

## This child is their treasure

*They not only saved their nephew from a slow death but also gave him love and hope for his future in paradise.*

Gary, my ten-year-old nephew, is the son of an alcoholic father and an alcohol and drug-addicted mother. I have looked after him since he was five months old when my husband Peter and I found him wedged underneath his mother who had blacked out on the floor. It was late in the afternoon that we found them and God knows how long he had been there. Gary is the youngest of her four children, two of whom have diagnosed Fetal Alcohol Syndrome. We were lucky that we knew about FAS when we first took him and we are also lucky that he has a formal diagnosis – not that it was easy to get.

Even though his mum drank up to a 'slab'\* a day, Gary started out doing well at school. He loved going to school until he was molested by another student. The school did not precipitate action because the student said that Gary was a willing partner. We transferred him to another school because we didn't like the way the principal and teacher handled the situation, but unfortunately now Gary hates school. He changed from a child who leapt out of bed in the morning to get ready for school to a child who is suspended or in trouble on a regular basis. He is suspended today because he got angry and instead of walking away he pushed a student.

\*a slab is a carton of 24 tins or bottles of beer.

It's so hard to get people to understand that he cannot control a lot of the things he does. It's the environment and the people around him who have to change. His teacher doesn't understand about FAS and isn't prepared to find out. Instead she has suggested that rebirthing would help him and even though I have told her that changing her expectations of him is the only way it will work for Gary at school, she is putting him in a behaviour modification course.

I can only assume the reason the teachers want to try to change his behaviour by sending him to a behaviour modification class against our recommendations is because they can't see anything wrong with him visibly so therefore there IS nothing wrong with him apart from his bad behaviour. He speaks well and looks perfectly normal and because of this they expect him to do things he can't then they get frustrated and he gets frustrated and suspension is the result. He is the sweetest most loving child but they can't see it because they expect so much of him that he can never hope to fulfil so they become disappointed and angry and he gets angry and frustrated and so that is who they see when they look at him.

Gary has a very good paediatrician and psychiatrist. The paediatrician referred us to a geneticist for a formal diagnosis but the geneticist wouldn't make the diagnosis because Gary didn't have enough of the physical features. So we asked our paediatrician for another referral but he was not happy that we had questioned the first geneticist's diagnosis. These doctors were too busy playing politics to consider what this was all doing to Gary. Eventually our psychiatrist ended up diagnosing him.

Over the years I've learnt how to avoid volatile situations with him – if I remain calm, no matter what is happening and how loud and aggressive Gary is, eventually he calms down and a very difficult and unpredictable situation is avoided. But if Gary starts to get angry and I also get angry then his anger and tantrums escalate until he is completely out of control.

He has found some stability with his medication now – without medication life would be intolerable. He is on Neulactil for psychosis and Endep to sleep. They combine to help him control his moods. A few years ago I tried ADHD medication – stimulants – but they didn't work at all even though he had been diagnosed with ADHD. Then came another eight or nine different types of medication until we found the right combination.

My husband Peter and I work together as a team with Gary but it's hard on the other children, they have to put up with a lot. I know that to other people it looks like we are giving in to him but it's not like that. We do what we have to do to keep him safe from himself and to try and keep him out of any trouble that will plague him for the rest of his life.

Raising a child with FAS is not like raising a child with a different type of disability. There are many changes that have to be made in the thought processes of the parents. Normal punishment or natural justice does not work with these kids. They cannot always learn from their mistakes or take responsibility for their actions. People have no idea what we have to put up with and I don't like it when people make instant judgements of Gary's behaviour. They only see him for a few minutes and they blame us. Gary doesn't like to be yelled at and reacts very negatively to loud and angry voices so we always speak quietly and calmly to him regardless of what is happening.

If coping with Gary is hard, then fighting for services and assistance for him is worse. If Gary had Down Syndrome there would be no question he would have access to services but because he has FAS and not many people know about it then we have to fight every step of the way for him.

I feel sorry that mums who drink while they are pregnant don't have the education or information that they are doing the wrong thing. It's totally preventable but doctors aren't even giving the correct information to people and if they aren't how can we expect pregnant mums to know? I know one obstetrician who tells his pregnant patients that it is okay to drink two drinks a day and if that wasn't bad enough, the Education Department has implemented a strategy for alcohol and pregnancy and they also say that it's OK to have two drinks a day. It is criminal to give this information out and everyone who knows about FAS knows that's true.

Medical practitioners need more information and education about FAS – the RIGHT information. There should be warning labels on bottles of alcohol, and women should be screened for substance abuse during pregnancy. We just shouldn't allow women to drink at all while they are pregnant – why do we allow it? Pregnant women are tested to ensure their babies don't have conditions like spina bifida and Down Syndrome and then the mother can decide what to do, but we let women drink while pregnant knowing that it is possible for them to have a child with a disability that is entirely preventable. Not only do we let them drink but its almost like the guidelines encourage people to have two drinks a day.

I wish people who are sceptical about FAS would take Gary home for a week to see what it is like to live with a child who has been affected by alcohol, so they can see what can happen if they drink.

I have a meeting with Disability Services shortly and I'm going to request that Gary's teacher is trained in FAS because the teacher he has at the moment won't read anything about it. Unfortunately it's understandable when I consider what was said at a meeting by the Head of the Children's Protection Unit – he said 'there is no such thing as FAS, it's just a fancy name for a set of symptoms!'

A child is a treasure. Gary is a treasure and it's not his fault he's the way he is. He has a little garden at the moment, he loves his garden and he knows a lot about plants. When I asked him why he was building a garden he said 'We need a paradise'. Gary brings a lot of joy to our lives.

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<sup>i</sup> \*slab : A carton (24) of tinnies (alcohol in tins) or stubbies (alcohol in small, stubby bottles), each containing about 1.5 standard drinks.