

The Townsville Hospital Presentation

I imagine it's very hard for a doctor to tell a mother that her child has a condition that can never be cured. And harder still to tell her that it was because of something she did in the first stages of motherhood.

I expect the doctor in this scenario would be asking himself or herself, "What is the advantage of giving her this diagnosis?" "What about the relationship with her husband or partner?" "How will this information affect her and her ability to look after her child?" "How will the child feel towards his or her mother?" "Will I be able to handle the 'aftermath' of this diagnosis?"

Even though I don't know how this doctor really feels, I DO know how the mother in this scenario feels and yes all those questions are pertinent BUT the most important question is "What is best for the child?" Will keeping the true diagnosis from the mother to ease HER pain help the child? No it won't!

I am the biological mother of two boys aged 24 and 20 who have Foetal Alcohol Spectrum Disorder. They have this condition because I drank alcohol while I was pregnant and, even though it may sound incredible, I truly didn't know then that alcohol could cause the sort of harm that it has.

I am sure you are aware that Foetal Alcohol Syndrome is at the higher end of the spectrum of disorders and alcohol related Neurodevelopmental disorder at the lower. Foetal Alcohol Spectrum Disorder is the umbrella term that encompasses all levels of prenatal alcohol exposure. When we say that there is only a small incidence of Foetal Alcohol Syndrome we are only looking at one tiny slice of the FASD pie. If we were to look at the whole spectrum of affects in industrialised nations, we would be looking at roughly 1 in 100 live births.

Where there are the facial features of FASD – that is short palpebral fissures, flat philtrum, thin upper lip and flattened midface, there is definitely brain injury BUT there can be significant brain injury where there are no facial features and this is the mistake that is often made – that if the child doesn't have the facial features of FAS, then they do not have the condition.

As a young girl I thought too much, hurt too much and drank too much and because of this my oldest son has Neurodevelopmental Disorder – Alcohol Exposed. This is the on the lowest end of the spectrum. He has no facial features but he has definitely been affected. He can live a normal life but he does have Temporal Lobe Epilepsy which has to be medicated with Tegretol.

As a baby, his milestones were delayed and his muscle tone was poor. He was at the doctors almost every day with upper respiratory tract infections, ear infections, colds, flu, bronchitis, fevers, and any virus that was going around. His immune system didn't function well and was sick more often than not. He also suffered dental abnormalities and suspected hearing loss.

But these were the least of his problems - at any rate that's what I believe now - because after I learned about FASD I realised there were things I would never know that were worse than that which he had already experienced.

For instance I would never know how many IQ points he had lost – how intelligent he WOULD have been had he not been affected this way and what this might have meant for his education, his employment and his subsequent financial security.

Even now, I often find myself imagining him on the campus of a University, studying for the degree that might have provided him with a generous income and a prosperous future. But this isn't the case and even though he is in a good job he will never earn at the level that he might have had he not been affected by FASD.

My youngest son has full Foetal Alcohol Syndrome. He suffers from many primary disabilities and most of the secondary disabilities.

The primary disabilities include learning problems, an inability to understand the linear logic of cause and effect, executive functioning deficits, poor impulse control, poor judgement, distractibility and attention deficit. Even though his intelligence is in the normal range and he should be able to do just about anything he puts his mind to, at 20 he often behaves like a 13 year old. Having executive functioning deficits cancels out any level of IQ. He also suffers from perseveration which has been one of the most difficult problems with which to deal.

Perseveration means that for him his first choice is the only choice. No matter what information becomes available after that decision is made, he is unable to change his mind. Before he had a diagnosis, trying to change his mind by arguing resulted in having to restrain him physically from hurting himself or others.

Because he was not diagnosed until he was 17, he also suffers from many secondary disabilities including schizophrenia and drug and alcohol abuse. He is unable to maintain employment without a support worker and cannot work for more than 3 days a week. He had trouble at school; every report card had the tag phrase "very low achievement" against each subject. He is unable to manage money to the extent that if he was backed into a corner financially he would resort to stealing – We know this from experience.

His future looks bleak doesn't it? But he may not have had a future at all if he hadn't been diagnosed.

There could be as many as 200,000 people in Australia affected by this condition who don't know they have an invisible disability; so consequently the people around them don't know and believe their friend or relative is just an ungrateful delinquent; an immature troublemaker, or a remorseless vandal.

For my husband and I, the defining moment in the management of this condition both emotionally and physically was having a diagnosis - experiencing the conversation in the first paragraph of this presentation - by far the worst moment of my life to date. But even though it was a difficult time, it was also the time from which we, as a family, were able to start truly helping our sons.

It was the moment from which my youngest son 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 -- unless they have an IQ below 70 which makes them eligible for special services.

I was lucky enough to eventually find a courageous and pioneering doctor who was willing to put aside his own fears and weigh up the emotional costs to us both against the benefits for my sons. Prior to this time I sat through many consultations, sobbed through some, was silent through others because those doctors for whatever reasons, were reluctant to even discuss the condition with me.

I can't begin to tell you how distressing and frustrating this was for me.

So while you may be right in believing that talking about this condition with a mother either before, during or after the event, will be a tremendous disturbance to the family – it is a responsible disturbance and one which you must be prepared to make - as long as support is available to help the family come to terms with the problem and move forward.

The Hippocratic Oath suggests “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.

Anne Russell

Elizabeth (Anne) Russell