

## A flawed jewel

*These two special people have not only provided a loving, caring family environment for their beautiful daughter, but now at the time when retirement offers the lure of relaxation and a break from the impact of raising four children, they have chosen to devote their time to increasing awareness of FASD in Australia.*

### Early Years

The wonderful holiday feeling was replaced with the oh-so-familiar knot in the stomach. It was substituted with the mixed bag of emotions that comes with the seemingly regular phone call from our youngest daughter Kate informing us that she thought she was in trouble once again. My wife Sally and I had just spent a week whale watching, kayaking and camping in remote coastal dunes along South Australia's west coast. We had escaped from all external pressures and as a consequence, were very relaxed.

Kate, who we had fostered since the age of 21 months, had left a message on our mobile phone to tell us that she thought she might be in a 'little bit of trouble and has to go to court'. We were on the 600km last leg of our trip and had intended visiting her on the way home. Therefore this time the message did not throw our current plans into chaos, but it did bring on the familiar nervousness in our gut, as we drove to where she was living in one of South Australia's major regional centres, another 300km away. We were no longer relaxed.

Bringing children into one's life obviously impacts on just about every facet of your plans and expectations for your future. Sally and I understood this clearly when we entered into a long-term foster relationship with Kate about twenty-two years ago. We already had a daughter and two sons, one of whom we adopted from South East Asia. The adoption process and all that it involves is another story; however, as part of the process, we had a relationship with the relevant Government Department and were already accepted as suitable foster parents when it was suggested by our social worker that this bright little child would fit in really well with our family. How could we realise that this tiny, appealing bundle of joy would later turn our lives around and lead us in directions that we had never experienced or imagined?

The instant we met her, our whole family fell in love with twenty-one-month-old Kate, and indeed she immediately slotted into the role of a much-loved youngest sister for our other children. The Department told us that Kate had been taken from her biological mother, who it was explained, could not look after her properly. Our social worker informed us that this was due to her spending too much time drinking in the local hotel. We, like most Australians at the time, had no knowledge of the effects of pre-natal alcohol exposure, so no warning bells rang.

We were introduced to Kate while she was in emergency short-term foster care with a very highly regarded family and we immediately formed a bond with her. The transition into our family went very smoothly and Sally and I did not anticipate any problems with either Kate or our existing children. All of our children were happy and developing 'normally'. As a family, we had previously coped very well with the issues surrounding an overseas adoption, so Sally and I thought that the long-term foster arrangement would be straightforward. In fact we hardly discussed the matter.

Kate was healthy, happy and brought her special brand of joy to the family. The arrangement appeared idyllic and it was inconceivable that things would change.

With four children aged between seven and two, our home was filled with constant activity, laughter, tears, a lot of love and all the ups and downs of a growing family. The added complications of an interracial adoption and fostering seemed to pass unnoticed. In the beginning, none of us were aware that Kate had some very special needs and indeed had a profound developmental disability that was change our lives.

At first Kate appeared to be developing normally, although she had one or two unusual behaviours that we regarded as endearing rather than problematic. If we knew then what we know now, we would have understood these to be indicators of her disability.

When Kate first started kindergarten, it became apparent that she was developmentally delayed. Also at this time, she became drawn to Australian Aboriginal dreamtime stories, art and culture. Although we always suspected it, we were not told that Kate was Aboriginal; however, as she grew older it became clear that she was of indigenous descent. Her school principal contacted me one day to tell me that the Aboriginal Child Care Agency had made enquiries about Kate. He explained to me that their involvement in Kate's life would only cause problems and he had told the Agency that Kate was definitely not Aboriginal. With unforgivable ignorance and to my eternal shame, I agreed with his approach.

Kate came to us as a non-Aboriginal placement; however, and notwithstanding this, satisfying Kate's Aboriginality became a prime concern. With the Stolen Generation being a major political issue in Australia at the time, we knew and understood that it was important that Kate had connections with her people and her indigenous culture. Serendipitously, our eldest daughter had developed a relationship with a young Aboriginal who to this day regards himself as a de-facto son, and at the same time she had a very close girlfriend who was Aboriginal. Over time, and through these connections, we developed a circle of much-valued Aboriginal friends who have given Kate a sense of kinship and belonging that we would not have otherwise been able to provide.

Sally tried to research Kate's biological history and spent several years trying to trace her ancestry. She consistently drew blanks and I should add that this search has sown a seed of cynicism towards officialdom as Sally was told on more than one occasion that records were water damaged, or simply lost. Kate's official Departmental file and her social worker hinted that her mother may have associated with Aboriginal people from time to time. The trail reached dead end after dead end.

Although we have never been able to find her 'country' or her 'people' Kate now feels very comfortable and proud to say that she is Aboriginal. She is regarded as a 'sister' by our group of Aboriginal friends and is recognised in public as 'belonging'. It is unfortunate that despite intensive research she does not know her country.

Kate's developmental delays and learning difficulties soon became our major area of concern. She remained a bright, happy and contented member of the family, but she had difficulty developing and maintaining friendships at school. On more than one occasion, she and one of her classmates were the only girls left off birthday party invitation lists. Her poor socialisation skills, excusable in early childhood, were not developing with maturity. Interestingly, she had an uncanny ability to discern immediately whether or not someone liked her on first contact. Early childhood relationships with peers can be very topsy-turvy, but Kate never enjoyed a sense of popularity. Kate's schoolwork degenerated to classroom attendance with almost no academic comprehension of the curriculum. Despite her being our fourth child, and the others developing 'normally', we felt that our parenting ability was being questioned.

Kate, while still the very loving and loveable youngest child in our family, was not developing as she should. She did not seem to know how to behave socially, she did not learn from her mistakes, she had no numeracy skills, and although she could read, she had no comprehension of what she had read. Kate appeared to have no sense of cause and effect or right and wrong when it came to her actions. A lesson that was understood one day appeared to be lost the next and she did not recognise boundaries with respect to property and space. Sally and I were worried that she would be unable to manage her life without these abilities.

While I went to work each day, Sally spent a large amount of time taking Kate to a variety of medical specialists, psychiatrists, psychologists and educationalists in an effort to discover what the cause of Kate's difficulties was and what could be done to help her. Over the years these efforts resulted in diagnoses of central auditory processing disorder, borderline intellectual disability and developmental delay. Although this helped to a point, we were still not equipped to fully understand Kate's behaviour and therefore develop strategies to overcome her by now very apparent 'differences'.

By contrast, during this time, very close and remarkable friends of ours were fostering a young boy, who was also initially presented by the Department as having no problems, and was diagnosed as having William's Syndrome. They found a support group with considerable knowledge about the syndrome so their understanding of the issues and strategies involved with the management of this child enabled him to be the best that he could be. While I am not diminishing in any way the enormous effort that a person with an intellectual disability demands of carers, at least this child's problems were understood and as much as possible, expectations could be established and met.

When the time came for Kate to progress from primary to secondary school it was clear that we needed to find a school that would provide a caring, understanding environment for her. After an extensive search and several interviews we selected a caring private school in Adelaide. Neither the school nor ourselves had any reason not to enter Kate into a normal curriculum, but she was given a few hours a week of one-on-one lessons with a wonderful special education teacher who concentrated on teaching life skills.

Kate had to catch the bus to her new school and we soon discovered that she suffered from panic attacks brought on by a variety of environmental conditions. Buses, planes, multi-storey buildings, lifts, heights, noise and crowds all present major stresses to Kate. We now know that these were brought on by sensory overload. She also began to lose contact with her one primary school girlfriend, and she developed her first relationship with a boy.

Secondary school served to highlight Kate's lack of academic ability and she left school early achieving only attendance assessments in a couple of subjects.

### The Revelation

When Kate was initially placed with us, our social worker told us that she suffered alcoholic withdrawal at birth. This comment was made almost casually and there was no significance given to the comment apart from a degree of sadness.

When Kate was about ten years old, Sally, by chance, came across a magazine article that reviewed a book written about an American foster father's experiences with a child with an intellectual disability. The description of the child and its associated behaviours made Sally feel that the book could have been written about Kate. It was the first thing that she had ever read about behaviour similar to Kate's that made sense. The child had Fetal Alcohol Syndrome. Could this be the root cause of all of Kate's problems? This thought was to remain with us for the next seven years.

I can recall a period of several years when Sally took Kate to specialist after specialist in the hope of exploring this possibility and finding the key to what we could do to help her. Each time we were filled with hope, and each time the management strategies were found wanting. Prenatal exposure to alcohol was not considered seriously by any of the so-called 'experts' and specific knowledge of the effects of this was virtually unknown.

The revelation came when Sally found out about a conference on Fetal Alcohol Syndrome (FAS) in Canada. Amazingly, no one seemed to know anything about FAS in Australia, yet it was understood to the extent that they had a whole conference devoted to the issue in Canada, and they held it annually! With the help of all our accumulated frequent flyer points, Sally travelled to Canada and attended the conference.

What became immediately and glaringly obvious to Sally was that the Canadian health authorities recognised the cause, effects and the costs to the community of the most significant preventable cause of

intellectual/developmental disability in the Western world – Fetal Alcohol Spectrum Disorder (FASD). We were alarmed to learn that every bottle of Australian wine exported to the USA carried a warning label advising pregnant women that the consumption of this beverage may harm the unborn child. Where are the Australian warnings, is there a missing duty of care towards Australian women here? We learnt that Kate's behaviours were consistent with FASD. Why didn't anyone in Australia tell us this? We learnt that the management and treatment techniques being used by ourselves and Kate's teachers would not work. We already knew that, but now we started to learn why. What also started was our journey down the FASD lane.

After the conference, Sally managed to gain a medical diagnosis for Kate from a FAS specialist in Canada who was prepared to give it on the basis of various psychological evaluations, birth records, early childhood photographs and details of her mother's drinking habits during pregnancy. This information was obtained from the Department's file that also contained some hospital records.

We had a diagnosis. We finally began to understand Kate's courageous daily battle to be the same as everyone else.

From the overseas work that has been carried out, notably in Canada, but also in the United States, New Zealand and some Scandinavian countries, we now had an understanding of Kate's problems. What amazed and shocked us was that we could not get this knowledge in Australia. It seemed incomprehensible that the alcohol industry or the medical profession were not educating women to the fact that alcohol freely crosses the placenta and the developing fetus has the same blood alcohol content as its mother and therefore the development of its brain will be compromised by the known teratogen – alcohol. It is that simple.

It all made sense! What didn't make sense was that this message was virtually unknown in our country, but well known in other Western countries that we like to compare ourselves with.

Since then, Sally has devoted most of her spare time researching, advocating and counselling in the area of FASD and has become nationally recognised for her work. She has found an incredible amount of information from overseas resources, most of which has been published on the Internet. She belongs to mailing lists and an online support group for FASD. In this light, it is distressing that there is still opposition from some health authorities and professionals in Australia to this internationally accepted material.

Unfortunately for Kate, we soon discovered that we were too late to put in the most effective interventions and strategies that were known in the overseas countries to enable FASD-affected children to develop in the best way possible.

However, we had a diagnosis and an understanding of the issues. This has made an enormous difference to the way we now manage Kate and her behaviours and is helping us to help her to become the best that she can be.

### Late Teenage Years

In the meantime, Kate, with the help of her boyfriend, had periods where she ran away from home, mixed with drug takers and behaved sexually inappropriately – with disastrous results. She already had to cope with an incident of sexual interference by a trusted (ex) friend. She started lying and stealing, even from family. Eventually she left home and moved in with a new boyfriend who turned out to be physically and mentally abusive. She lost her supported employment and he introduced her to binge drinking which I am sure has contributed, along with the effects of FASD, to her becoming an alcoholic. She has now had several dangerous psychotic attacks as a result of inappropriate alcohol consumption resulting in police forcibly taking her to hospital on multiple occasions. She has spent time in a psychotic ward and two uncompleted periods in an alcoholic rehabilitation facility. Sally and I struggled with strategies to manage Kate's life and keep her safe.

Throughout all of this, we had a relationship with social workers from firstly her juvenile and then her adult or post-18 years Social Welfare Department. At a social worker level, Sally and I felt that Kate and indeed we had a

degree of support. These workers invariably operated with constraints and I have no issue with any of them on a personal level. I do openly criticise the Department's management of foster children with a developmental/intellectual disability or mental health issues. As an aside I am of the view that most, if not all children who end up in the foster system have psychological problems that are not properly recognised or dealt with by the Department. I am also critical of the Government's lack of funding in the area of intellectual disability and its readiness to leave it to unpaid carers to take responsibility for the safety and welfare of these individuals. In short we felt then, and even more strongly now, that the Department had let us down badly. The Department was after all Kate's legal guardian.

Kate had, however, and still has, a very well-developed survival instinct. When she felt that her life was beyond her control, she would ask to be rescued and returned home to live with us. Initially these periods would be harmonious and she reverted to being a loving and lovable daughter, full of remorse for her actions, and Sally and I would lapse into a false sense of security. Invariably, after a period of time, in an effort to overcome extreme loneliness and gain peer acceptance, Kate would feel drawn to form inappropriate friendships. Destructive behaviour was the inevitable result.

Kate moved from living with her abusive boyfriend to emergency accommodation that led to an unsuccessful period of living independently and then supported accommodation. There was always some incident that terminated her living circumstances and this would be followed by Mum and Dad coming to the rescue and setting up some other arrangement.

Throughout all of this turmoil, Kate remained loved and loving. We could never give up on her. The thing that enabled us to continue was our increasing knowledge of her disability, and the faith and hope that eventually she may be able to live safely and independently with support, not necessarily from ourselves. If we gave up on Kate, there was nobody else.

#### An Aside

Several years ago Sally received a phone call from a woman who thought that she may have caused her two boys to be affected by her alcohol consumption during pregnancy. As Sally had mostly dealt with carers who were not the biological parents of individuals with FASD, this presented her with the dilemma of what to say to a birth mother who clearly would have to deal with deep emotions including the burden of guilt.

What started with a tentative contact has developed into a deep friendship. Acceptance and the journey that this woman has been forced to make, coupled with the courage and strength that she has demonstrated, make her quite remarkable.

The strong message is, don't drink any alcohol while pregnant, if you are drinking while pregnant, stop now and if you have consumed alcohol while pregnant, seek a diagnosis and an understanding of FASD so that the appropriate interventions and management strategies can be put in place.

#### Now

As I write this, Kate is living with her current partner of almost two years. They have a loving relationship. Her partner also has an intellectual disability that manifests in similar, but in many ways complementary behaviours to Kate. They share a unit in a pleasant Adelaide suburb and both are in full-time supported employment. Sally and I are in daily contact with them and assist with money management, shopping, medication and getting to work on time. We are determined to prevent yet another cycle of failure and we feel that this time we are better equipped to do this.

Without our acquired knowledge of Kate's and hence her partner's disabilities, these tasks would be impossible and they would be heading for yet another failure. Overseas studies and research indicates that without significant support, these young adults would fail and end up in the judicial system for crimes of which they have little

understanding. We have willingly arranged much of our lives around this exceptional child of 'ours'.

The tragedy is that we had to gain this knowledge from overseas and the disability is not understood in Australia. It is only in very recent times that FASD is becoming recognised in this country and I believe that Sally has influenced this in no small way. Education, prevention and management strategies are necessary and are yet to be developed.

Kate is only the very small tip of a very large iceberg. I am utterly convinced that had we known about FASD before we fostered Kate, Sally and I could have greatly improved the quality of Kate's life. As it is, I am sure that we have kept her out of prison, drug dependency and a life of abuse and or crime. I am just as sure that there are many other undiagnosed FASD sufferers in Australia who have committed often violent crimes as a result of their disability, not their personality, upbringing or lack of social opportunity and all we do as a society, is incarcerate them. This has been at an enormous national social and financial cost.

Sally and I are not abstainers; however, we are convinced that alcohol and pregnancy do not mix. We feel that the community needs to be provided with a balanced view on the effects of alcohol consumption and the current positive emphasis on health benefits does not allow the community to make reasoned choices about the nature and safe level of its consumption.

We, perhaps especially Sally, are not the sort of people to abandon Kate or the FASD issue that she represents. Kate deserves to have a rich and fulfilling life. Society must be made to understand that FASD is the biggest preventable cause of intellectual disability in the Western world. We owe it to FASD sufferers to create the social environment to allow them to succeed and be the best that they can be. Society must take responsibility to educate and support intending parents on the dangers of prenatal exposure to alcohol so that Kate becomes the last generation of affected individuals.

How we treat the disadvantaged is a measure of our worth as a community and I am of the view that the way Australia is treating its intellectually disabled and people with mental health problems in general is unacceptable.

### The Roller Coaster

I have often thought that no matter how Kate is behaving or managing her life – well or not so well – things will always change. Kate's life, and as a consequence the lives of those near to her, is a roller coaster. It is now several months since I submitted my scribbles to Elizabeth for her book, and in that time Kate's life has travelled both up and down on that roller coaster. She has had an extended period free from alcohol, stable employment and exemplary behaviour, but things are about to change.

Relatively recently Kate lost her job and commenced sporadic drinking again. Although she has regained her job, she and her partner have decided to return to live in the regional centre where they previously had alcohol problems, inappropriate friends and subsequent trouble with the police. We are unable to convince them of the retrograde step they are about to take.

I must remember what I have just said about change!

### Conclusion

There are many issues that I have not detailed in this account as I feel uncomfortable committing them to paper. Suffice to say that they relate to the normal needs and aspirations of young adults; however, for people with FASD they present huge moral and ethical issues. Society is all too ready to allow people to learn from their mistakes, but what happens when in reality, through brain damage caused by prenatal exposure to alcohol, a person loses the capacity to learn from the mistakes they make over and over again?

