

## The Power of Knowledge: Reflections from the Experience of a Birth Mom

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Sir Frances Bacon first said that 'Knowledge is Power' but I'm not entirely sure he's correct. I've worked for almost 11 years in FASD. People ask me to train them, present to them, help them – I know about FASD but it doesn't seem to have any power at all when I'm trying to explain my son's needs to someone just out of University.

I say he has a brain injury and ask for a case manager; she sees a teenager with an IQ of 106; I explain he has a significant disability; she sees a strong and healthy young man; I say he has good days and days when he forgets everything he has learned; she sees him on a good day; I say he can't manage his money and that it is financially draining on the family; she sees a mother who lacks parenting skills; she sees a seemingly compliant teenager; I see him stamping his feet like a 2-year old; I see my beautiful son so distressed that he cuts "I want to die" in our furniture with a knife; he denies it to her and she believes him; I beg and cry to her for help because I am losing my son; she tells me tough love will teach him responsibility.

Of course, most services in Australia are well meaning, and they have superb skills when it comes to dealing with people with 'mainstream' problems.....but when they are presented with someone with FAS they really don't get it at all. This is my experience and the experience of many other mothers to whom I have spoken, but still I generalise terribly and to those who do things differently please forgive me.

If I were to reflect on my experience as a birth mom, then contact with medical professionals and social type services has been the most frustrating, humiliating and demoralising experience I have had since Seth was diagnosed 10 years ago.

Even taking information on FASD along with me to consultations and appointments as well as Seth's medical, social and educational history; and, in later years, a diagnosis from Sterling Clarren didn't change the arrogant posturing of some professionals I visited.

When I was young, I accepted the knowledge of others without reservation – the most unfortunate was the advice from my obstetrician that drinking during pregnancy wouldn't hurt my babies.

And I didn't have any experience which would counter this statement. In fact I don't think I had ever held a baby before I held my own. I was young and damaged and charged with the monumental task of carrying and raising two children to be responsible, happy, well adjusted members of society which, because of my childhood, was something I wanted more than anything on earth.

Now I'm confident and relatively happy - my guilt doesn't always overwhelm me or define me like it used to. While there are still times I crave the sort of contentment that only comes with ignorance, I know that without knowledge of the condition, Seth would not have the same opportunities that he does now. He may not even be here – he was very intent on suicide during his teenage years.

But unless they request training, I am at a loss to know how to get those services in Australia to stop being so arrogant and start listening to the people who know more about their children than anyone else –parents.

For FASD in particular, parents and carers seem to hold a lot of the knowledge. Some parents and carers can understand the scientific and medical facts associated with FASD but it's almost impossible for medical and scientific personnel to understand what it's like to have a child with FASD.

Children with this condition are extraordinarily difficult to nurture and they need us to be there for them and to love them when no one else takes the time or makes the effort to understand how hard it is for them, and how hard they are trying.

Knowledge of FASD and my experience tells me that when my child yells at me, he needs me to know that it's just frustration or from being overwhelmed with choices or problems, even though they are choices that are very easily made by you or me.

He needs me to know that when he perseverates about something it's because he **cant** change his mind, not because he chooses not to.

He wants me to be there for him regardless of how much he annoys me, or how often I have to bail him out of some predicament that he may have unknowingly set in motion.

He also needs me to advocate on his behalf if necessary, for medication and other things that will improve his quality of life. And above all, he needs me to keep coming back to him no matter how many times he tells me to leave him alone.

But if he exhibits behaviours that are dangerous to himself or to his brother, his father or me then that's when he needs me to be at my strongest and do whatever I can do to ensure the safety of everyone because occasionally he becomes so overwhelmed that there is very little I can do but call the police.

And there were times that I thought that there was nothing I could do and no service I could access that would stop him from destroying himself.

There are two things that connect us here today. The first is our experience with FASD and the second is that all of us here understand that while knowledge is power, with both comes responsibility – the responsibility to provide others with the knowledge and awareness of this condition and its cause.

Because of this responsibility, I so dearly wanted to speak with other birth mothers to find out how they coped. I wanted to read about their experience and connect with them on a deep personal level. I wanted to know that they felt what I was feeling. As the years past I saw that having a support group would be one of the most valuable tools we mothers could have to escape our various dark holes.

That was when I wrote the 12 steps for mothers in the hope that eventually Support Groups would spring up around Australia and that if they did, they may wish to use these steps. I know this process helped me. They are based on the 12 Steps of Alcoholics Anonymous and they were written specifically for birth mothers and they are in the syllabus.

Despite all this my son Seth grew to be a 26 year old man (an age that I never ever expected him to reach) with a lovely wife and two beautiful children both of whom are not affected prenatally by alcohol.

Last week he applied for a job – the first for 6 months as he usually needs a break of between 6 and 12 months after he has finished a job before he looks for another one. He came to my work to pick up his resume. He was dressed up, showered and shaved and I was so stunned my tongue tied when I introduced him to my colleagues.

We have very special children to protect - even though they look like adults they are still children. My son has taught me the meaning of fear, pity, compassion, despair, joy and unconditional love. I believe in reincarnation so I used to believe that Seth had chosen me to be his mother for something he wanted to experience ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,but I am beginning to question whether this experience was for him or for me.

I would like to read a poem I wrote when I first found out about FASD to explain what its like to be a birth mother.

#### Reflections of a Birth Mother

There's something inside her at last  
For the longest time there was nothing  
She gazes into the mirror  
And raises her glass, drinks and turns away  
Pragmatism wins over introspection  
Her glass is empty  
She already loves her baby more than she has ever loved herself – but will that be enough?  
She imagines how he will look when he is born, how she will dress him  
What sort of man he will become  
He nudges her and she smiles briefly  
She feels different now – special  
And for someone who has never felt special in her life  
It's a good feeling  
She watches as her image fills the glass and raises it to her lips  
And as she sips the only thing that has ever made her happy, her baby waits to be born