

Mothers at Margins Presentation

Good morning my name is Elizabeth Russell.

I will be speaking today about what it is like to parent a child with a disability which affects approximately 220,000 people in Australia but for which there are no specific services, no specialists, no clinics, no diagnostic teams and no support groups.

The condition is called Fetal Alcohol Spectrum Disorder. Using statistics from Canada where they drink less than we do, it looks like we have 220,000 affected individuals in Australia. We have no clear statistics here and must use extrapolation to estimate.

With so many people affected why are there so few supports available?

Unfortunately FASD is a difficult condition to diagnose. The full syndrome which results in a classic facial phenotype and is the easiest to identify is not diagnosed for several reasons:

1. the potential 'stigma' to the parents
2. Doctors do not wish to add stress to parents by telling them that something that they have done has resulted in this condition in their child/children
3. there are as yet no Australian diagnostic guidelines
4. there are no specific diagnostic teams and no diagnostic clinics
5. FASD and its diagnosis is not taught in medical school
6. there are no specialists to which GPs may refer

This makes things very difficult when not having a diagnosis means that the child/teenager or adult is not eligible for services such as the disability support pension, disability services, school support and other crucial services.

An accurate diagnosis is important but unfortunately this condition is often misdiagnosed as ADHD/ADD/Autism/Asperger's/bipolar and/or reactive attachment disorder, oppositional defiant disorder, antisocial personality disorder and on.

It is possible of course that the child has these conditions as well as FASD but unless the extent of the brain injury is recognised, the parenting strategies and interventions for other conditions may not be appropriate for these children.

As a mother, I have learned this and more over the last 10 years. In 2001 when I first saw the words fetal alcohol syndrome, I knew in an instant that my son was suffering the consequences of my alcoholism.

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 and how difficult it is to parent a child with this condition.

My two sons are Mick and Seth have FASD. Mick is now 30 years old and Seth is 26.

Seth is the most affected with full Fetal Alcohol Syndrome and was born in 1984. I wasn't screened for substance abuse and I guess that was the norm for those days. Alcohol wasn't 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 labour.

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.

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 results. 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 or driving around the neighbourhood trying to find him. 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 with the rules as we had negotiated.

He could 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.

Getting him to go to a doctor's appointment was not something I could assume would occur simply 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.

Life with a child with FASD turns normal parenting upside down. I never thought I would have to succumb to some of the techniques I used to keep Seth safe during the years between 12 and 25.

Those years resulted in a tired, weary, frightened, mother dependent on anti anxiety medication because I was never sure how it would all pan out. Would he really kill himself as he had tried many times? Would I come home from work one day and find him hanging from one of the beams in the shed? Would he get picked up by the police and put in jail?

There were times when I thought that option would be the best possible outcome as it would keep him away from the people he was hanging with who were getting him to do all sorts of things that would eventually lead him to his destruction. Jail would have been a relief to us both.

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.

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 desperation felt like. I am a recovering alcoholic and when I was drinking, any excuse to drink was a good one. Finding out about this condition and that my children were going to have to deal with this for the remainder of their lives, was the best excuse to drink that I have ever had.

This next chapter I will read is from my first book. When I wrote it I remember feeling that I would never get over this, that these feelings would kill me. They haven't, and I don't feel like I did when I first wrote this, in fact I rarely feel that way now. It is more a case of putting those feelings away and not letting them out. They are destructive and unnecessary to me these days.

Here is the Chapter:

For me, being the birth mother of two children with FASD is like living in a continuous state of grief, fear, confusion and remorse. I grieve at the loss of a normal life for my children. I'm afraid for their future and whether I will be able to manage my own life well enough to help them through theirs, and most destructive of all, I experience such consuming remorse, such crushing anguish that I really know no words for it. My children were conceived to be individuals with hopes and dreams and the potential for good. But now, through misfiring synapses and damaged neurons, their only hope is to survive; their dreams will have threads of tragedy; and their potential for good is often outweighed by impulses they ache to subdue.

The unconditional love I feel for them is now tinged with a compelling sorrow, knowing they will have to live with pain, frustration and misunderstanding all their lives. When you know that your child will need care and attention for quite possibly the remainder of his life, and will always need medication to keep him from killing himself or someone else, everything is a nightmare that hurts constantly. When things are bad, all I can do is hope that tomorrow will be better.

The very nature of the condition has forced me to closely examine my feelings and make a decision that negative emotions will not prevail over recovery, awareness and action. If they had, my children would have come in second to my addiction.

It was very tempting when I first made the discovery of FASD to pick up a drink. But the thought of what they might think of the person who had not only injured them, but continues to abuse the substance that caused the damage in the first place, stopped me.

I know at this stage they bear me no overt resentment, but that could easily change if I chose to drink, and although I wouldn't encourage it, I wouldn't expect anything else. I know of no other way to ensure my children have the chance of a happy and fulfilling life than to find an acceptance of what has happened and do what is best for them. If I can be the best I can be my boys might have a chance to be the best they can be.

I was also tempted to pretend FASD didn't exist. I could have denied the condition as a way of coping, denied that Seth's symptoms were similar to FAS - I knew beyond a shadow of a doubt that I could have done it effectively. After all, if alcoholism is the only disease that tells you that you don't have a problem, then as an alcoholic I could easily tell myself that Seth didn't have FAS.

Thankfully that thought matured – if I was going to cope with this, I would do it on my own terms. I would acknowledge responsibility for his condition and contend with it that way or not at all. I would not deny it or rationalise it or attribute it to symptoms of ADHD, mental illness or drug psychosis. This was my doing and I would actively participate in Seth's rehabilitation as far as that might be possible.

To find courage and determination within oneself, one needs to experience an event that calls for those attributes, otherwise they may remain locked away, the individual never conceiving of the qualities inside them that could forever change the way they look at themselves and at life. When my children were born, I felt blessed and very, very frightened. Never before had I allowed myself to be so completely exposed and defenseless. I knew that if anything untoward happened to my children, anything at all, then I would die.

But I did find strength and courage that I didn't believe I had because something did happen to my children. If it had to happen this way, then I am grateful I was not denied the opportunity to discover this about myself.

I believe that the depth of our grief is evidence of our love, and that while grief can be overwhelming and even unbearable, eventually it will come back to love - for our children, for others and for ourselves.

When I'm at my lowest I think that a mother could have done nothing that equals the harm I have caused and that perhaps they would be better off without me, but I have to remind myself of the many things I do that help them. If I were not here I wouldn't have the chance to make their lives a little easier. No one would advocate for them as I do, no one would have the strength or the energy or the understanding or the love I have to make sure everything that can be done is done.

I have an added wisdom, optimism and increased awareness that perhaps wouldn't be so evident had I not had the opportunity to encounter contrasting emotions and experiences throughout my life. If you never experience "hot", how can you understand "cold"? I trust this will be one of the things I have found in the past that although at the time appeared utterly "bad" actually provided me with an opportunity for growth I wouldn't otherwise have had.

Even as I write this I am aware of the selfishness of this statement – wanting to "benefit" from this experience when my children may not. There is no doubt that this condition will try the sanity of anyone who has suffered its fallout.

When I first disclosed that my child has FAS and how it was caused, there were comments like, "How couldn't you have known?" "Why did you keep drinking, it's only common sense?" But I'm sure there are many more people out there who are thinking, "I drank during my pregnancy, thank God my children are okay."

Although I do not have any FAS-related conditions, I follow the pattern Dr Clarren describes in his research on birth mothers: sexual and emotional abuse, post-traumatic stress disorder, anxiety, depression and alcoholism, but some women may not. Alcoholic women are by far the easiest to identify and even they aren't being recognised by professionals. It will be far harder for women who drank socially during their pregnancy to relate their child's behaviours and problems to a few regular drinks years before – especially if they don't drink or drink very little now.

Its not hard to see that I was a bit of a mess at the time.

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 – on the lives of Seth and Mick.

Before I could help Seth, I needed to get the opinion of my doctor. I never once considered that I wouldn't get the support I needed. 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. I thought if I could find out as much as possible about the condition I could help my son even without a doctor. 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.

I think the reasons I had no real response from doctors was because they were hoping to spare me the guilt they believed would be associated with an acknowledgment that FAS 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, was and is bleak.

Now when I present to medical people, I tell them that this guilt that birth mothers often feel is not something that they should be taking 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 with a view to offering 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.

We eventually had to go to the Northwest Territories in Canada to obtain a diagnosis.

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. We also didn't feel so alone – we knew that there were many other parents coping with this condition if we could just find them.

Along with the heartbreak of being a birth parent, 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 with normal genetics – it would be unfair and damaging.

If an attempt is made to raise a child with FASD in the same way that a “normal” child would be raised then that child is likely to suffer secondary disabilities as a result of the frustration associated with being treated the same as other children. This is where the majority of Seth’s problems stem from. Apart from the brain injury Seth now has mental health problems including depression, anxiety and paranoia, suicidal ideation, has had trouble with the police, problems keeping a job, he is a recovering addict and an incipient alcoholic.

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

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 my husband Don and I his ‘trying hard’ is like everyone else’s ‘stuffing up’.

At this moment Seth is 26. He has a wife and two beautiful children. People with FASD have great problems parenting and it’s true that I don’t believe Seth could look after his two children by himself ----- but with support from his wife Hayley he seems to do very well.

He said to me last night that he couldn’t work away because he would miss his family too much. He also said that he couldn’t have been a doctor (a goal of his when he was little) because he would feel too much compassion for his patients. From the perspective of his condition, he isn’t supposed to be able to feel compassion and empathy but he does.

He has overcome so much in his short life. I wish for him only joy and peace and happiness – it’s no less than he deserves after what he had to cope with in his life.

Anne Russell

Elizabeth (Anne) Russell