

## Is Fetal Alcohol Spectrum Disorder a Rural or Remote Issue? – A Mother's Perspective

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*Conference: Rural and Remote Australia: The Heart of a Healthy Nation*  
*Location: Perth*  
*Presenter: Elizabeth Russell*  
*Date: 14<sup>th</sup> March 2011*

### **SLIDE**

Good afternoon. Before I commence my presentation I would like to suggest we have a moments silence for those people in Japan who are suffering after the Tsunami.

THANK YOU –

I would like to pay respect for the traditional owners of the land past and present on which this conference is taking place.

Thanks also to the organisers for inviting to speak today.

### **SLIDE**

My name is Elizabeth Russell and I am the Queensland Representative of the peak body for FASD in Australia NOFASARD and the founder of the Russell Family Fetal Alcohol Disorders Association. I work on behalf of these organisations but my primary role is that of a mother to two adult children with fetal alcohol spectrum disorder.

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 and help raise awareness of FASD.

If alcohol is a rural and remote issue, then Fetal Alcohol Spectrum Disorder is a rural and remote issue. Because FASD is caused when alcohol is consumed while pregnant, the two are permanently and irrevocably entwined.

I've just returned from the 4<sup>th</sup> International Conference on FASD in Canada along with some of my co-presenters. There were a thousand delegates at this conference and it was wonderful to talk to so many people who understood FASD.

I heard some amazing information and research at this conference that surprised me, but one of the things that didn't was that some researchers have re-estimated the prevalence of FASD upwards. Their estimate means that we have around 220,000 people affected with this condition in Australia.

### **SLIDE**

When I was my children were young I was living in the rural mining towns of Greenvale and Tieri both in Queensland.

### **SLIDE**

Greenvale was a nickel mine and Tieri is in the Bowen Basin. Alcohol and one-upmanship were the key links between many of the people in these towns. Each weekend was an excuse to have a barbeque or to go to the pub which was considered by many including myself to be an extension of our lounge room.

### **SLIDE**

I drank no more or less than other young women my age pregnant or not. I often wonder what has become of the children of my friends in these towns where the consumption of alcohol did now slow for pregnancy.

At this point I should explain what having Fetal Alcohol Spectrum Disorder means to the individual.

**SLIDE**

FASD is an umbrella term for disorders which can be caused when alcohol is consumed when pregnant. The alcohol, no matter how much or how little, crosses the placental barrier and circulates through the baby's system.

The alcohol remains with the baby longer because the mother metabolises it with a fully formed liver whereas the baby's liver is small and undeveloped.

**SLIDE**

There is no known level of alcohol consumption during pregnancy that is safe for the baby because alcohol is a neurotoxin and a teratogen which is a substance that causes birth defects.

**SLIDE**

There are a range of effects on the child from "mild" to severe. The mild effects may not result in mental retardation or any overt or obvious disability but it is possible that the brain has been damaged and the executive functioning of that person compromised. While the child grows and appears normal there could be subtle and not so subtle problems associated with the prenatal injury including quite significant behavioural problems because alcohol is also a behavioural teratogen – a substance that causes behavioural problems.

**SLIDE**

At what many people call "the severe end" but in actuality is not when it comes to obtaining services and support, there can be the same behavioural problems but the child will also have the facial features of FAS and could be intellectually compromised ---- but not always.

**SLIDE**

A flat philtrum, thin upper lip, flat midface and short palpebral fissures should alert health professionals to look further.

**SLIDE**

In a study on primates undertaken by Dr Sterling Clarren, a world renowned expert on FASD for over 30 years found that the only way for a child to have the distinct facial features of FAS is if alcohol is consumed during the period of gastrulation which often occurs on the 19<sup>th</sup> or 20<sup>th</sup> day of pregnancy.

**SLIDE**

If alcohol is not consumed during that period, the child will **not** have the facial features, and therefore will **not** get a diagnosis of FAS, but will still sustain permanent brain damage and possibly organ damage.

Years after we left rural Queensland, I found myself through a series of related and unrelated jobs working in an employment agency under contract to the government to provide employment services to very remote indigenous communities in the Northern Territory, Cape York and Northern Western Australia.

**SLIDE**

It was clear that alcohol played a huge part in the destruction of families and the culture of our Indigenous friends. In fact Alastair Hope a Coroner from Western Australia declared 'You know how you destroy a culture? ...You make sure that kids are born with alcohol foetal syndrome, (sic) they won't be able to pass on the dreamtime and the culture.' And indeed this is what is happening. From my experience FASD and alcohol between them are decimating Indigenous culture with people who were once warriors sitting in gutters begging for coins to buy another bottle.

People with FASD themselves are giving birth to children with FASD who grow up not being able to successfully participate in the mainstream programs that employment agencies like the one I worked for designed and developed to help them out of their difficulties because their brains work differently.

I can't think of a more important issue for rural and remote Australia. Services need to be trained; sufferers need to be identified and parents and carers need to be supported and of course work must go into the prevention of this condition through education and awareness. The Liliwan Project in Fitzroy Crossing will help in raising awareness of FASD and will also provide the first minimal prevalence study in Australia of FASD.

**SLIDE**

Included in my presentation are photographs of my boys – particularly of my most affected son Seth. 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 may have been different to the life he lives today. But like most mothers, all I saw at the time was my beautiful boy.

**SLIDE**

Seth is 26 years old with a diagnosis of full fetal alcohol syndrome and his own family.

**SLIDE**

Right now he seems to be doing extremely well however he has a two year old which overwhelms him sometimes, he is overweight because of his last job as a taxi driver but he is a good person who tries very hard not to do anything wrong.

**SLIDE**

Seth was born in 1984. Smith and Jones had published their observations about FAS in 1973 eleven years prior to his birth. I wasn't screened for substance abuse nor was alcohol mentioned or discussed at any time by my obstetrician until I had an amniocentesis. Then he told me to go to the pub and have a few drinks to stop me going into labour. Twenty six years later – thirty seven years after Smith and Jones published, only 2% of medical professionals feel confident in dealing with FASD and from reports from parents and carers received by NOFASARD and the rffada, most do not give a consistent message about alcohol and pregnancy.

At the time of Seth's birth I don't believe I was alcoholic. 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**

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, focused on sex more than the average 12 year old and became completely unmanageable.

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, I 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. Don and I explained the rules to him over and over and over and over without seeing any change in his behaviour.

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. **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 two year old.

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. Later though bribery became an excellent method of getting him to do things that were essential to his health but which he refused to do.

**SLIDE**

Getting him to go to a doctor's appointment was not something I could assume would simply occur because it was important. 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 – because if I didn't he would not attend even if his life depended on it.

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.

I am very aware that regardless of his delinquent behaviours, underneath, where most people would never have cause to go, he was and still is a loving, caring person 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.

Until he was diagnosed and properly medicated, the misfiring synapses and damaged neurons that inhabit his brain created so many difficult situations for him I often wondered how he was able to keep going.

When Seth was 15 I knew I needed to get more information about what was happening to him. He had just been sacked 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.

**SLIDE**

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 - they were talking about my son!

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 many years ago may have something to do with their child's academic fiascos, behavioural anomalies 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 caused the bottom to drop out of my world. It not only heralded a huge transformation in the future of my family but also violated the principles on which I had lived for most of my life. Alcoholism and integrity are not mutually exclusive.

I genuinely thought I had got through without hurting anyone with my drinking. The children didn't realise I was alcoholic; my marriage was still solid; I hadn't done anything too stupid; I didn't sleep around ----- I was arrogant in my belief that I was the only recovering alcoholic in the world who had spent 30 years drinking and lost nothing.

While believing that FASD was the missing piece of the jigsaw puzzle that had baffled 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. In the small town that we lived in during this time my options were limited. In Greenvale there was a health clinic staffed by nurses and in Tieri there was one hard drinking, hard working, extroverted, Irish doctor.

However during the period where I was trying to find support for Seth, I was in a town which had several medical professionals so I never once considered that I wouldn't get the support I needed from one of them. Nevertheless 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 and continued my research on the Internet where, after wading through so much information I hesitated to truly believe I had never before heard of FASD, I found information from a South Australian woman called Sue Miers.

#### **SLIDE**

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. It was a powerful experience for me that I sought and couldn't find a doctor to help me and even though I have the highest regard for medical professionals, I felt betrayed and probably worse - misguided about my admiration for them.

However as a consequence of another thwarted suicide attempt, Seth and I met 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.

The relief I experienced at having someone 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 Seth appropriately medicated.

I think the reasons I had no real response from doctors before I found the locum, was because they were hoping to spare me the guilt they believed would be associated with an acknowledgment that FASD was Seth's problem. While I think this played some part in it, I also had a strong conviction that none of the doctors I went to knew anything about

FASD, one even told me so. So coupled with the complete absence of any FASD specialists in Australia, our situation and the situation of others in the same position, is bleak.

But the guilt that birth mothers often feel is not something that doctors and other medical professionals need to take into consideration when deciding whether or not to discuss FASD or alcohol and pregnancy with his or her 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 wellbeing of the baby to keep the guilt from the mother because eventually it will come out. Whether it's because FASD has been identified or because the mother blames herself for her child's behaviour she will feel guilt of some sort. It is the nature of motherhood.

#### **SLIDE**

In late 2001 Seth, then 17 years old and Mick 20 were preliminarily diagnosed by Dr Sterling Clarren in the United States.

For my husband 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.

Doctors must discuss alcohol with pregnant women 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.

Doctors 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 experience 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.”

Doctors in rural or remote settings have a far greater responsibility to their patients. While a single discussion about alcohol and pregnancy can filter through a rural or a remote town in a heartbeat so can advising one woman that it is okay to have a few drinks while pregnant. The former can produce healthy children and the latter can cause no end of pain and suffering over a lifetime.

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 medical 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 first book that I wrote was my 'responsible disturbance'. It is called Alcohol and Pregnancy – A Mother's Responsible Disturbance and is now available as a free download from my website. 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.

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 agitate – and to disturb!

FASD is devastating. Do you know of any other disability that results in sufferers being good at small talk but without substance? A kind heart but a violent temper; complex needs but no insight; a small frame with big expectations and perhaps worst of all, a damaged mind and a beautiful face.

THANK YOU

20mins

Questions