

Growing up with Fetal Alcohol Spectrum Disorder – The Effect on Child Development and the Family

60 minutes

Good morning my name is Anne Russell and I am the birth mother of two children with Fetal Alcohol Spectrum Disorder (FASD). I am also a recovering alcoholic.

Who has heard of Fetal Alcohol Syndrome?

Do you know how much alcohol is safe to consume while pregnant?

Does anyone know what the symptoms are?

When the symptoms are said like that they don't sound near as important as when you are actually living them

For those of you who are pregnant, have a family member who is pregnant, is planning on becoming pregnant or have clients likely to be any of these, this is the most important information you will receive -----why? Because it will save yourself and your family and the families of those people mentioned above ---- a lifetime of heartache and pain.

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Alcohol is a teratogen which is a substance that causes birth defects. Alcohol damage far exceeds prenatal exposure to tobacco or other illicit drugs. Alcohol is in the same category as mercury or thalidomide – they are all teratogens. When we think of them as all being in the same or similar category then we have an idea of the damage that alcohol can do to a baby.

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I don't remember thinking specifically about alcohol when I was first pregnant and that it might cause damage to my children. I did think that the placenta was a very formidable piece of equipment and that it would stop any substance from damaging my baby.

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I was surprised to find 17 years later when I first suspected that Seth had this condition, that it was not the supreme barrier that I thought it was. Alcohol freely crosses the placenta. In fact the blood alcohol concentration is the same in the baby as in that of the mother. So if mum has a blood alcohol concentration of .05, so does the baby. Actually it can quite easily be higher and stay longer in the baby because the baby has an underdeveloped liver so does not metabolise it as quickly.

This was a complete revelation to me and one about which I have often wished that either I or my doctor knew. When I was first pregnant with Mick and before I knew I was pregnant, I went to a party and drank quite a bit. On asking my obstetrician if any problems could have occurred he said 'no...of course not'. From then I was sure that my baby was safe and these few seemingly innocuous words were probably the unconscious green-light for the drinking that ultimately changed the lives of all members of our family. I am making no excuses. I believe in personal responsibility and I have never tried to blame anyone including myself. Although if anyone asked me how that was going for me, my answer may indicate that I need a little more practice in the personal no blame no shame area.

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So with all this information available now, doctors should be giving a consistent message and that message should be.....while pregnant there is no time or amount of alcohol that is safe for the fetus I've heard many women on talk shows and on the Internet expressing their sincere belief that it is their body and they will not be told what they can or can-not consume. I agree with them; however they are making an error about who this message is for. We are

not saying that alcohol is not safe for **their** body; we are saying it's not safe for their **baby's** and not only that but it will have life-long implications for both. It is important for everyone in Australia to understand this message otherwise the decision to drink while pregnant is not an informed one.

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When I began my research on FASD and prenatal alcohol exposure I was again surprised to learn that only one weekend binge session is more than enough to place a fetus at risk for serious effects.

This can occur before the pregnancy is even known because when combined with the statistic from the March of Dimes in the United States, that 50% of pregnancies are unplanned; it's easy to make an inference that we have an epidemic on our hands. In fact I was talking the other day to a person who feels very strongly that Far North Queensland has one of the highest rates of FASD in Australia if not the world. Unfortunately there are no statistics to verify this because we have no diagnostic clinics.

However there are several frightening statistics on this slide ----- 50% of women continue to consume alcohol after they have found they are pregnant! This is because we lack a consistent message. Until recently the NHMRC guidelines for drinking while pregnant were 7 drinks in a week or 2 drinks per day. I am a recovering alcoholic and if I had used that particular recommendation as the guiding principle for my pregnancies, I would have saved those drinks up and had them all on the one day ----- each week on a Friday or Saturday night, I would have binged and caused immeasurably more damage to my children.

Well of course that has already happened but actually what I remember drinking was a little less than that. I remember drinking 2 or 3 drinks on 2 or 3 days of the week. That is what I remember but we all know that it is probably not what really occurred. I remember drinking rum and milk because it was the middle of winter and I was always cold. I remember thinking that it would be okay because the alcohol was combined with milk. But I don't remember thinking 'damage' at all.

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This condition has had a profound effect on my life and the lives of my husband and my two children Mick and Seth. Even though Mick was the least affected and can live and work independently and live a normal life, I can see that he has been affected in other ways. Watching his younger but bigger brother wave a knife in his mother's face; threatening to kill us; finding that it was his brother Seth who stole his car; having to go to a neighbour's house after school instead of coming home because I didn't want him to be the one who found his brother's body (not that he knew this at the time) ----- have all left their mark.

I did hope that the trauma would bring them closer together but apart from their shared upbringing, they are really two very different people. Mick is cautious, clean and tidy and generally happy, whereas Seth was a risk taker, messy and disorganised and generally discontented. Mick is smallish 5 foot 10 inches and Seth is 6 foot 2 inches.

While I believe and fervently hope that if there was ever a time where one or the other was in trouble, each would come running: other than that, I doubt they will see each other often as adults. That saddens me no end. I had hopes that my children would share a closeness that I, as an only child, can only imagine and dream about.

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I read an article on the Internet last week by a medical professional from New Zealand who said that it was okay to drink after the first trimester because the baby's brain stopped growing after that.

It was and obviously still is..... a common belief that the fetus' brain stops growing after the first trimester. This is why many professionals have told women that drinking small amounts are acceptable after this time.

If you look at this slide you can see that it is not the case. The brain is growing throughout the pregnancy and beyond. There is no safe time to consume alcohol while pregnant. Whatever is growing at the time that the alcohol is consumed is likely to be affected. For instance, if sufficient alcohol is consumed while the heart is growing then the heart will be affected. If it is consumed while the kidneys are growing then the kidneys will be affected. Mick is small for my husband's and my size, had a tumour in his jaw which had to be removed, skeletal malformation and temporal lobe epilepsy – all indicators of prenatal alcohol exposure.

What we don't know and I hope we never spend the money to find out is how much alcohol can be consumed while pregnant before obvious damage is caused. What we do know is that any amount of alcohol causes changes at a cellular level and that every woman and her baby are different. Effects are compounded by the nutrition of the mother, other drug use, stress etc.

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Alcohol affects certain regions of the brain several of the most vital being the corpus callosum, the hypothalamus and the frontal lobe or the executive functioning.

The corpus callosum is the part of the brain which links the right and the left side of the brain. Without this part working properly, the individual can recite the rules but not be able to put them into practice. The hypothalamus is that part of the brain which controls appetite, emotions, temperature, and pain sensation. Commonly people with FASD have compromised pain sensations. They can have a high pain threshold. Seth once went to a birthday party and managed to cut his fingers to the bone. Because he didn't want to leave the party he didn't tell anyone just wrapped his hand in a dirty rag and kept playing. When I arrived at the party I asked him what the rag on his hand was for and when he showed me I just about fainted. He ended up having many stitches in his hand and a night in hospital. Conversely he has asked me to call the ambulance because of a splinter – to be honest it was quite a big splinter 😊

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Most people have heard of Fetal Alcohol Syndrome but not Alcohol Related Neuro-developmental disorder. FASD is the umbrella term but not a diagnosis. If a patient has been diagnosed, it will not be with FASD but with either Fetal Alcohol Syndrome; partial FAS; one of the alcohol related neuro-developmental disorders or alcohol related birth defects.

Seth has Fetal Alcohol Syndrome while Mick has been diagnosed by Dr Sterling Clarren from University of Washington with Neurodevelopmental disorder alcohol exposed which is one of the many diagnoses based on the 4 – digit diagnostic code from the University of Washington.

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FAS and partial FAS are the only diagnoses that make the condition 'visible'. The facial features of FAS consist of a:

- Flat philtrum
- Thin upper lip
- Low set ears
- Flat midface
- Cute little nose
- Sometimes an underdeveloped chin
- Short palpebral fissures

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In this photo of Seth when he was almost 2 years of age you can see the flat philtrum, thin upper lip, low set ears and cute nose but if you didn't know about them you wouldn't know that this little boy has a significant disability. Many many more people who look like you and me have a hard time of it because they have no distinguishing physical characteristics to mark their disability - their behaviour and history are the only indicators. And because they don't look different, their behaviour is believed to be within their control. This is sad because along with FASD comes an ability to speak as if they have no problems but a lack of ability to comprehend what others are saying which severely limits their understanding of the world in which they live.

Many times Seth has obtained employment because he was able to speak clearly and seemingly competently but then not be able to live up to the expectations the employer then had of him because of his inability to understand what was required of him; the instructions he was given; his immature behaviour and the tasks he was expected to perform.

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When I first found this next piece of information I was blown away. The facial features that many of us believe are the 'face' of FASD are only seen in the minority of people. These features only occur if alcohol is consumed during the period of pregnancy called gastrulation which can occur during a very short period of time – some say the 19th or 20th day of pregnancy.

Its easy to imagine that prenatal alcohol exposure results in only behavioural and cognitive problems but we know there are also actual physical complications associated with FASD.

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20 – 25% of people with FASD will have an IQ lower than 70. The majority will have a normal IQ but be unable to use it because of the damage to the executive functioning. This means that any services for which eligibility is based on IQ will not be able to be accessed by the majority of people with FASD who will need those services.

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This is clearly what makes Fetal Alcohol Syndrome the tip of the iceberg of all people prenatally exposed to alcohol.

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When I asked Mick about the time he spent growing up with Seth, all he said was ‘let’s not go there!’ I took that to mean he really doesn’t want to remember or to talk about those days. While he is a caring, well-balanced young man, he is understandably very much caught up in his own life. He has just become engaged and they are busy planning their wedding. They are both in good jobs and have a reasonable disposable. I’m happy for them but it looks like Mick has tried hard to forget his time growing up with Seth and I think that Seth has had cause to be a little unhappy about Mick and his commitment to unconditional big brother love and friendship.

I have given Seth and his behaviour a great deal of thought over the years and I have come to the conclusion that because he has done so much better in his life in the last couple of years than in any other period of his life, without his particular brain injury he would have been a truly amazing man. I know that its every mother’s right to overstate her child’s abilities, personality and looks but because of the nature of what we have been through as a family, I think I am less prone to hyperbole than might be expected.

To answer the question about what it was like growing up with FASD I talked to Seth for as long as he was able to keep still. I was pretty sure I knew what he was going to say and the more we spoke about what he went through, the more I felt so sad for him. I knew what he had been through – I was there. I didn’t want to hear about how difficult his life had been for him again but if he was willing to talk about it, I needed to be willing to listen.

Predictably Seth said he didn’t really know how to describe how he felt but he thought that when he was growing up he was sad, depressed, lonely and embarrassed and very difficult. From my perspective, I feel quite sure that his comment, while quite insightful for someone with FAS, was incredibly understated. The damage that prenatal alcohol exposure causes to the brain makes insight, understanding and expressing feelings almost impossible. These feelings must have been very strong for him to describe them that way.

Seth required more attention, more emotional and financial support and much more supervision than Mick.

Seth was born by caesarean with no complications – unless you count me being able to feel the operation as they didn’t give me sufficient anaesthetic but I believe that would probably have made things better rather than worse for Seth. My beautiful little baby had an Apgar score of 10 and was sent home when he was a few days old. His health and development was everything that Mick’s wasn’t. Mick failed to thrive, had trouble sucking, was sick all the time with various viruses and infections, cried all the time, missed key milestones, and was generally a small, undernourished baby.

As a baby Seth was a strong, bouncing baby who met and exceeded his milestones, fed well, put on weight the way he ought to and seemed to enjoy life. If I went back to that time knowing what I know now I would have predicted that Mick was the most affected and Seth would have been able to live a normal life----- however that’s not what happened.

We didn’t really understand the depth of Seth’s disability until he was around 12 years of age. He began experiencing puberty at that time and very quickly his behaviour deteriorated to the point of daily brushes with the Principal at school and daily brushes with his family to the extent that our lives were in a constant state of tension and turmoil. My mental health had been affected as a child and this period in our lives magnified my anxiety to something with claws.

While our lives, mine, my husbands and Micks were in a state of turmoil never knowing what was going to happen next, Seth's life must have been horrendous. He began using drugs and drinking, had become sexually active at 13, had also began the cycle of self-harm which didn't end until he was well into his 20s.

Every day consisted of not knowing whether he would be alive when I returned from work; not knowing whether he would return when he went out; not knowing whether the sirens that we heard were for him and constantly wondering what he was doing and whether he was participating in the use of heavier drugs than marijuana and alcohol. Along with that was knowing that he was not a happy boy.

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One night a friend rang me to say she was concerned about him – he had threatened suicide and had consumed a great deal of alcohol. When I found him he threw his arms around me. He sobbed that everything he did turned out wrong, he could never keep his friends, he was not doing well at school and he hated himself. I have never felt so sorry for another human being in my life. The pity I felt then surpassed any other feeling I have ever had to this day. But it was too strong to keep feeling. It was then that I learnt how to put up some really solid barriers against my emotions. I have felt a lot of things since then, particularly when I found out that it was my drinking that was causing him to do these things and feel this way but I could never ever feel that again and still be sane.

No mother ever wants to be responsible for her child being so distressed about his life that he would chose death just to stop feeling so bad.

When I became a mother I promised to myself and my children that I would never do to them what my parents had done to me. I was the product of a dominant, angry, aggressive, mentally unstable mother and a depressed and irresponsible father. I never wanted my children to feel worthless, stupid and unloved and I can tell you that I didn't pass that along to them. I did unknowingly pass along a brain injury which ensured they would never be able to move outside the cognitive parameters of their condition. That is the reason I have continued to work in FASD since I first found out about it in 2000.

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I don't believe there are any women in Australia or in the world who want to deliberately harm their child. I believe the reasons are primarily lack of education because we in Australia have never had a consistent message about alcohol and pregnancy. We have heard about tobacco and pregnancy which does harm but not to the same level of harm that alcohol does. We have heard about folate, soft cheese, nitrates, even coffee but when it comes to alcohol, we have had closed ears and mouths.

When I started opening mine, I found that there were huge stores of information on the Internet. Canada and the United States had been researching since 1973 and even before. But getting back to the reasons that women might consume alcohol while pregnant, I would like to list what I think they are:

I think they are ranked like this:

- Lack of consistent information
- Social drinking and the culture of drinking we have in Australia changes the way we view alcohol
- Untenable living conditions like domestic violence, sexual abuse and other types of abuse which create a situation where alcohol might be the only option for sanity
- 50% of pregnancies are unplanned
- Mum has FASD herself
- Not really understanding the consequences to the fetus (which is I guess – lack of education)
- Self-induced miscarriage
- Peer pressure to drink regardless of pregnancy

And I guess we could go on and on – I believe the major reason in Australia which can thankfully be ameliorated is lack of education and information. We need a national media campaign which provides consistent, accurate information in plain language.

Doctors will need to be aware that some women may prefer a termination and will need to be counselled about their choices. But without this campaign or rather without this information being given consistently and regularly to the people of Australia, we will continue to relegate our children to lives of hopelessness and isolation.

Finding out about FASD has given me the determination and resolve to do something about the situation in Australia which helped create these problems for our family. What I say next is not to absolve me of responsibility nor does it point the finger at anyone else because in those days information about alcohol and pregnancy was a little inadequate.

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There may have been some justification for the health professionals who didn't ask me about my alcohol intake in 1980 when I was pregnant with Mick --- there may even have been some defence in 1984 when I was pregnant with Seth ----- but there is absolutely no excuse in 2012 for medical professionals to tell pregnant women that it is ok to "drink what you are drinking now" without asking the patient about her current drinking habits – -----true story!

They also need to be sure that all are aware of the isolated and desolate life that people with the condition live even if they have the support of their family.

Even though our family is close and we have always been there for the kids, Seth still developed all of the secondary disabilities cited by Streissguth apart from 'confinement' although he was hospitalised.

The other reason that diagnosis is so important is that it might prevent subsequent children being affected----- when Mick was around 12 months old, his paediatrician said he thought Mick might be 'retarded' and we would have to wait for a further six months to know for sure. I have spent a lot of time worrying this statement "He could be retarded" than I should have over the years. Did the doctor have any reason in the back of his mind as to why Mick might be retarded? Did he know the symptoms? Did he think it might have been from my drinking? If so he never mentioned it – this was 1981 almost 10 years after Smith and Jones released their findings about alcohol and pregnancy in the United States.

What do you think might have happened if the paediatrician had asked me if I had consumed alcohol while I was pregnant? This is one of those 'if only' times ----- there are many of them in life -----for me, they all relate to my experience with alcohol.

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Our finances took a turn for the worse during the global financial crisis but they were already in trouble through trying to keep Seth out of debt and ----- if he ever lived past his 21st birthday ----- in a position that would not affect his credit rating or his freedom. For this we needed to shell out many many thousands of dollars.

Until we were able to get Seth's finances overseen by the public trustee, he would walk into a loan shop and take out a loan for something. Unfortunately between the time he received the money and the purchase of the particular item, the money got spent. On top of that one of the dodgy finance companies sent him a credit card ready to use which he immediately used to the tune of \$2,000; he bought a car with us as guarantors which was fine but then he wanted to put a turbo in it. He was seconds away from signing another loan shop contract for ten thousand dollars when I found him. The only way I could stop him from going through with it (at that time he was an adult and presumably could make his own decisions), was to tell him I would help him borrow the money the proper way – through a bank. So by the time the Public Trustee became involved he was in debt up to his eyeballs.

All his debts are paid off now and he isn't able to take out a loan without the public trustee approval ----- they have placed his name on some list which means that any organisation he approaches for a loan will see that they are, by law, not allowed to do so.

He also began taking things from us. Calling the police would have resulted in charges and probably a conviction because he would have pled guilty. We didn't know what the right thing to do was but we hoped that this would work – eventually it did but not before we lost a lot. Im sure there are some people asking in their minds – 'why didn't she just let him suffer the consequences – natural justice right?'

Natural justice and tough love do not work with people with FASD. If for instance we hadn't paid the loans for him, he would have defaulted because he can't manage his money, he would have been sent a letter which he wouldn't have responded to because he can't respond to mail; then another letter and another until perhaps someone would come around to repossess his car or his stereo or whatever it was that he had purchased.

Then because at that time he wasn't medicated, he would have become angry and aggressive and threatened violence, the police would have been called and he would have escalated the aggression adding more and more changes and until he was thrown into jail. At that time one would say 'well that's tough love – you have to love them enough to let them reach their bottom right?'

Unfortunately with FASD the bottom is prison or death or both and we were trying to make sure he didn't carry any burdens that would affect him if he ever had a long-term relationship or marriage.

As it turns out he found a beautiful girl, Hayley; they married and now have two beautiful children.

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So our days, weeks, months and years from when Seth was between 13 to 21 were filled with anxiety, despair, fear and grief and that was just mine – Seth suffered worse than that but there is one saving grace that I cling to – people with FAS live in the moment. They are all about what is happening now! I'm really hoping that he doesn't dwell often on the past.

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The brain injury that is FAS results in behaviours which almost mimic anti-social behaviour in fact anti-social personality disorder --- and many people with this condition are labelled with a behaviour disorder rather than a brain injury.

With a behaviour disorder it is presumed that the individual is able to make changes – with a brain injury it is obvious that no changes can be made because his brain has bits missing.

When he was going through puberty and we were all going through some really difficult times, I doubted that Seth would live a long life or even make it to 15 – in fact I remember sitting on the end of my bed listening to an ambulance or police siren shrieking past our house and wondering whether it had been called for Seth because he was not in the house. It was 3am in the morning – he was 13 years old and I had no idea where he was.

I have heard often that parents should be responsible for where their children are at night – something with which I agree; and that they must keep their children at home and not let them wander the streets drinking or drugging - - something with which I agree in theory but in practice it is impossible to do within the law. It is not possible to keep a child with FAS in the house if he wants to go out unless a diagnosis has been made at a young age.

Because they have no concept of consequences it's hard to get them to do something because 'something will happen or something will not happen'. I have thought quite a bit about how I would have kept him at home knowing what I know now and came to the conclusion that I could not have done anything different. There is no way to keep a teenager with FAS in the house at night unless:

a) the house is completely locked – no windows, security screening, doors locked from the inside and you believe that the teenager won't break a window or a door to get out – a n d - you are willing to risk locking everyone inside the house if there is a fire

b) you tie him up – which can never happen

c) you lock the door to his bedroom and his window and again you believe that he won't break anything to get out – which really is on the cards for a teenager with FAS - o r and this is the best option but one which is unlikely in Australia -----

d) you were able to obtain a diagnosis as a small child and were able to repeat over and over again the things you wanted him to know and do and virtually inculcate the behaviours that you expect. In a situation like the latter, you have much more chance to support the individual through their teenage years without bequeathing additional mental health, financial and criminal justice problems for him to deal with.

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His memory of this time was that he was lonely and bored and wanted to find friends. Unfortunately his 'friends' were people he might meet in the streets that night. He was always so desperate for friends. He didn't realise that the people he met at 2 or 3am wandering the streets like he was, might not have been his friends. He would invite these people into our house in the middle of the night. **He** was being friendly; **they** were scoping the house for valuables. Many nights I woke up to check on him and found his room full of people I didn't know. I was so upset at these times --

-- having to get these kids to leave and then having to calmly tell Seth he was never to bring strange people into the house. Of course his understanding of this was that I was being unfair and that I didn't like his friends. He would also say that I had been asleep and he didn't want to wake me to introduce me to his friends; and thirdly of course they were not 'strange' people, they were his friends and he trusted them. All rational and reasonable according to FASD logic.

He would be deeply hurt and distressed if these 'friends' of his did something he didn't expect friends to do such as steal something, wreck his bedroom, steal his stash, or otherwise take advantage of his hospitality which they did regularly and because of his inability to generalise learning this would happen time and time again hurting him time and time again.

He says he realises that now but I'm never sure whether that is really the case or not.

That is just one example of the many complex and intertwined problems associated with FASD and an ill-timed or no diagnosis.

In many ways, Seth has moved outside the parameters of his condition and to my great relief and joy has surprised me. He is a good dad if he is given sufficient time to gather himself or wind down. Of course that means more work for Hayley but she seems to cope very well. In fact she is an amazing young girl. Our grandchildren are beautiful – they are healthy and emotionally stable and well-balanced. The great joy of my life at the moment is watching Seth play with them. Watching him carry them, hug them, play with them, laugh with them, and the look on his face when they call him 'daddy'.

He is working part time as a courier driver which he enjoys; he has just purchased an old four wheel drive because that is his hobby. He helps his father fix dad's old world war II military vehicle and he lives an otherwise uneventful life now. I don't think of suicide, prison, hospitals or police as often as I used to. In fact now the things I think about as regularly as I used to think about those are my grandchildren and our next outing to the 'big shops'.

There are still the times when he storms out of the house without saying good bye to his children or his wife. She seems to understand why he does this, but I feel shamed by his behaviour when I should understand that like the rest of us he is a product of his brain.

I was both deeply moved and deeply dismayed the other night when they were over. I watched my 'disabled' son play with his sons – get on the ground with them and play horsies and the 2012 version of cowboys and Indians which is using a NERF gun to shoot whatever moves. They all giggled together and I felt a way I couldn't describe. In my wildest dreams, I had never imagined a future like this for him.

But then because of some problem with dinner and what he wanted to eat and what he didn't want (I was cooking), he stormed out of the house and drove away. I no longer worry too much about his driving when he does that but it just about broke my heart to hear my oldest grandson say quietly after Seth had slammed the door "Bye Daddy!"

OMG I so wanted someone to tell me that my grandchildren will love their father and understand the reasons for his differences when they get old enough.

There are three things to take away from this presentation:

1. alcohol and pregnancy don't mix and don't listen to someone when they say its ok to have a few drinks
2. even though FASD is generally a disability from which many people do not find positives, it is clear from our story that it is possible -----so don't give up -----and
3. if you identify someone you think may have FASD, please remember they CANT not that they WONT'.

FASD is a disability that results in sufferers being good at small talk but with no 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.

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