Dunedin Presentation

Good morning/afternoon, my name is Anne Russell and I am the founder of the Russell Family Fetal Alcohol Disorders Association. I am also a recovering alcoholic and the biological mother of two children with fetal alcohol spectrum disorder.

I have a visual presentation running in the background with some important dot points and about FASD and photographs of my children. Please forgive the Australian statistics instead of New Zealand statistics.

I would like to be very clear about the difference between fetal alcohol syndrome and fetal alcohol spectrum disorder. Fetal alcohol syndrome or FAS is caused by heavy drinking during a short period in the first trimester.

From primate studies it is believed that that window is on the 20th day of pregnancy. If the mother drinks at that time there is a likelihood that the child will have the facial features of fetal alcohol syndrome such as flat midface, short palpebral fissures, flat philtrum and thin upper lip and small ears set back on the head.

If the mother drinks at any other time during the pregnancy the baby's brain could still be injured but there will be no identifying features. In other words the child will look completely normal but will still have been damaged. This alcohol related brain injury covers the remainder of the spectrum. Most children with FASD have normal intelligence and normal facial features which belies a significant disability.

For example if the spectrum were one metre long, fetal alcohol syndrome would be 2 centimetres and the remainder – alcohol related neurodevelopmental disorder would be 98 centimetres long. So you can see that children with the facial features are just the tip of the iceberg.

The condition has different symptoms and different behaviours at different times during the child's growth. As a baby the affected child will cry a lot, not meet milestones, have failure to thrive, will have a poor sucking reflex, a low birth weight and a small head circumference. As a toddler they might be hyperactive, and have a great deal of trouble sleeping. They may have trouble eating certain foods. As a young teenager their behaviours may become increasingly delinquent, they may begin using drugs and alcohol, often be truant from school, be the bully or be bullied, be suspended or expelled from school and by at risk for not completing intermediate, and begin getting into trouble with the police. As an older teenager, they may not complete their schooling, have trouble with employment, further substance abuse issues, mental illness and have more and more contact with the police.

How does this affect a family who is unaware of the reasons for this behaviour?

Towards the end of my drinking I found I had come to a crossroads. I could either continue to drink and leave my family so they would not have to watch me deteriorate to the gutter drunk that I believed was my future, or I could stop drinking and concentrate on assisting my then 14 year old son Seth with his behavioural problems.

With unqualified gratitude I chose the latter. It may seem like a simple choice to you, but I can assure you that the mind of an alcoholic is complex, irrational and very peculiar.

When I achieved sobriety, I talked with my family and encouraged them to be frank with me about what they had suffered during the years of my drinking. To my complete and utter joy, they said that they were unaware I was an alcoholic and that nothing I had said or done had given them cause for concern.

Because I was just naïve enough to believe that this was actually possible I cried with relief and for a long time afterwards felt absurdly delighted about my competency as an alcoholic.

After four years coping and not coping with Seth's behaviours, anger and immature behaviour; and four years of substance abuse, calls to and from the police, dismissals from jobs - and daily and sometimes, hourly uncertainty about what calamity had befallen Seth, I was completely baffled. What on earth was the matter with him? Why didn't he hold down a job? Why did he become so angry I feared for my safety? How could he even consider being a drug dealer? What had I done wrong for him to do these things?

I was looking through the Internet in order to discover the answers to these questions and chanced upon three words which physically and emotionally brought me to my knees ---"FETAL ALCOHOL SYDNROME".

As I read, everything came together but it also fell apart. Seth's behaviours and idiosyncrasies at last made sense. Until then I could believe I was one of the few alcoholics who had come through to sobriety without causing any harm.

Instead I had stolen my sons' potential and my husband's dream of having two healthy, happy children.

I didn't know that alcohol could harm my babies.

Surprisingly I wasn't completely unaware of the requirements of a healthy pregnancy - I took folic acid, iron, multivitamins and I stopped smoking. But to my never-ending sorrow, alcohol did not have the same sinister implications for me at that stage as did smoking. Regrettably for some it still doesn't.

Mick is my eldest son and is now 24 years old. He has been diagnosed with neurodevelopmental disorder alcohol exposed. As a baby and a toddler, he was markedly developmentally delayed, he cried almost non-stop for months on end, failed to thrive as a baby, had a poor sucking reflex, and did not achieve his milestones on time – symptoms so typical of prenatal alcohol exposure.

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, 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 we thought was "cute" and merely identified him as a "live-wire" and a "go-getter" became inappropriate and unacceptable.
This unfortunate and immature 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 he was a sad, frightened little boy. I could see that the things he did confused him just as much as it 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 the 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 derided by 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.

My heart would break when he came home from school 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.

I am paying particular attention to the distress this condition has caused Seth and his family because I want to ensure that everyone understands just how destructive, painful and confronting this condition can be.

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, and attempting to hang himself until my husband and I found a noose and ladder hanging from a beam in our shed.

In my experience of FASD it is far better to have an accurate diagnosis no matter how disturbing it is than to wrestle with the seemingly unconnected behaviours and problems as we did over the years; and it is far better for the person to know.

When I revealed my suspicions to Mick and Seth about their prenatal injury, Seth was as delighted as I was distraught. Finally there was a reason for his behaviour and he now knew he was not the "loser" he thought he was – he had a name for what was wrong with him and we had a diagnosis.
With this came a prognosis and proven strategies that we could use to help him. We also understood that Seth had a disability and had been unable not unwilling to do what had been expected of him at school and home.

He is now on a Disability Support Pension which means that he is not required to carry out mutual obligations in return for his allowance. Without a doubt he would not have any income support if he were obligated under his allowance to undertake job searching activities or to attend scheduled appointments.

On first meeting Seth he seems capable, healthy, agreeable and certainly able to work. Anyone assessing him without a neuropsychological assessment and extensive knowledge of fetal alcohol syndrome would surely assess him as competent.

I believe this is one of the most appalling aspects of the condition – it is primarily an invisible disability unless the people performing the assessments have experience with FASD.

The facial features exist only in the most severe of cases and in some instances blend in with the normal facial features of the individual, so it is not always able to be identified as easily as some other disabilities.

Where there are the facial features, there is always a brain injury but there can be a brain injury without the facial features.

In many cases, unless you actually live with the person it is hard to believe they have a medical condition let alone a disability.

I know that many times when accessing services for Seth, I have been viewed as an overly involved mother rather than a persistent and informed advocate.

As you may know, the primary characteristics of fetal alcohol spectrum disorder are:

- neurological problems (such as impaired motor skills, poor coordination, hearing loss, visual problems);
- behavioural and/or cognitive problems such as:
  - intellectual disability
  - learning difficulties;
  - poor impulse control;
  - problems in social perception;
  - problems in memory, attention, reasoning and judgment and
  - deficits in some mathematical and language skills.

However, the secondary disabilities are just as distressing if not more so than the primary characteristics

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Seth suffers more from the secondary disabilities that he developed through being undiagnosed and having to live up to the expectations people have of non brain injured individuals.

So along with his teachers, employers and friends, we placed expectations on him that he was never going to be able to fulfil.

The first secondary disability that became noticeable to us was a mental illness.

He gradually became more and more depressed and anxious. This in turn triggered his use and abuse of drugs and alcohol. At twenty years old, he is still using drugs heavily, and uses alcohol sparingly but with a predisposition for alcoholism. Ninety four percent of people with FASD have a mental health problem and thirty percent abuse drugs and alcohol.

Seth found intermediate and high school very difficult, once again because of the expectations placed on students at that level. He struggled through to year 10 but left before he was able to complete the final exams.

His results until that time had been very limited – a failure in every subject. He has a normal IQ – 106 but his executive functioning is compromised by his condition so that he is not able to use his intelligence. Forty three percent of people with FASD drop out of school early.

When he left school he found a job. He is verbally competent and therefore very competitive in interviews for unskilled positions.

Because his receptive language ability is nowhere near as good as his verbal expression, he constantly sets himself up for failure by talking up his ability in an interview with an employer and then not being able to follow through in practice. Seth has had many jobs but until he was able to access on-the-job support, none lasted longer than a couple of months and then no doubt with a great deal of patience and/or exasperation on the part of the employer. Eighty percent of adults with FASD have trouble in employment.

Until Seth was diagnosed with schizophrenia and placed on the appropriate medication, he was a hair's breath away from becoming seriously involved with the legal system. Sixty percent of people with FASD have been in trouble with the Police.

The last secondary disability is "inappropriate sexual behaviour". Forty five percent of people with FASD exhibit these behaviours.

It's not hard to link some of the items we see in the newspapers and on television about the perpetrator of a rape or sexual assault who has shown no remorse. Inappropriate sexual behaviours combined with lack of understanding of the relationship between cause and effect is a combination that can have serious consequences and result in such news items.

Seth's problems have far reaching consequences for him, for us and for his future partner. He is unable to see these consequences, which in a way, is a good thing because they may not be pleasant.

At the moment he cannot see, nor would I want him to see that many people with his condition are in the papers for rape, assault, child abuse, stealing, neglect and murder. Many victims of FASD are struggling to live happy, contented and financially viable lives and are only rarely succeeding.
This is not a condition with a happy ending, only a series of happy events throughout the life of the person and their family.

The catalyst for me to research ADHD and discover that fetal alcohol syndrome existed was the day he was dismissed from a job for stealing.

Seth still believes that the employer who dismissed him did so for no reason at all. Even after he was found with incriminating evidence in his pockets and witnesses to his theft he does not believe he was responsible. Even now, four years after the event he still cannot connect the two.

Not being able to link cause and effect has considerable repercussions in employment, social and personal relationships and just about every aspect of life.

Combine it with the impulsivity that is inherent in the condition and it is a recipe for disaster both at an individual and a community level.

Seth also has great difficulty budgeting and managing money to the extent that I am his official financial administrator. Without assistance I am absolutely certain he would now be living on the streets – homeless.

And this is what happens to many people in Seth’s position. Family disown them or set them loose to learn the consequences of their actions for themselves – which of course leads to serious trouble for an individual with substance abuse, mental health, a propensity for illegal activities and no stable family environment.

It is estimated that in Canada approximately 70% of inmates could have FASD.

For some mothers, even though it is a societal rather than individual guilt, knowing they have played a part in bequeathing this condition to their child will be enough to cause unbearable anguish.

A mother will react according to her upbringing, her stability, and the level of support of family and friends. I certainly wondered if I would ever get over the remorse, fear and anguish that brought me to my knees almost daily for months after I discovered FAS, until I realised that this reaction would not help Seth, Mick or my husband – and would, in fact, add to their burden. So I searched, read, learned and became as informed as possible about FASD. When I had put into place for him everything I possibly could, I turned to the wider community.

In a way it was a selfish move because as long as I was busy and helping people I was able to cope with what I had done.

I know it is difficult to discuss alcohol consumption with a pregnant woman but what will happen if you don’t? Who will do it if you don’t?

Will she have children like mine? As beautiful as they are we would both prefer they still have their God given potential.

It is difficult to tell someone they have cancer, it is distressing to assist in the birth of a still born, it is challenging to live with the guilt of being responsible for decreasing the ability, happiness, potential and promise of one’s child - but it is harder still to be that child.

If I were to be asked to describe an adult with FASD – how would I describe him or her?

In my experience, they are good looking and agreeable but have probably been in trouble with the police in the past. They always seem to get into strife, sometimes even for the same things over and over again, they can get angry quite quickly but if you change the subject they also calm down quickly. They want to be needed and liked and they will do almost anything for the people they call friends even to the extent of giving them something, the loss of which, will impact quite dramatically on their own lives.

They usually have a mental illness of some sort, probably depression, sometimes schizophrenia or bipolar. They are ‘good’ people in a ‘child like’ way. They treat strangers like friends and friends like family.

They are probably not in employment, but will tell you they have had quite a few jobs and tell you they aren’t working now because they didn’t like the boss or a colleague.

They will probably not have finished school and will not have done well with their grades. They will have been truant for some of the time certainly in secondary school but probably also in the higher grades of primary school.
They will not have a car unless their parents have provided it and help run it. They a

re not likely to have any money and will usually spend their welfare payment the day they receive it. They will usually be in debt to someone, either their friends or family. They may take money or valuables from those closest to them because they don't understand about property. And unless they have been diagnosed at birth and have had continual access to services, they will know what Cash Converters can do for them.

They need help before they become involved with the police for something that will land them in prison because in prison they will learn skills that could keep them caught in a cycle that will lead them inexorably to tragedy.

Also from experience I know that medication is crucial.

Because there are no statistics available for New Zealand and Australia, I have had to use figures from North America. Using this guide, there could be as many as 39,000 people in NZ with fetal alcohol spectrum disorder and as many as 500 affected babies born each year.

This condition places strain not only on the individual and his or her immediate family, but also on friends, relatives, the community in which they live and society itself. How long are we going to allow these individuals live lives of desperation, failure and despair simply because they have an invisible disability? How long are we going to accept that our babies are being sacrificed so as our anxiety remains at a reasonable level? When are we going to consistently hear that no alcohol in pregnancy equals no risk?

The Hippocratic Oath suggests “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 for allowing me to speak with you today.

Anne Russell

Elizabeth (Anne) Russell