

An Interview with Anne Russell about her experience with FASD

The questions below are those that have been asked by delegates at conferences and by various media representatives over the last few years. For some people, the birth mother's perspective fleshes out the condition where medical information and statistics cannot. Indeed, there is no way that any medical or allied health professional can truly understand the enormous impact of this condition on the affected person and his or her family without recognising and accepting this perspective.

Q. What was it like for you when Seth and Mick were diagnosed with Fetal Alcohol Syndrome and Neuro-developmental Disorder – Alcohol Exposed?

A. I am sure that the feelings a mother has for her children are without doubt the most uncomplicated yet powerfully complete emotions that human beings are capable of experiencing. I love my children so unconditionally that I am completely overwhelmed by what I would do for them.

I am proud of them. They didn't need to achieve academically or in sports although if they had I would have been pleased for them. All I needed to see for me to be proud of them was what I see every day of their lives – their inner strength, personality and character and their courage in the face of their individual difficulties.

When I found they had FASD, I was devastated. I felt a mixture of relief and disbelief. I was relieved there was only one problem for us to deal with instead of a number of unrelated problems, but at the same time, I couldn't believe that Seth particularly was so disabled because of something I had done. I have never been able to describe this feeling adequately. I felt so completely *responsible*.

I knew I couldn't keep feeling those negative feelings because I would not be able to cope if I did, so I used a cognitive behavioural technique called 'thought stopping'. Every time I started getting those feelings and thinking about Seth, I stopped the thoughts. Eventually I was able to think about it and talk about it without having those destructive feelings and this is where I am now.

Q. How did the children react?

A. They seemed to be okay initially. There wasn't much of a reaction. They wanted to know what it meant for them and of course we didn't know at that stage - we didn't know what we didn't know. Seth told me later he was relieved because once he had this diagnosis, everything made sense to him; why his behaviour was the way it was; why he couldn't manage at school; why he couldn't make any friends and why he had so much trouble at work. They were good to me; didn't lash out or lay blame. Don and I had agreed that they may say some hurtful things because the consequences to them were so great. We agreed that we would allow them to have their say for a short time but would not support censure or criticism in the long term.

Q. How did you explain Fetal Alcohol Syndrome to your children?

A. We were all gathered in the kitchen. Mick was sitting on the kitchen bench, Don was sitting on his chair and Seth and I were standing. It was sunny – a Sunday morning. I started, 'I've always thought that my drinking didn't cause you both many problems, but I was wrong. A couple of months ago I found there was a condition called Fetal Alcohol Syndrome. When a pregnant woman drinks alcohol, it can cause this condition in her baby...' I tried to explain the rest as well as I could. Sometime during this Mick said, 'What does that mean for us?' I hated telling them but the boys deserved an explanation. So that's how they reacted initially – with surprisingly little emotion. Mick has always been okay about it because he was not so severely damaged, but Seth – there are times when I don't know why he just doesn't yell, 'Why did you do this to me!' But he doesn't. In a way, I wish he would.

Q. How did your husband (family, friends etc.) react?

A. They were all so very supportive, of Seth and Mick of course, and also of me. They have supported everything we have done. Don has never blamed me or said anything to hurt me and the boys have both been wonderful.

Q. What do you find the most challenging about FASD?

A. I don't think there is any one thing more challenging than the other. Everything about this condition is challenging. It seems that the brain injury results in symptoms that, when combined, couldn't be more devastating. What disability results in sufferers being good at small talk but with no substance to their observations? Then add 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 but a beautiful face.

Q. What are your thoughts that we should not diagnose FASD because of the guilt that will be experienced by women?

A. I think if we do that, the child is sacrificed so that the mum does not have to bear any guilt. We don't do that with any other disability in the world. We are throwing away any chance the child may have for a better life when we do that. People have no idea what they are sentencing the child to when doctors choose this route. To make a choice to condemn a child to a life where he or she has a significant, invisible disability with no one to turn to, no supports, no understanding that he or she has a disability, no friends who understand. I don't imagine any mother would want that for her child if she had the choice.

Q. If you had the power to make any changes in Australia in relation to FASD, what would you do?

A. I would like to see a massive campaign targeting all Australians aimed at educating them about the devastating results of using alcohol in pregnancy. I would also ensure there is a clinic in every capital city and every major regional centre that provides free multidisciplinary service for parents, carers, friends and family of affected individuals.

It would also be important to provide training in all aspects of support for affected people of all ages, support groups for birth mothers, support groups to cope with behaviour of affected children. Then I would ensure that everyone in Australia understands the link between prenatal alcohol exposure and crime, drug and alcohol use, recidivism and rising mental health problems, violence, relationship breakdown, child abuse, sexual abuse, parenting problems, literacy and numeracy problems, rising levels of autism, Asperger's syndrome, attention deficit hyperactivity disorder Having said this, I know that we need to prepare various studies and research relevant information and statistics so we have our own information, but my focus is on affected people and their parents and family. There are enough people suffering to warrant services in each city as an adjunct to community health with people who completely understand the behaviour of an affected person and completely understand what parents and family members need to deal with on a daily basis and what services the individual needs to live a full and satisfying life.

Q. Why is it so important that FASD be diagnosed sooner than later?

A. I don't think this question would be asked if the disability was diabetes or epilepsy, or a heart condition. There really shouldn't be any debate about this. The sooner that FASD can be diagnosed, the sooner appropriate strategies and interventions can be put into place to support the individual and his or her parents and carers to minimise the damage. It will also reduce the risk of a subsequent birth of a child with FASD; it will ensure the correct strategies and interventions are used; it gives the individual, his or her family and friends reasons for the individual's behaviour and it will give us a better understanding of the incidence of FASD.

Q. What were the implications of a late diagnosis for your children?

A. Neither of the boys had the support of a one-on-one assistant at school or the benefit of understanding teachers. There could have been so much more I could have done to help, particularly Seth. He has almost all of the secondary disabilities which may have been prevented with correct support. We could have made changes to the way we managed money by introducing the Public Trustee as a matter of course at a younger age. He could have died at any time – that very difficult time for us all may have been avoided. An early diagnosis is imperative.

Q. There are many services overseas to support people with FASD. Why do you think it is taking so long for Australia to acknowledge and accept the condition exists?

A. I don't know – we have such a great reputation in other health areas so I really don't understand it.

Q. What are the challenges in liaising with health providers?

A. There are four challenges that I feel personally:

- 1 The number of people who tell me that they know about FASD on the one hand and then tell me that Seth must take responsibility for his life on the other
- 2 Not being able to access services because he has a normal IQ
- 3 Inconsistent messages from medical and allied health professionals, and
- 4 I hate it that I sometimes cry with frustration when I am trying to advocate for Seth to some of these services because they simply refuse to accept that Seth has FAS and needs certain support even though I have it in writing from reputable sources

Q What services would you like your son to have?

A. I know exactly what he needs but to actually put it into place has been frustrating and expensive and we only have half of it in place at this time. He needs a case manager or social worker to coordinate his services, organise his accommodation, liaise with his job coordinators and the Public Trustee and be there for him when he is depressed and suicidal. He also needs someone to work with him to help him organise his day so that basic household tasks are completed. I would like to see someone help him plan regular sporting or hobby activities and go shopping with him. Hayley does much of this but she needs support as well and these services would help her too.

Q. What is your reaction now when you see women who are pregnant consuming alcohol?

A. I go over and talk to them. I described the situation in my last book, *Alcohol and Pregnancy – No Blame No Shame* by writing a 'letter' to a pregnant woman who was drinking:

'Pubs are so much different these days to the way they were seven years ago before I had my last drink. These days they encourage families to have a meal or celebrate special occasions by incorporating play areas for children into their interior design. Coffee and tea is available for those people who prefer not to drink and I guess all in all it's progress. It's far better than it was when only men were allowed in a pub and women spent many hours alone at home or waiting in the car with the kids. But for all of our progress in this quarter, there has been no progress in warning women about alcohol and pregnancy.

So when I saw you and your partner celebrating your friend's birthday with party poppers, laughter and what looks like an expensive bottle of wine 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 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 funny discourse as your husband pats you gently on your large round 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 walk over to you. 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 or your husband 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 say, 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 one little truth, one little word – 'abstinence'.

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.'

Q. What role do you see potential fathers playing in preventing FASD?

A. Fathers can have a huge influence on their partner's habits. That's why I don't like saying things like, 'When a pregnant woman consumes alcohol'. It's more than just the mum herself who is involved. It's the partner – male or female – family, friends and even, as you can see in the letter above, complete strangers. We all have a part to play in helping other people understand this condition.

Q. Given that FASD is totally preventable, what would be the best medium to educate people about FASD?

A. For me, the jury is out on whether this condition is in fact totally preventable. Granted, all a pregnant mum has to do is to not drink alcohol and the child is not born with FASD, but it is not always as easy as that. For instance, what about a woman in a remote Aboriginal community? (not that this is purely an Indigenous issue) She may be surrounded by friends who are also drinkers, there may be domestic violence involved; she could be hurting emotionally and physically and have nowhere to turn. She may not realise that alcohol can cause these problems. All her friends drank through their pregnancies and their babies seem to be okay. Many people don't realise that it's very difficult to tell at birth whether or how badly affected the baby is. It's usually around puberty that the behaviour of the affected person begins to deteriorate.

Q. How do you inform new people to your life about FASD and your children?

A. I used to be very ashamed and just the thought of telling someone almost made me sick. But after the first book was published, I couldn't hide. I actually didn't want to hide by then anyway because I realised that there were so few birth mothers in Australia who were able to speak out that I had a responsibility. As I became more comfortable, it became easier to tell people. And then when I wrote and published my second book, I realised that I couldn't write one thing and then behave differently. For instance, my second book is called *Alcohol and Pregnancy – No Blame No Shame*. If I behaved as though I blamed myself and felt the level of guilt that I felt, then I would be going against what I expected other birth mothers to feel. I didn't want them to see a person who was so debilitated by grief and guilt that she couldn't function. I wanted them to be able to move on themselves, because I would not in a million years blame a birth mother, so why did I blame myself. So in answer to your question – I just tell them.

Q. Can you explain what it is like to navigate a service system with no dedicated services for people FASD?

A. It's very difficult. FASD has the potential to be a terminal condition for Seth. I know what services might save him but we have been rejected for those services. My husband and I have put a lot of money into helping him stay safe and I worry about him when we are not around. I would do anything to save him but I have no control over the eligibility criteria for these services. I have spoken to Ministers, written these books, been an active participant in NOFASARD, established the rffada and still can't get the services that Seth needs to stay safe in the long term.