Tasmanian Conference Presentation

SLIDE 1

My name is Elizabeth Russell. Thank you for inviting me to speak here today. My sincere thanks go to all those people who participated in the organisation of this conference. Even though this conference is a breathtaking milestone for Australia, those people who have tirelessly and persistently worked for years in this field know that it is still only the beginning. As we have heard from other speakers throughout this conference, we must educate, prevent and diagnose, then we need to work with case managers, case workers, consultants, psychologists, counsellors, and anyone else who may come into contact with people prenatally exposed to alcohol. At the same time we must alert mothers to the dangers of alcohol and pregnancy, and support those who unfortunately already know. And in my mind the most important, although they are all important, is the ongoing appropriate support of those individuals who face a lifetime of obstacles – so many in fact that the average person surely cannot comprehend. We do have a long way to go – we don't yet have a diagnostic team in Australia although we are closer than we have ever been.

SLIDE 2

I am here both as a member of the rffada and because of my experiences as a biological mother of two children with FASD, both of whom have fetal alcohol spectrum disorder.

SLIDE 3

The title of my presentation today is the title of my latest book Alcohol and Pregnancy – No Blame No Shame.

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 just yet, 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.

SLIDE 4

My two children Mick and Seth have given me permission to talk about them if it helps us all to better understand this condition.

SLIDE 5

This is a photo of my son Seth at about 4 years of age.

Had I known about FASD when this photograph was taken, Seth's 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.

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.

SLIDE 6

Seth features more predominantly in my first book Alcohol and Pregnancy – A Mother's Responsible Disturbance, because he is most beset by behavioural, cognitive and social dysfunction.
In these books my boys are called Seth and Mick.

SLIDE 7
Mick is 26 and Seth who has the full syndrome is 22 and about to be married. To maintain consistency I will call them by those names throughout my presentation.

Mick suffered most in the months from his birth through until he was about 5 years old. Then, apart from having regular 'absences' which were later diagnosed as symptoms of temporal lobe epilepsy, he seems able to function normally.

SLIDE 8
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, possible cognitive difficulties and late milestones.

SLIDE 9
Seth on the other hand was a model baby and toddler, and although very active, his behaviour was considered to be within 'normal' limits. But as he grew older, the brain injury from his exposure to alcohol manifested in more antisocial and dysfunctional ways.

SLIDE 10
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 recover from the grief and guilt. All I wanted to do was to read how another birth mum coped so I could get what I had done into perspective. My second book is written specifically for birth mums and this particular need in mind. Along with a very short version of the story as to how our family came to hear the words 'fetal alcohol spectrum disorder', I also interviewed 17 people who had been affected by FASD either as sufferers or carers in the hope that those people who did not connect with our experiences described in my first book might be able to connect with one of theirs.

Mick is now 26 years old and is still the least affected of my sons with a diagnosis of Neurodevelopmental disorder – alcohol exposed. Seth is 22 years old 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.

SLIDE 11
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.

SLIDE 12

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 presumably to stave off labour.

At the time of Seth's birth I don't think 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 13
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 13
At that stage, for reasons probably related to the disease of alcoholism and the abuse I experienced, I operated only on a very superficial level and did not think too deeply about anything apart from my terrible sense of inadequacy.

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, sexually active and COMPLETELY unmanageable.

SLIDE 14
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, I locked the doors, we put security screening on all our windows but still he went out whenever he wanted by breaking his screen. 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 had agreed to abide by them. If he wanted something, regardless of how ridiculous or costly 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 balance 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 four year old.

He could also become violent and he has ruined our 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 discovered the art. It was a skill that I soon learned well. Bribing him became the ONLY way of getting 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 into a teenager, I could not assume Seth would do these things simply because they were important and his health or security was at stake.

He could not see that going to the doctor was crucial to his physical and mental health. He would not respond to urgent mail and still doesn't. I used to 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.

SLIDE 15

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 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. 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'.

Until he was diagnosed and properly medicated, the misfiring synapses and damaged neurons that inhabited his brain were his 'arch enemies'.

When Seth was fifteen 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 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 as we all know are not mutually exclusive. I spent two months trying to bring order out of the chaos of my mind before I shared my apprehension and knowledge with Don.

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.

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 investigations on the Internet where, after wading through research after research paper and website after website, it was difficult to truly believe I had never before heard of FASD.

SLIDE 16

Luckily, the consequence of another thwarted suicide attempt from Seth, resulted in he and I meeting a locum doctor from South Africa, who immediately understood what was needed to stabilise Seth's mental health. 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 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 Seth safe. I still didn't have a diagnosis but until then at least we had him appropriately medicated and I wouldn't have to keep such a close eye on him. I would often come home from work, look in every room keeping myself steeled to find his body even though I had rung him several times during the day. There have been many times since then that I have had to talk him down from suicide and I suspect my doing so successfully only a few days ago, won't be the last.

I think the reasons I had no real response from doctors before I found this locum was because they were hoping to spare me the inescapable feelings of guilt.

SLIDE 17

Shame, guilt and remorse are emotions that no health professional needs to take into consideration when deciding whether or not to discuss this with a mother 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. Doctors and other health professionals who are reluctant to diagnose cannot continue to sacrifice the baby for the mother's emotional state. I would rather go through nine months of anxiety than my child suffer a lifetime of difficulties.

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

SLIDE 18

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.

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.

Anyone who discusses this condition with a pregnant woman 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, or because she does know the potential for damage and can't stop.

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 it must be said.

Any health professional who is faced 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?

So I beg each and every one of us to ensure that we don't judge people for their behaviour because we know now that exposure to alcohol in utero can result in antisocial and delinquent behaviour – and how do we judge someone negatively when they are behaving in a way that is consistent with every expert opinion on their condition; and as for pregnant mums who drink? Well we know that alcoholism is a disease and I personally believe that FASD is NOT 100% preventable for 100% of women no matter what anyone says. There are far too many factors associated with people drinking alcoholically and it is far too presumptuous for us to say that some people can stop drinking just because we tell them to. It is also more likely that these mums already have an overabundance of guilt, shame and self blame. To add more is counterproductive and cruel. But because research has shown that 96% of children with FASD are born to mothers who drink socially, the abstinence message will count for **them** and maybe for THOSE mums, there will be NO shame, blame or guilt because they saw the warning label on that bottle.

Whenever I present, people in the audience tell me 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 and we all need to remember to place no blame on those mothers who are at the heart of this condition. To any birth mums in the audience, if you don't hold your head up when you are talking to your son's teacher about the best strategies for him, or the public trustee when organising her finances, then others less informed will think it is a condition of shame for both you and your children. The last thing our kids need is to feel ashamed of their disability. There will be enough hardship in their lives and the last thing that we, as birth mums need, is for others to blame us – we will be doing enough of that ourselves.

SLIDE 19

The Hippocratic Oath implores us to "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. Lets use this conference to keep up the momentum for the 200,000 people affected by FASD and the people who love them.

THANK YOU

Anne Russell

Elizabeth (Anne) Russell