

Brisbane Writers Festival Presentation

Author's Note: Unfortunately I was not able to deliver this presentation. I flew to Brisbane waited in the foyer – 30 minutes before I was due to give this presentation I took one small bite of a little quiche which must have been near a peanut or peanut oil. I have an anaphylactic reaction to peanuts. I spent the rest of the day and night in hospital and the day after that trying to overcome the effects of the drugs I was given in hospital. I felt very bad for the organisers and very responsible for what had happened. Anne

Thank you for inviting me to speak today at the Brisbane Writers Festival.

Even though I have a tendency toward humour, my story isn't a happy one, in fact if I had to give it a genre it would be horror.

To include comedic relief would dishonour what has happened to my children so I would rather tell my story the way it was.

In 2003 I decided to write a book. Someone had said 'your life is like a book' and that's all it took. Not that I thought my life was particularly interesting but because I desperately wanted to read about someone in the same position as me – I wanted to know that I wasn't alone in my experience. Even with the benefit of Google I could find nothing ---- here or overseas.

So if I couldn't read someone else's experience perhaps I could eventually read my own. And that was the crux of it. It was because I had tried to find something to read that would help me get through what was happening to my family.

So I started writing. The way I approached it sort of reminded me of an experience once when I was young and riding motocross. We were living in Greenvale a nickel mining area and the word was that this hill hadn't been conquered by anyone riding a bike. I sat on my bike at the bottom and just decided to ride up a little way. My goal definitely wasn't to get to the top it was just to see how far I could go and then I would turn around and come back down. Anyone who has ridden hill climb or even anyone who can actually *think* would have known that those words had just identified me as a complete idiot.

Getting back to the metaphor, I started writing the book in the same way I climbed that hill. Just to see how far I could get.

But after a few months, I was hooked. Every spare moment after work before work and sometimes in the middle of the night I would be tapping away at the keyboard.

I wanted to write about my experience as a mother who had unwittingly physically harmed my two sons and I wanted to tell other mothers about the dangers of alcohol and pregnancy.

I am a recovering alcoholic, sober since 1998. Who in the audience knows that alcohol causes birth defects?.....

Who knows what the primary birth defect is?

Right.....and that is what I wanted to write about.

I was good with English and grammar and I was a good proof readerI thought that might make me a good writer. My first draft proved to me that while all of those skills were certainly helpful, they did not a writer make.

My second, third, fourth, fifth and sixth drafts resulted in the same assessment; however having always appreciated the notion that perseverance is the key to success, I kept going.

As you can imagine, the topic about which I wrote was a very personal one to me – it's an emergency of the greatest order both for me and the great many other people in Australia who have fetal alcohol spectrum disorder or who could be saved from a life of unremitting pain if we all knew the truth about what alcohol can do to a fetus.

I was alcoholic from the first drink I took at 13 and I will always be alcoholic.

I have two boys, Mick who is now 30 years of age and Seth who is 26. In 1994 when the boys were twelve and nine, I went to my first AA meeting. I remember it being a very perplexing time for me. On the one hand, I must surely have had an idea that something was wrong to even think of going to AA, but on the other I was completely in denial. I recollect thinking that I *could* have bit of a problem with scotch or Sherry or any alcohol really, but even as I was thinking that, I was also telling myself how ridiculous that was because I knew I could stop drinking any time I wanted. So I attended the meeting with a closed mind ----- an attitude that was bound to give rise to negative results. I couldn't or wouldn't relate to anything that went on at the meeting. I didn't identify with the people there because they were simply far more dysfunctional than I was. Things had happened to them hadn't happened to me so that made *them* alcoholic and *me* interesting.

Some had had their children taken away from them, others had broken marriages, and still others had lost jobs – I couldn't be an alcoholic because those things hadn't happened to me. I left the meeting early, bought a bottle on the way home and didn't venture back for four years when my choices had run out and I had to admit that I had a terminal disease.

An example of what I would drink in the couple of years prior to getting sober in 1998 ----- I was drinking first thing in the morning, always on the weekends, but sometimes even during the week before work. I could even have a drink for morning tea or lunch and then buy a bottle on the way home from work.

I rationalised this behaviour (alcoholics have to rationalise while social drinkers don't even think about it) by saying that I was not hurting anyone, I was providing for my family and feeding them, I still played with the boys, read to them at night and helped them with their homework. I fed them, didn't hurt them either psychologically or physically when I was drinking, I loved them and they knew that I loved them. I had forgotten that sometimes love is not enough.

During the previous five or so years, I had begun to have breakthrough memories of some of the incidents that had occurred in my life. Emotional and sexual abuse, post-traumatic stress, flashbacks and guilt at having "killed" someone (these are side issues that I don't have the time and I'm sure you don't have the inclination to hear) were always on my mind and a new level of depression and sadness became a constant in my life.

Although I was still going to work, it was as if I existed only as a shell with no substance. The counterfeit me knew what I was supposed to do and say and even looked like me, but the real me was in a dark hole that had no substance and no heart and seemed to have no end.

Alcohol staved off these emotions briefly and made me feel “normal”, but they would always resurface in the morning and haunt me during the day until I could have another drink. This became the pattern of my life for years. There were times when I planned to kill myself because I couldn’t think of any other way out. It’s curious but I didn’t consider alcohol was the reason I was feeling this way, I just thought this was who I was – a sad, stressed individual with no future that I could see.

Surprisingly, even though for most of my life I had been drinking excessively, I still achieved well at work and in the community. I studied for, and gained, a Graduate Diploma; I became a black belt in Tae Kwon Do and began instructing. I also worked hard for the Leukaemia Foundation and was awarded the Australia Day Citizen of the Year award in 1988. My bosses at the time, nominated me for an award for innovation through the Australian Institute of Management that, to my surprise, I won. Through all these successes I still felt like a failure. Nothing seemed to make any difference to the person I knew I was inside.

As each achievement came and went, another had to be accomplished. I was driven, always striving for something that might make me feel whole. I thought I would find it by working in the community, or doing well at work and sport.

I enjoyed drinking but at the same time I also knew it had to stop, I couldn’t live this way and I didn’t understand what was happening to me. I didn’t mind a challenge, but I was very tired and was not sure how much more I could handle and still keep my family and my job together.

On the 19th May 1998 I had my last drink. My children hadn’t realised that I was alcoholic and I still had my husband. I was the only alcoholic in the world who had been drinking for 30 years and hadn’t lost anything. Two years later I read the words fetal alcohol syndrome on the Internet and knew that it was not me who had lost; it was my beautiful, innocent boys.

Seth had lost the life he was supposed to have had – a life of intelligence, informed decisions, positive relationships and happy endings. Mick had lost his potential. I had been sure he would attend University and gain a degree. He would be prosperous and well loved.....a leader among men, a good kind man with a strong mind and body.

Both boys are good men and Mick is prosperous and well loved. He has a good mind and heart but his body has problems associated with the poison we call alcohol. He is a relatively small person given my husband's and my height. Mick has temporal lobe epilepsy and some skeletal deformities however he can work full time and he has a relationship with a lovely young lady -----for all of which I am grateful ----it could have been a lot worse for him.

Seth is far worse off. The alcohol has affected every aspect of his life. He has depression and schizophrenia and is taking anti-depressants and anti-psychotics, is an alcoholic and an addict. He has central nervous system damage to the extent that he can never live a normal life. He is unable to live independently, he must take medication all his life, he is on the Disability Support Pension and is unlikely to ever be able to work full time. Without medication he is violent and would end up confined either in prison or a mental institution.

It sounds bad doesn't it?

It is

All because I used alcohol while I was pregnant.....

I don't know how much I drank when I was pregnant with Seth but I know it wasn't as much as you might think. I remember drinking maybe three or four nights a week---- maybe three or four drinks at a time. I don't recall ever becoming rolling down drunk but I could have.

Even though I am by nature an optimist, I find little to be positive about. However with this condition.....If things are bad, it may only be a day before we are back to the status quo and conversely, if things are good, they don't stay good for long.

I value the gift of a toxic childhood and young adulthood ----- the experiences of sadness, fear, abuse and trauma in hindsight were crucial to my understanding of happiness, love, confidence and self-esteem. If we didn't have poverty, how could we experience the joys of abundance, if we couldn't feel sorrow or pain, we wouldn't know loveand if there wasn't infirmity – how could we ever appreciate the feeling that good health and vitality give us.

Unfortunately Seth has rarely experienced the positive side of these equations but he knows they exist. The alcohol has allowed him a good IQ but has damaged the part of his brain which helps him make good decisions based on sound judgement and the knowledge that for every cause there is a consequence.

The characteristics of a FASD related brain injury include an inability to grasp abstract concepts, impulsivity, attention deficit, poor decision making, addictions, mental illness, trouble with the police, problems parenting, problems in employment, problems academically, problems with relationships and trouble understanding time, problems handling money and problems understanding cause and effect. There are more.

Even with these problems Seth has found a wonderful, beautiful, amazing wife and has two beautiful children. We can't leave him alone too long with the children but he can look after them individually for short bursts.

There is not a day goes by that I'm not grateful for what I have – my husband, my boys, a good job and great friends. I am also thankful for whatever I have inside that has enabled my recovery so that I can be with and help Seth and his wife with the children. They are only on the pension so we support them financially as well as socially.

When I found that my darling little boy with the innocent smile and the charming manner had fetal alcohol syndrome, I couldn't imagine how I was going to move past the guilt and grief. I didn't understand at the time that I saw those words and read the content of the web page what it would mean to us as a family ----- now I do.

Nothing will stop me from talking to people about the dangers of alcohol and pregnancy. When my first book was published, I thought I could do it without really revealing who I was. I thought I could remain relatively anonymous my real name is Elizabeth Anne but I am called Anne. I wrote as Elizabeth Russell – not exactly anonymous but I was hoping that I could just get it on the shelves, hide and the message would still get out. Seth and Mick had both given me permission to use their experiences in presentations but I really thought that once I had written the book I could say that I had done my bit.

But that's not how it happened. When it was released in 2005, the Salvation Army wanted me to launch the book in conjunction with their position on alcohol and pregnancy so I had to do the media thing – photographs, presentations.....it was a big commitment from an introverted, depressed, esteem challenged little girl who had never gotten over being bullied at school for her stick thin legs and her old fashioned clothes.

I thought I could come 'out of the closet' once and then run back in and hide. But after telling my story once, other people asked to interview me and then I was asked to give presentations and I became more and more confident and better understood that I had inadvertently made a commitment to my children. I would work in raising awareness of FASD for as long as I could.

So instead of reading about other birth mothers, I wrote about my experience and how I coped and functioned and felt. I hoped that people would understand about alcohol and pregnancy and FASD from the personal perspective because it really does flesh out the condition like lists of symptoms and characteristics cannot.

I hope that parents who think that their children may have been affected prenatally will come forward and talk to their medical professionals. I hope that they will at least feel a little less isolated and a little more confident about coming forward for the sake of their children.

I had asked Seth and Mick to 'write' their own chapters – they dictated and I typed. One draft – done!

I desperately hope that for those people who make judgements about the latest young man in the news who has shown no remorse for his actions or for the 13 year old who has just burnt down his classroom will be revised by the knowledge that perhaps alcohol must at least take part of the blame for their actions.

I would like to close by reading a few paragraphs from Alcohol and Pregnancy a Mother's Responsible Disturbance.

What disability results in sufferers being good at small talk but without substance? 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.

But having FASD does not diminish those living with this condition. Mick and Seth have found that growth is facilitated more by "bad" fortune than good, and that every experience in our lives can be a gift. They have learned that ignorance is not "bliss" and that knowledge is liberating. They have had and will continue to have problems associated with their condition, but they can still be satisfied they are doing well. The satisfaction would probably not have come as readily had their lives been "normal" and they can be confident this involves a level of effort that other people do not have to expend in order to get the same result.

My boys' lives will always be closely entwined with FASD but they won't always be limited by it. They can strive to move outside the normal parameters of their condition while understanding that not achieving their goals does not mean failure; it just means they will need to reassess their objectives.

So I wrote a book, then another and another and in each there are words, sentences and paragraphs that I still can't believe I actually penned and if I tried to write again, I wonder whether I could be as articulate. I think there was someone helping me write – my higher power, God? Someone.....??????

Thank you for inviting me to speak at this Festival.