

Primary Care Mackay Presentation

Thank you for inviting me to present to you. 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.

Im sure you are aware that 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 renown expert on FASD for over 30 years, 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.

As you can see, 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.

A primary care provider is a health professional who, in partnership with the patient provides care, education and support to people. He or she can also work with women and families during pregnancy, birth, postnatal and early parenting.

This places primary care professionals in unique positions to provide education and support to women about alcohol and pregnancy.

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 fear 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 only when they attain the teenage years 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.

If you have any indication that the mother you are interviewing may have been drinking or may BE drinking, it is important that you give her a brochure, leaflet or pamphlet on the consequences to their baby of continuing to drink and go through it with them word for word while they are there with you. Then use whatever referral options you usually make use of and follow up, support, more support and more follow up. It is also crucial that you are aware 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 21 years old next week, but he often behaves as if he were thirteen. He requires antipsychotic medication to stop him from hurting himself and others, can only work three days a week with assistance from an on the job support worker and is on the disability support pension.

He will never be able to live independently, he can't manage money and he has abused drugs and alcohol since he was thirteen and is now and alcoholic and an addict. Nevertheless he is an innocent. He believes what mates say after knowing them for a day, but only now believes me. He trusts that strangers have his best interests at heart but if I tell him that something he is doing will hurt him, he won't listen. 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. He is now on antipsychotics and they have made the world of difference to us all.

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.

I drank much more than I should have for a healthy pregnancy, but I didn't drink as much as some people I have seen. I know I had maybe two or three drinks some but not all evenings when I was pregnant with Seth. This consumption is only a little more than the National Health and Medical Research Council 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.

What if my doctor had told me that alcohol was harmful to my baby?

What if I had been screened for substance use?

What if he or she had then described what life would have been like for my sons if I continued to use alcohol?

What life would my sons be living now?

Could they be looking forward to more financially, socially and personally rewarding lives?

Seth would not be on the Disability Support Pension, nor would he currently be unemployed. I would not need to be the official administrator of his finances because he would be able to manage his own money.

He might be looking forward to graduating from university this Christmas instead of looking forward to getting his licence back after six months suspension.

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.

All health professionals could make such a huge difference – they could be the 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.

You will need to be well prepared because it will not be easy to discuss this with a mother who may have been drinking alcohol.

She may 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 they must be said. In the United States only 10% of children with FASD live with their biological parents.

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 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.

When you are wondering how your patient will take the news about alcohol and pregnancy and how much anxiety it might cause if she has been drinking, please think of that.

With the appropriate support she might stop drinking. At the very least she has the knowledge to make an informed decision.

North American statistics show that without intervention a mother who gives birth to one child with FASD is very likely to bear subsequent children with the condition unless the first child is diagnosed. If Mick, my first child, had been diagnosed early, 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.

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 we help?

We can talk about alcohol and pregnancy, discuss it with the mothers in your care, and help them 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.

Thank you for inviting me to present to you because by doing this you are guaranteeing that my family’s experiences are now their contribution to others.

Anne Russell

Elizabeth (Anne) Russell