

# Women's Referral and Access Conference Presentation

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Thank you for inviting me to speak today at this conference. I am here as a member of the rffada and also because I am the biological mother of two children with fetal alcohol spectrum disorder or FASD.

Behind me a visual presentation will loop. Photos of my family interspersed with dot points about FASD but will not correspond to my presentation

As you heard earlier, FASD is an umbrella term for disorders which can be caused when a pregnant woman drinks alcohol. If a woman drinks while she is 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.

This means that there is no known level of alcohol consumption during pregnancy that is safe for the baby.

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 a behavioural teratogen – a substance that causes behavioural problems.

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

In a study on primates undertaken by Dr Sterling Clarren, a world renowned expert on FASD 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.

So 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. In fact research by Doctor Margaret Clarke a Canadian researcher found that 96% of mothers who have children with FASD are social drinkers and only 4% are alcoholic women.

Many times over since I found out about FASD, I've wondered what difference it would have made to us as a family if only one person had asked about my alcohol intake during my pregnancies. If just one of the many health professionals I visited had mentioned that alcohol was damaging to my babies. Its one of those 'if only' moments that wont make any difference to my family now but might make a world of difference to others.

This one comment from my medical practitioner might have resulted in my youngest son having a very different life to the one he lives today. But not only does the question have to be asked, but the answer has to be followed up and put to use. For some people asking once whether they have been drinking might not be enough. They will be the alcohol dependent, or the women with far too much stress in their lives for them to cope without the help of alcohol or other drugs. So follow up and support are two of the three most important aspects of helping people who are at risk of having a child with FASD. If someone had asked, I might have said I had been drinking, but unless the person who asked explained to me the consequences of my drinking, I may not have taken this information seriously enough. This was because I had known people who drank through their pregnancies and they had delivered apparently normal, healthy babies. Peer experiences often outweigh information given by professionals.

Of course now that I know more about the condition, I understand that it is often hard to tell when a baby is born that they have been exposed to alcohol. For some children like my son, who had an Apgar score of 10, it is often only when they reach puberty that a true understanding of the consequences can be appreciated.

So while health professionals may advise a pregnant woman about alcohol and pregnancy, her peers and their experiences may 'outrank' the information that's provided.

This puts women, especially mature women in a powerful position when discussing childbirth and pregnancy with younger women. If you have any indication that a pregnant mum may have been drinking or may BE drinking, it is important that you take the time to discuss with her the consequences of continuing to drink. It is also crucial to understand that 50% of mothers who give birth to children with FASD have FASD themselves so for these mothers just telling them that alcohol is dangerous to their child will not be enough. If they have FASD they may understand what you are saying but will lack the ability to put that advice into practice when they are with their friends.

My youngest son's name is Seth and he is 23 years old next month, but he often behaves as if he were fourteen. He requires antipsychotic medication to stop him from hurting himself and others, can only work with support and is on the disability support pension.

It is unlikely he will live independently, the Public Trustee is his financial administrator and he has abused drugs and alcohol since he was thirteen and is now an alcoholic and an addict although that is only my opinion. Nevertheless he is an innocent. He calls people mates after only knowing them for a day and believes everything they say even when the rest of us would clearly be cautious about their agenda but only recently has trusts me to act on his behalf.

Every decision I make has multiple consequences for Seth.

In the past I have bought his drugs for him. I am being honest because it is an horrendous condition not just for the individual concerned but also for the carers who must discard everything they know about successful parenting and parent by the seat of their pants. Natural justice does not work with these children. So I bought his drugs, because not doing so would have meant a hole in the wall at the very least, or at the worst, he would have hurt himself or someone else. But that is in the past – I hope.

My oldest son, Mick will be able to live a normal life but needs to take medication for temporal lobe epilepsy. I have only just found out how devastating this sort of epilepsy can be. Fortunately Tegretol keeps him stable.

As a baby Mick was delayed developmentally, late for all his milestones, failed to thrive, cried almost non stop for what seemed like months and appeared to have a hearing disorder which was later found to be a processing fault rather than a mechanical problem.

His paediatrician preliminarily diagnosed him as “retarded” when he was six months old only to be reassessed at twelve months as “normal”.

You might think that someone who has given birth to children with problems as significant as these would have consumed a great deal of alcohol during her pregnancy.

Drinking any amount of alcohol is not conducive to a healthy pregnancy but I didn’t drink as much as some people may expect. Actually, in the media recently a well known medical professional was quoted as saying, “you would have to drink eight drinks a day to have a child with FAS.” This of course is not true. As I said earlier research has shown that a mother would have to drink on the 19<sup>th</sup> or 20<sup>th</sup> day in order for her baby to have the required facial features of full FAS. So many people are unaware of FASD even those who should be aware.

As far as what I drank when I was pregnant: I know I had possibly two or three drinks some but not all evenings when I was pregnant with Seth. This consumption is only a little more than the NHMRC Guidelines of two drinks per day. I did stop smoking and I took the vitamins recommended for pregnancy but I didn’t know that alcohol was dangerous. No one told me and it wasn’t in any of the books I read.

If I could only express to you what I go through when I see Seth drunk or stoned, when I see my beautiful son suffering because of something I did ----- there are times when I don’t how I will live through the night with grief so overpowering it almost seems impossible. I thought my life had been hard but when I visualize Seth’s future I realise I know nothing.

But even though our lives can be difficult, it is better for us because we know what’s wrong with Seth. There are many many families who do not understand why their children are behaving the way they are. These are the families who may have no idea that their child is affected until he or she reaches puberty when the behavioural problems are exacerbated by hormones and the higher expectations placed on teenagers.

By then it will no doubt be difficult to relate back to the pregnancy and the few glasses of wine each day or even, in some cases, each week.

Women and our community in general could make such a huge difference – we could be courageous and consistent voices in the melee of information about healthy pregnancy. If you don’t do it can you assume anyone else will? Not from my experience.

If I could go back in time, I would say to my health workers 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.”

This is not the hardest way for women to learn about FASD.

Even learning about it after they have been drinking during the pregnancy is not the hardest way. My children have learned about FASD the hard way.

But harder even than this is having the condition and not knowing. And this is the way it is for hundreds of thousands of people in Australia.

Parents of these children might be completely baffled by their behaviour. They might be utterly at a loss wondering when these kids will ever understand the consequences of their actions.

And why, if they were given every opportunity in life have they chosen to run around with peers who disrespect property and people and use drugs and drink?

Why, with educated and thoughtful parents do they do so poorly at school?

Why, when the work ethic has been so thoroughly ingrained in them by two working parents, do they not keep their jobs for more than a couple of months?  
Learning about it this way is the hardest way of all!

I am in a better position than most parents of children and teenagers who cause them concern. I don't need to ask “What did I do to cause my children to behave in this way?” or “What could I have done differently?” or “Why is this happening?” I know what has caused these problems for my sons. There is no need for me to wonder and, while it is difficult, it is better than not knowing at all.

Before Seth knew he had a “condition” it was hard for him. He experienced an inordinate amount of emotional and psychological pain. He has lost friends, has had suicidal thoughts most of his life, he knew that he wanted things but when he tried to get them nothing worked out the way he planned. He is intelligent enough to know what he wants but too damaged to be able to make it happen.

He has had the pain of addiction, the challenge of appearing outwardly capable, and the anguish of not being able to meet others' expectations.

He has known the sorrow of awareness that others feel contempt towards him but does not know how to make the changes that would turn that opinion around.

When he first found out he had a “condition”, a medical problem from which most of his problems stemmed he was as relieved as I was distraught. Now that I can comprehend just how much he needed to know that his problems weren't because he was a “loser”, I am also relieved ---- and thankful that circumstances provided us with the opportunity to discover this.

If Mick, my first child, had been diagnosed as a young child, Seth would **not** now have FASD.

Along with the heartbreak of being a birth mother, there is also the very real and hugely complex task of parenting a child or children with FASD. It is exceptionally demanding, in fact, to paraphrase Diane Malbin, a FASD worker in North America ----- parenting children with FASD is like trying to navigate around Sydney with a map of Melbourne.

People who do not have intimate contact with this condition will not understand, so parents will have the added burden of being judged by those around them including their own family.

Unfortunately the methods of raising children with FASD by definition have to be different. A child with Down Syndrome would not be raised in the same way as a child who has normal genetics – it would be unfair and damaging to the child with Down Syndrome.

If an attempt is made to raise a child with FASD in the same way that a “normal” child would be raised which is what I did until Seth was 16 years and Mick was 20 years of age, then that child is likely to suffer secondary disabilities as a result of the frustration associated with being treated as though there is no brain damage and they can do the things that are expected of other children. This is where the majority of Seth’s problems stem from.

For the sake of the child, parenting has to be markedly different with these children.

In most cases the affected child will do things regardless of the wishes, advice, demands or approval of the parents. Many of the things Seth did when he was young were not done with my approval or my husband’s approval, they were not part of the value system with which he was raised, they were not socially acceptable nor desirable, but most were outside his control and very indicative of his brain injury and the condition itself.

So what is happening to the children in Australia who aren’t aware that they have a brain injury and whose parents, relatives, friends and teachers aren’t aware?

They are slowly but almost surely developing secondary disabilities.

In the absence of identification, people with FASD often experience chronic frustration. Over time, patterns of defensive behaviours commonly develop. These secondary disabilities include **Mental Health Problems** - the most prevalent secondary disability experienced by ninety four percent of people with FASD. Sixty percent of children with FASD have ADHD and are often diagnosed with ADHD as the primary condition.

**Disrupted School Experience** (suspension or expulsion or drop out) is experienced by 43% of school aged children. **Trouble with the Law** is experienced by sixty percent of those people aged twelve and over. **Confinement in an institution** is experienced by sixty percent of those aged twelve and over. **Inappropriate Sexual Behavior** was reported in sixty five percent of adult males with FASD and the last secondary disability is **Alcohol and Drug abuse** which is experienced by thirty percent of individuals aged twelve and over.

Every night we see these people on the news.

It is my hope that along with information about FASD my presentations serve to generate a more balanced discussion about the most recent news item where a young person does not show remorse

about what he has done, or the mother who is convicted of murdering her children who is later identified as having alcoholic parents, or the latest figures on bullying at school, or the increase in cases of ADHD.

Instead of immediate condemnation of these people perhaps we can listen with a more informed ear and speculate whether there might be more to these cases than first meets the eye.

How can you help?

We can talk about alcohol and pregnancy, help women give birth to children not burdened by this preventable condition. We must always remember regardless of the circumstances, regardless of whether the mother knows that alcohol is harmful, and regardless as to whether they are alcoholic or social drinkers, there MUST be a “NO BLAME – NO WAY” ethos. Without that mothers may not seek assistance for their alcohol abuse or they won’t disclose that they drank during pregnancy. We must all be caring, compassionate and prepared to help. This HAS to be a no blame condition. For most mothers the life long sentence of guilt and remorse will be punishment enough – there is no need to add to it.

Four months ago my employer offered me a promotion of sorts from site manager to program manager. The catch was that I would have to relocate to Cairns. I expected that Seth and Hayley would want to come with us and that Mick would prefer to stay in Mackay. I was wrong on one count – Seth and Hayley chose to stay. This posed a huge dilemma for Don and me but we decided that we would go to Cairns and leave the kids in our house in Mackay. This would test their ability to live independently from us physically but still with a high level of support from us financially and emotionally.

Since June this year, many very difficult things have happened in their lives but they have coped albeit with difficulty, at no time have they decided to give up and move to Cairns. I am very proud of their tenacity under the most difficult of circumstances. In this order, the following situations occurred for them:

- Seth ran over a little girl who was taken to hospital but was discharged that day. The police did not take it any further because it was not his fault but he cried for days
- Because of trouble at work Seth lost his job
- His car required \$2,000 worth of repairs
- He took too long to pick up his medication from the doctor and went 7 days without an antipsychotic which resulted in more holes in the walls and Hayley ringing me in tears worried about his behaviour, yelling, threatening to kill himself
- His cat was killed
- Hayley was not paid by an employer for work that she did
- Hayley and Seth were paid \$250 to clean her sisters new flat however it wasn’t up to the standard the owner required and it caused all sorts of relationship problems between Hayley and her sister

They have managed these issues and more and have retained their sense of humour however I fear for them, I ache for them and I just want to hold them both until life treats them as well as they both deserve. I will do everything I can to prevent other people from going through what my son is going through. Thanks for giving me this opportunity.

I have written a letter to a pregnant mum based on personal experience that I would like to share with you all today – Do I have time?

**My letter to a pregnant woman**

When I saw you and your partner celebrating your friend's birthday with party poppers, laughter and ample alcohol I was tormented. Is it a contravention of a woman's civil liberties to advise her that drinking can harm her child? Or is it a contravention of the baby's human rights not to?

I glance at you again and I can see you've been drinking. You toast the birthday girl with red wine and a short speech. You're happy and everyone laughs at your story as your husband pats you gently on your large rounded tummy.

After what seems like hours of deliberating but is only minutes, I make a decision in favour of the baby and walk over to your table. My husband knows what I am thinking and grabs my hand silently asking if I know what I'm doing. I do – I think. My son and his fiancé watch me. And this is when we meet.

By writing this I wanted you to know what went on in my mind before I spoke to you - what I was thinking and how difficult it was to make the decision to do so. I wanted you to know that I considered your feelings, your partner's feelings and your friends' feelings but none of that came close to the health of your baby. There really was never a time from the moment I saw you with a drink in your hand that I was not going to speak to you.

I sit down on an empty chair next to you and from the corner of my eye I can see my husband staring apprehensively at us, no doubt wondering if he would need to physically remove me from your table should you react badly to my message.

I say 'Hello, my name is Elizabeth.' I pause and moisten my lips which have become suddenly dry, 'I wonder if anyone has mentioned to you that alcohol can be harmful to your baby.' I said looking down at your tummy. You stare at me and I can see that you are considering whether you are in physical danger from me.

Then you say quietly but with authority, 'My doctor said it was OK to have a few drinks!' I nod and reply, 'Doctors aren't giving a consistent message – in the United States they recommend abstinence.' From the corner of my other eye I see your partner stop talking and look over to us. I feel surrounded but hurry on. 'If you stop drinking now it will increase your chances of having a healthy baby.' Your partner moves closer and I say 'Hi.' He nods back.

I smile at you both and before I move back to my own table I give you my telephone number. I tell you to ring me if you would like to talk to me. I also tell you I have more information if you want it. I leave – more nervous now than I was on the way over. I wonder what I have done, knowing all the while that if I truly believe in the title of my first book then I have done the right thing. Discussing this condition almost without exception will cause a disturbance but also without exception it will be a responsible one. I hope that you enjoy the rest of your pregnancy alcohol free and I hope that you don't worry too much.

I know that telling you not to worry after my earlier warning is next to futile, but I would much rather have spent nine months concerned about the health of my baby than knowing that my beautiful son's ability could have been protected by someone revealing to me that one little truth.

As I walk back to my table, I can see the unease in my husband's eyes. He would rather I mind my own business, but he also knows that I can't – not with this issue anyway. He's a good man but doesn't like to ruffle feathers. God knows how he has managed in the last few years.

I glance back at your table and see you looking at me. I also see disquiet in your eyes and I'm sorry it's there. But it's better now than later.

I hope that one day you will know somehow that my intentions were good and my information was accurate.

Goodbye and good luck.

*Anne Russell*

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