberately tried to run into a brick wall in his car, thumped his car so that there are dints in the bonnet, punched holes in doors and walls and generally been miserable. But he can't seem to make the connection that the medication will alleviate this anger and pain for him if he takes it regularly.

He uses drugs and alcohol to excess and gets angry if he can't buy cannabis. I have facilitated these purchases many times because the alternative is beyond my comprehension. I understand though that some of these behaviours are exhibited by anyone with an addiction regardless as to whether they have a brain injury or not.

Getting him to go to a doctor's appointment is not something I can assume will simply occur because it is important. He can not see that going to the doctor is crucial to his physical and mental health. I sacrifice everything that I know is proper and correct as a mother by buying him cigarettes as a bribe for his cooperation.

I have never blamed anyone but myself for my sons' problems but I often used to say "If only" ----------
If only Mick had been correctly diagnosed, Seth would NOT be affected.

If only the paediatrician had said that Mick's retardation appeared similar to that seen from pre natal alcohol exposure.

If only the obstetrician had not tacitly given me permission to drink after the amniocentesis.

If only I had not been an alcoholic – then Seth would be fully able to use his God given potential.

A woman does not usually set out to deliberately harm her unborn child – if it occurs the reasons are multifaceted and complex.

The reasons I drank through my pregnancies are because I had no idea alcohol could harm my babies and I am an alcoholic. If I had any reason to believe alcohol was harmful I am sure I would have stopped drinking but I can't say this with certainty unless I had been told very clearly that by drinking I could be sentencing both my child and myself to a lifetime of pain. If they had also told me that the baby I was carrying could be the baby who cries all day and night for months; could be the child who screams and throws tantrums in the supermarket; could be the young teenager who uses drugs and alcohol and roams the streets at night; or that my baby could grow into the young man who will never be able to live a normal life, or work in a normal job, or live independently then I know I would have stopped – but who would have had the courage to do that for me?

My first pregnancy occurred 24 years ago but medical professionals are still allowing pregnancies to go through to birth without asking these questions or giving relevant information about alcohol and pregnancy.

I believe that we all need to be more prepared to discuss the combined effects of alcohol and pregnancy amongst ourselves, with our colleagues, with our clients and most particularly with our patients.

I know that not wishing to discuss this issue with a mother has its roots in sensitivity and compassion but it is the child who will suffer if the condition is not diagnosed and appropriate strategies put into place. By not discussing alcohol and pregnancy through misplaced compassion, we are hurting one person for the sake of another. Very few mothers would want that but that is exactly what is happening – by not discussing this thoroughly with mothers children are being sacrificed to ensure that the anxiety level of a mother is kept within acceptable limits - neither mother nor child will benefit from this methodology. It is far better for both parties if our concerns are expressed and questions raised that few have been willing to raise in the past.

Many times, the secondary conditions such as mental illness (schizophrenia, depression and anxiety), substance abuse, autism, RAD, ODD, ADHD, ADD, Asperger's Syndrome are diagnosed as primary conditions when in fact FASD is the primary condition. Some of these diagnoses imply that even though the condition elicits behavioural anomalies, the affected child does not have a brain injury and so is able to make some changes to their behaviour if they wish to. This is not the case with FASD as there is a structural brain injury and so the child is unable not unwilling to make the changes necessary.

A correct diagnosis can prevent subsequent children being born with FASD. It is always crucial that the correct diagnosis is given no matter now tough it is for the mother or the doctor because the strategies that will be used to assist a child with the above conditions will be different to the strategies used to help a child with FASD both at home, at school and in employment.

This will no doubt cause a disturbance, but if it is moderated by appropriate support it will be a responsible disturbance.

So what are the symptoms and signs of prenatal alcohol exposure?

A pregnancy is a "whole of family" experience and each family member has a role to play and a stake in the outcome. But when a mother finds out that her child has been harmed by her alcohol consumption she is likely to bear the guilt and remorse solely on her shoulders and it is not a lightweight burden. It can be overwhelming, overpowering, debilitating and destructive and can cause many other problems for the individual and her family if it is not managed adequately and support is not forthcoming.

I remember when I first saw the words fetal alcohol syndrome and made my own desperate connections, collapsing on the bathroom floor sobbing in grief like I never knew was possible, surrounded by wet towels and Seth's T Shirt thinking that I would never move from that place on the floor. But I have moved in body, mind and spirit – not all the time, but most of the time now not letting my grief and guilt rule me. I have fortified myself against it somehow because my children and my family have always come first (alcoholism, integrity and devotion aren't mutually exclusive).

It took many weeks of research and introspection before I was willing to discuss this even with my husband. I wondered if he would leave me, whether he would blame me, or whether this was the end of our marriage of almost 30 years. I had borne guilt before but nothing like this. I spent many nights shaking with anxiety - and still sometimes do – when I think of what I have done.

My husband being the man he is did not blame me, although I know he is desperately sad for our children.

In Australia research just released has found that 1.2 million women have during past pregnancies consumed alcohol or are currently consuming alcohol while pregnant. These are horrendous statistics and do not bode well for future generations. Health professionals, government and non government organisations from all countries need to give consistent messages to their patients, clients and the community that there is no safe level of alcohol consumption during pregnancy. No alcohol equals no risk. No one these days would consume mercury or thalidomide during pregnancy – alcohol is a teratogen, a substance that causes birth defects and as such as no place in pregnancy.

My sons' lives could be vastly different to the lives they currently live and their futures would have been different. All I ever wanted for my children was for them to live a happy healthy life which I am sure is all most women want for their children. My husband and I have a long and loving marriage, my sons have not been abused in any sense of the word, they are part of a loving, caring family whose values and morals would have placed them in an excellent position to live happy lives filled with love and joy. We could have provided a good education for them, but because I drank alcohol while I was pregnant, their happiness and health does not rest on the shoulders of their loving childhood environment but at the door of ignorance, addiction and denial.

I would do anything to change that if I could but at the very least I can help make changes in other people's lives – the changes I would give me life to make in my own.

The Hippocratic Oath clearly exhorts "Above all do no Harm". Sometimes the harm that is done is not done by doing something wrong; it's by doing nothing at all.
Thank you

Anne Russell

Elizabeth (Anne) Russell