

## How could this happen to such beautiful children?

*Her nieces are beautiful, loving children and the rest of her family is committed to them even though Eliza and Chiara have an incurable, irreversible condition which will see them need care for the remainder of their lives.*

I am the mother of five, three are my own biological children and two are my nieces. I have a son aged 23, and two daughters, 21 and 16, and I also have a granddaughter, Nadia, the daughter of my oldest daughter. My nieces are Eliza 3½ and Chiara 2. Eliza was officially diagnosed with Fetal Alcohol Effects (FAE), an out-of-date term now that indicates she has some of the features of Fetal Alcohol Syndrome.

Eliza was removed from her mother (my sister-in-law) at four months and was placed in care until I was able to take her at eight months old.

When she arrived she looked just like a newborn. She was not able to smile, take solids, couldn't roll over and would often 'zone out' for minutes at a time. My brother (her father) and my sister-in-law are both alcoholics. Between them they have four children all of whom are in care.

When we were told that Eliza was under a Protection Order and that these orders only lasted for six months we realised we had to make a difficult decision. We had a family conference to discuss our options as to whether we would or could care for her. It was a fait accompli – all members of the family agreed to look after her. Even though my family has all participated in her care, the most outstanding carer is my granddaughter Nadia. Nadia is almost 4 years old and Eliza is 3½ but Nadia treats Eliza like her own baby. She will put her on her knee and feed her and every day comes home from preschool to tell me how Eliza has been during the day. She will say things like, 'Eliza has eaten well and had a good sleep at preschool today, Nana, so she should be a good girl tonight.'

It was tough in the beginning for our family because I am a single mother. I felt very, very sorry for Eliza. She has unexplained scars and has obviously been traumatised by her environment during her first four months of life. It must have been hell for her at that time. She didn't bond with me for a long time and didn't want to be held or cuddled and was a very frightened little baby, but now even though she still gets anxious at times she has become very loving and has bonded with the whole family and they with her.

Every day has to be planned for Lizzy and Chiara. I can't take them shopping with me because Eliza can't handle crowds. The 'zone outs' she had as a baby were eventually diagnosed as seizures and crowds cause over-stimulation and over-stimulation causes seizures.

She still doesn't sleep through the night and will often wake between six and seven times. I decided the best way to handle this when she got older was to 'child-proof' her room so she could get out of bed when she woke up and play by herself. Children with FASD don't sleep well or deeply and often have very difficult sleeping patterns. So when she wakes up she can play without me having to worry about her hurting herself or me getting out of bed to ensure her safety. Her Therapy Team is not happy with this idea, they want me to 'pat' her back to sleep again but I have tried that and it doesn't work, she wakes again as soon as I move away. I can see that they are concerned about her ability to function at preschool but I know there is nothing I can do to get her back to sleep before she is ready. She is just not like other children.

It's very important that people who care for a child with FASD realise that they cannot modify the child, they have to modify the environment. This is the only thing that has worked for us. I would still be in her bedroom trying to pat her to sleep and still be losing sleep and failing if I believed that her behaviour could be modified.

Another example of this is that Eliza doesn't like the water but her Therapy Team wants her to learn to swim. One day she may, but not at the moment, and from experience I know there is nothing I can do to change this.

She may lose her fear of water as she gets older but right at this moment she hates the water and to try and force her to swim would be very distressing for us both. I have high expectations for her but I have undertaken a lot of research on FASD and believe that my expectations are achievable for her given her condition. I want her to achieve her potential whatever that may be but I don't want her traumatised by the journey. She has had enough distress in her short life.

I have discussed her condition with her teachers at her Special School and they believe there have been many children through their school with this condition. It's just that it hasn't been diagnosed or has been misdiagnosed. Because of this they have asked me to give presentations to the school which I am happy to do. I take any opportunity to inform people about FASD, none of which is about blaming the mums in any way. Her mum was and still is addicted to alcohol – she has a disease.

Eliza's speech is quite good and she is starting to come home with little incidents that happen at preschool. One thing that is particularly distressing for me is that she tells me that the other kids are going to the toilet at preschool. She wants to be potty trained but she just can't get it together. I can see it in her eyes that she knows others in her class can do it so she should be able to. She says to me 'I go toilet?' and I say 'Yes, honey – one day.'

The Special Education Development Unit which is part of Education Queensland has been wonderful and I highly recommend it for children with any problems like Eliza's. But even with this assistance my concerns for Eliza and Chiara continue. I have investigated Australia's current management of FASD, which suggests that Eliza's health and wellbeing may be at risk in the future. Examination of current literature reveals that the incidence of FASD is currently underreported and prevalence is unknown in Australia.

Medical personnel are under-educated in the use of diagnostic tools and treatments/therapies. A lack of valid and reliable local data on FASD and possible interventions is evident in Australia, which leads to a deficit in services. So, if positive diagnosis operates on a hit and miss basis (i.e. positive diagnosis by a paediatrician is reliant on that doctor's level of training, interest in FASD, belief in its existence) – where does this leave Chiara? Will she be tested for FASD? Will she return a false negative result due to subjective assessment? What if she returns a true positive result like Eliza? Where do we go for services?

What about this current therapy that Eliza is undertaking? Now that we know that Eliza has FASD are these current interventions appropriate? Could they be doing any harm? Discussions with Eliza's therapists reveal that all have heard of FASD but all admit to only very limited knowledge on the condition or appropriate interventions. Case workers, team leaders and managers at the local office of the Department of Family Services communicate the same message with regard to FASD. If all these professionals know of the existence of this condition but nothing about how to deal with it, what is the hope of my two nieces reaching their full potential whatever that happens to be – and how will we know?

My family and I quickly learned to adapt to the needs of these two wonderful little girls. We all cherish them and advocate for their best interests at all times. Contact with my brother and sister-in-law is now sadly limited; they appear to have gotten on with their lives without the girls, but we will continue to be committed to their care for as long as necessary.