

Darwin Presentation –No Blame No Shame

Thank you for inviting me to speak at this workshop. My name is Anne Russell and I am the biological mother of two children with FASD.

SLIDE 1

SLIDE 2

It will forever be my greatest wish not to have experienced that which brings me here today, but as that isn't likely to occur I appreciate this opportunity to tell my story.

I encourage you to ask questions at the end of my presentation which I will endeavour to answer candidly - and please don't leave questions unasked in an effort to spare my feelings.

Included in my presentation are photographs of my boys – particularly of my most affected son.

SLIDE 3 AND 4

Had I known about this condition when they were taken, his flat philtrum, thin upper lip and idiosyncratic behaviours would have screamed out to me, and subsequently, his life would have been very different to the life he lives today. But like most mothers, all I saw at the time was my beautiful son.

SLIDE 5

Since finding out about FASD and the damage that alcohol has done to my children, I have written two books both of which are available for sale at this conference. In these books my boys are called Seth and Mick. To maintain consistency I will call them by those names throughout my presentation.

Seth features more predominantly in my books because he was most beset by behavioural, cognitive and social dysfunction from the age of 12. Mick, on the other hand suffered most in the months from his birth through until he was about 5 years old. Then, apart from having a small stature and regular 'absences' which were later diagnosed as temporal lobe epilepsy, he has been able to function normally. In my first book I describe how he endured constant crying, poor feeding, failure to thrive, constant viruses, colds, and flus, and most unhappily, potential hearing problems, cognitive difficulties and slow milestones.

Seth on the other hand was a model baby and toddler, and although very active, was considered within 'normal' bounds. But as he grew older, his behaviours manifested in more antisocial and dysfunctional ways.

Even though there was a lot of medical and factual information on the Internet about FASD, there did not appear to be anything specifically for birth mums with the intention of helping them to recover from the grief and guilt. All I wanted to read was how another birth mum coped so I could get what I had done into perspective. My second book is dedicated to birth mums and is entitled Alcohol and Pregnancy – No Blame No Shame. I also interviewed 17 people who had been affected by FASD either as a sufferer or carer in the hope that those people who did not connect with my story might be able to connect with one of theirs.

SLIDE 6

Mick is now 26 years old and is still the least affected with a diagnosis of Neurodevelopmental disorder – alcohol exposed. Seth is 23 years old and has full fetal alcohol syndrome and is permanently and irreversibly disabled.

My books would not have been written and I would certainly have nothing to offer people such as you had I not accumulated a reasonable list of the mental illnesses and conditions Dr Sterling Clarren, in his research, found consistent with alcoholic birth mothers.

My mental health was seriously compromised by a series of events that occurred during my childhood and adolescence and when I discovered what alcohol could do for me, I truly and passionately believed that it was my salvation and the only way I might be able to continue living.

I was a functional alcoholic for almost 30 years during which time Mick and Seth were born. However it would be a mistake to imagine that only alcoholic women will give birth to children with FASD. In research undertaken in Canada, it has been found that 96% of women who have given birth to children with FASD are described as social drinkers.

Mick was born in 1981. Smith and Jones had published their observations about FAS in 1973 eight years prior to his birth, but I was not screened for substance abuse nor was alcohol mentioned or discussed at any time by my obstetrician until I had an amniocentesis. Then I was directed to go to the pub and have a few drinks to stave off labour. Twenty six years later – thirty two years after Smith and Jones published, doctors in Australia are *still* not giving a consistent message about alcohol and pregnancy.

At the time of Seth's birth 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 at the pub.

SLIDE 7

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 "little idiosyncrasies". I certainly 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.

SLIDE 8

My view of Seth's health changed completely when he reached 12 years of age and began to have serious trouble at school outside of his poor academic showing. He started using drugs; his normally low grades plummeted even further. He became more unruly, was focused on sex more than the average 12 year old and became completely unmanageable.

SLIDE 9

By "unmanageable" I mean I had **no** control over him. If he wanted to go out at night he would go out. I could tell him he wasn't allowed to go out at night, I locked the doors, we put security screening on his windows but still he went out whenever he wanted. I spent many many nights awake, waiting for him to come home. My husband Don and I explained the rules to him over and over and over and over without seeing any change in his behaviour even though he agreed to abide by them.

If he wanted something, regardless of how ridiculous it was, he would nag and nag. It didn't matter that we didn't have the money to buy whatever it was he had become obsessed with. I could show him our bank book and he could see that we didn't have the money. The thing – whatever it was he perseverated on was usually a silly toy, a trinket, it was so strange. **He** didn't have the money to purchase it but he would come back again and again pestering and harassing me, often stamping his feet like a four year old. Many times I felt sorry for him, that he would have to resort to this sort of behaviour to get what he wanted. Often my

heart broke for him because he was also uncoordinated and clumsy and others would treat him with disdain and over and over again my heart went out to him. I think some of these feelings came from my own childhood and I hope now that he didn't feel the way I imagined he was feeling because that would be too horrible to imagine. I could never ask him if he did because I could not cope with the answer if it was 'yes'.

He could also become very angry and violent and he has ruined furniture by cutting it with knives (when I used to leave them out), has threatened me physically and punched and kicked holes in walls and doors. 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.

Bribery didn't work at that time because I hadn't yet honed the art. It was a skill that I soon learned well. Bribing him became the ONLY way to get him to do things that he HAD to do, things that are a part of our everyday world that we take for granted. These things such as going to the doctor's and attending Centrelink or other appointments, we just assume are easy for everyone to do, but not so people with FASD. As he grew older, I could not assume Seth would do these things simply because they were important and would result in negative experiences for him and by default, Don and I.

He could not see that going to the doctor was crucial to his physical and mental health. I would sacrifice everything that I knew was proper and correct as a mother by telling him that I would buy him a packet of cigarettes after he had been to the doctor.

In what I thought was desperation at the time – I found out what real desperation was a few years later – I took him to a paediatrician who subsequently diagnosed him with ADHD.

This was a relief to all of us - including Seth. I could see it in his eyes and in his behaviour that having a reason for some of the things even **he** couldn't understand was very important to him.

The thing that as his mother, I am so very aware of, is that regardless of his delinquent behaviours, underneath, where most people would never be bothered to go, he was and is a loving, caring young man and I don't think there has ever been a time in his life that he has not tried hard to do the right thing. And that is the one thing that completely undoes me when I think too long and hard about it. The fact that he tries and tries to do the right thing, the best thing, the loving thing, but to everyone but Don and I, his 'trying hard' is like everyone else's 'stuffing up'.

SLIDE 10

When Seth was fifteen I knew I needed to get more information about what was happening to him. He had just been dismissed from his job for stealing money to purchase drugs; and the previous night my husband Don and I had found a ladder and noose in the shed that he agreed later he had erected in order hang himself. The day after this had occurred, I searched the Internet for information on ADHD, and found an article on fetal alcohol syndrome and it hit me in the face – that was it!

I am sure it is only because I am an alcoholic that I believed my instincts when I saw those words. There must be tens of thousands of mothers who have no idea why their children are behaving the way they are, no idea that their drinking many years ago may have something to do with their child's academic fiascos, behavioural anomalies, poor mental health and escapades into alcohol and drugs.

I have to say here that finding out about this was a very emotional time for me – it was when I found out what real desperation felt like. It was something I may not have survived without the support of family and friends. In all my life I wanted to make a difference, save a life, ensure that my life had meaning not only to my family but to others with whom I came in contact and above all else I wanted to make sure my children didn't suffer the same sort of abuse that I had.

This item in the Internet shifted the ground from under my feet. It not only heralded a huge transformation in the future of my family but even though I was an alcoholic, it violated the principles on which I had lived for most of my life. Alcoholism and integrity are not always mutually exclusive. The guilt I felt was huge. I remember driving to work one day and when I thought about what I had done, my heart hammered in my chest and I wondered how I would ever make this right and whether Seth would live past the next five years.

This guilt was more than I had ever experienced in a lifetime of guilt and I wanted more than anything now to read something written by a birth mother to see how they coped. I dreamed of it at night and thought about it during the day.

I didn't understand why that one important voice that had been so silent when to me it was so crucial that we hear from it. Was it because of the shame and guilt? If so wasn't that just perpetuating more shame and guilt through not speaking out? It was baffling – but I had more important things to content with at the time.

While believing that FASD was the missing piece of the jigsaw puzzle that had mystified us for years, it took years before we truly understood the impact that it would have on our lives and more importantly – the lives of Seth and Mick.

Before I could help Seth, I needed to get the opinion of my doctor.

Many unhappy and unproductive visits later – to GPs and paediatricians, I was still no further forward in unearthing the factor or factors that would save my son from an almost (at this stage) inevitable suicide. I gave up on the formal diagnosis or any assistance from the medical profession at that stage and continued my research on the Internet. I found so much information I hesitated to truly believe I had never before heard of FASD. As I looked through it all two things hit me. The first was that there was nothing from birth mothers and the second was that there was nothing from Australia. The more I researched the more that both of these incongruities were confirmed.

SLIDE 12

I emailed her and described my situation and the concerns I had about Seth and Mick. She suggested I continue trying to find a doctor who would help me. Luckily, the consequence of another thwarted suicide attempt, resulted in Seth and I meeting a locum, who immediately understood what was needed and prescribed Epilum and Aropax which was later reviewed to Zyprexa because of his decline into psychosis.

Until then, Seth could have died at any time.

This was a powerful experience for me and even though I have the highest regard for medical professionals, I felt betrayed and probably worse - misguided about my admiration for them.

So the relief I experienced at having a doctor understand the condition and prescribe appropriate medication was immeasurable; because now I had an ally, someone with whom I could share my fears and who would provide me with input and ideas and share the burden of keeping him safe. I still didn't have a diagnosis but until then at least we had him appropriately medicated.

I think the reasons I had no real response from doctors before I found this doctor was because they were hoping to spare me the negative feelings that their confirmation of my informal diagnosis might have.

But I believe that shame, guilt and remorse are emotions that no doctor needs to take into consideration when deciding whether or not to discuss this with his patient other than assessing her psychological health in order to offer support and referral options. There is no question that for the child's sake the condition must be discussed and diagnosed.

A doctor can't sacrifice the baby for the sake of stigmatising the mother or elevating her anxiety levels.

In late 2001 Seth, then 17 years old and Mick 20 were preliminarily diagnosed by Dr Sterling Clarren in the United States. It had taken almost five years from first seeking medical assistance to obtaining an accurate diagnosis for Seth.

SLIDE 13

For Don and I, the defining moment in the management of this condition both emotionally and physically was having a diagnosis. Even though 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 trying one unsuccessful strategy after another.

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.

The ONLY way to help and support a child with FASD is to have an accurate diagnosis because with a diagnosis comes a management regimen – without a diagnosis there can be disappointment, pain, mental illness, addictions, prison and death.

Alcohol must be discussed with pregnant women, women thinking of becoming pregnant and with mothers whose children exhibit the signs and symptoms of this condition.

Some mothers may not feel the same way I have; they will react according to their upbringing, their belief system, their ability to feel or their current family situation.

Health professionals will need to be well prepared because it simply will not be easy to discuss this with a mother who may have been drinking alcohol prior to knowledge of her pregnancy or because she may not have realised the potential for damage. She may *well* become anxious and distressed but so will the patient when he is told he has cancer. In both cases hard facts will hurt, but in both cases they must be said.

If I could go back in time I would say to my doctor with respect:

"Even though my baby has not yet been born I am a mother and I am already humbled by the exquisite phenomenon of motherhood. With complete and unqualified conviction, I charge you with the health of my baby first and above all else. I trust that you will not allow my beautiful child to be wounded for any reason that is preventable and that you will provide me with accurate information regardless of how it might affect me. I have faith that your agenda is the same as mine – to bring into the world a child who will not be burdened by the effects of a preventable illness."

Any doctor who is presented with a child, teenager or adult who has a history of ADHD, suspension from school, petty crime, aggressive or violent behaviour, drug and/or alcohol problems, eating problems, inappropriate sexual behaviour, suicide attempts, mental illness, getting into trouble for the same thing over and over again and who has a mother who presents as at her wit's end, should be asking her the question.

"Can you remember whether you used alcohol before you knew you were pregnant?"

That question is the least threatening because it suggests that the alcohol use was prior to the pregnancy being known. The answer to that question will give you the direction you need to take – ie whether there is a likelihood of the child having a brain injury or whether there is something else going on.

So I beg any health professionals in the audience to ensure that the discussion on alcohol and pregnancy is not omitted through your desire to alleviate a mother's shame, guilt and anxiety.

The book that I wrote in response to the lack of items in the internet from birth mothers is. I know whenever I present, people in audience say this information is the missing piece of a long standing and frustrating puzzle. It all makes sense to them and it gives them a reason for their child's behaviour, or the behaviour of their nieces or nephews, or their partner, their friends' children or that unruly child in their classroom.

It makes sense out of something that previously made no sense at all – that's why discussing this condition and bringing it out into the open is the only responsible thing to do. Blame, shame, guilt and remorse must be surrendered if we are to satisfactorily assist birth mothers. A long time ago I felt shame and guilt at having been sexually abused however I know now that it wasn't my fault. I also know that even longer ago, being sexually abused *was* considered to be the child's fault.

We have surely come along way since those days so I'm certain that if we put our collective minds together, we can make the stigma felt by health professionals, mothers and other members of the public diminish or disappear just as the stigma of having been sexually abused has diminished dramatically over the years.

We all need to be agents of responsible disturbance in our community. Once this condition becomes more well known in Australia it will be easier, but the only way that it will happen is for people to do something – to talk about it – to have conferences like this one – agitate – and disturb so that instead of blame and shame, we have a kind of affirmative action!

The Hippocratic Oath implores "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.

Anne Russell

Elizabeth (Anne) Russell