



a note from David Dossetor...



Fetal Alcohol Spectrum Disorders (FASD): Raising awareness of a preventable disability in our midst.

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Tristan is a 13 year old boy from Fitzroy Crossing, a community of 2500 in the Kimberley, 400km east of Broome, who travelled to Admiralty House, Sydney, to meet the Governor General Quentin Bryce on 5th April this year along with his foster parents including Marmingee and Geoff. The occasion was the launch of a short movie "Tristan" on Fetal Alcohol Spectrum Disorders (FASD) (Kirby, 2012). Members of the Lilliwun research and film team including Elizabeth Elliott, Jane Latimer, June Oscar and Marmingee Hand were also invited in May to present the film to the United Nations Permanent Forum for Indigenous Issues in New York to promote awareness of the dire consequences of drinking in pregnancy. In 2008 Elizabeth Broderick, Australia's Sex Discrimination Commissioner and Commissioner responsible for Age Discrimination and her sister Jane Latimer took the group's first movie called *Yajilarra* (to dream) to the UN. This film charted how, after 55 deaths including 13 suicides in the community in a year, two female Aboriginal elders from Fitzroy Crossing, June Oscar and Emily Carter, started a chain of reforms and persuaded the WA liquor licensing

board to ban the sale of full strength take away alcohol. This calmed levels of violence, eg. a reduction of alcohol related presentations to hospital by 42%, and brought the community of 5 Aboriginal language groups together through the Marninwarntikura Womens Resource Centre and Nindilingarri Cultural Health Services, to provide leadership in their challenge - FASD. This led the community to want to understand the importance of FASD, which was aided by another short movie *Marulu* (a Banuba word that means precious, worth nurturing). They invited a research team from the Children's Hospital at Westmead, the University of Sydney and the George Institute to do a study of child health and development in Fitzroy Crossing and the surrounding communities called *the Lilliwun project* (Kimberley Kriol for 'all the little ones') (Elliott et al, 2012) (Kirby, 2012). Mick Gooda, Australia's Aboriginal and Torres Strait Islander Social Justice Commissioner, has promoted this project as a best practice model of Aboriginal led research resulting in change (Gooda, 2010).

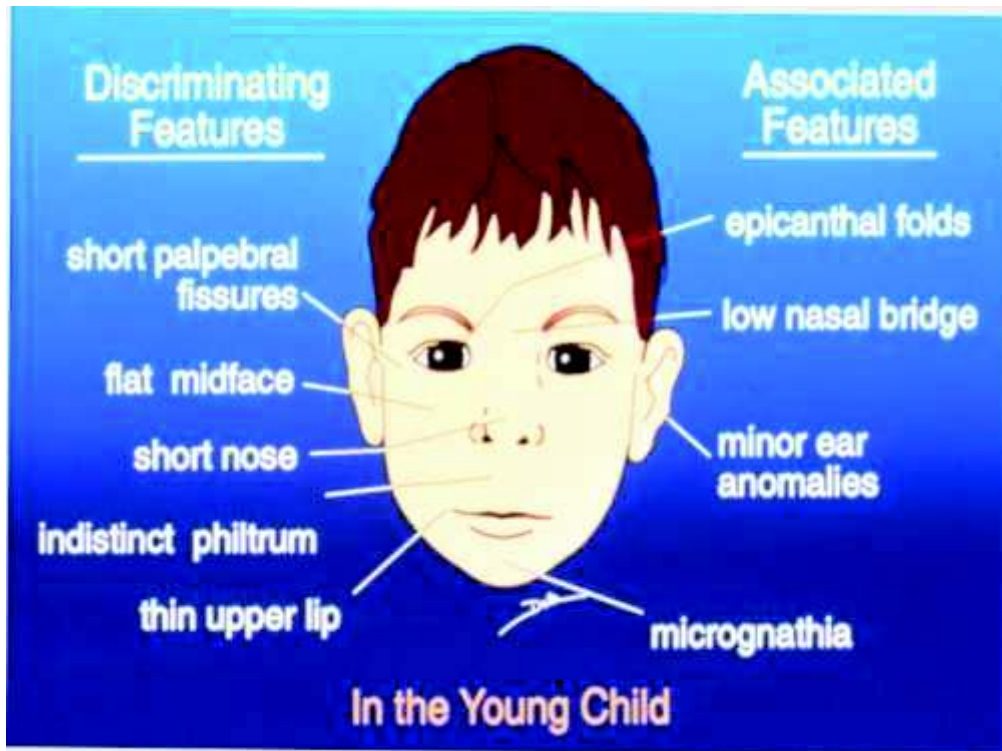
Tristan is a likeable and generally happy boy who uses repetitive sensory activities to help him concentrate and keep calm and has major problems of memory and connecting thoughts. This makes it difficult for him to engage in peer friendships. He has major learning difficulties needing individual support in school. He has high energy levels, with problems of distraction and benefits from plenty of outdoor activity such as being linesman for the local AFL team. Amongst his physical abnormalities is hydrocephalus, treated with a shunt. Marmingee (his aunt) and her husband Geoff are both teachers and highly skilled in providing a supportive environment for Tristan and his 2 younger foster brothers (Marmingee's grandchildren) who are also affected by FASD. Poignantly, Tristan wishes he was normal. His birth mother is now able to admit she was wrong in drinking during pregnancy. June Oscar describes how recognising FASD can make others more understanding of the condition and how this takes off some of the pressure of unrealistic expectation and gives children a chance for community support and acceptance.

Of course FASD is found in all populations and ethnic groups. Preliminary data suggest that 50% of indigenous women in the Fitzroy Valley drank in pregnancy - mostly at very risky levels - but other studies

show that 60% of non-indigenous women report drinking in pregnancy. The rising culture of teenage binge drinking means that teratogenic* harm to a developing baby can be done before the mother is even aware of being pregnant. Surveys show 25% of 14 to 19 year olds have had a drink in the last week and that 11% of females aged 18-24 years indulge in high risk drinking. Intake of 7 or more standard drinks a week in pregnancy has been associated with attention deficits in the child. Some studies suggest that alcohol in pregnancy is now the leading cause for intellectual disability with an incidence of 2-4% suggested! However lack of professional knowledge, enquiry and recognition limits identification.

"The rising culture of teenage binge drinking means that teratogenic harm to a developing baby can be done before the mother is even aware of being pregnant...."

A workshop I attended at the 2011 American Academy of Child and Adolescent Psychiatry Annual Meeting described the rising concern in USA and Europe. It has been known for 50 years that alcohol is teratogenic to the developing brain in animals and humans. Fetal Alcohol Syndrome was first described in 1973. The full Fetal Alcohol Syndrome is characterised by growth retardation, characteristic facial features as outlined in the diagram, and structural abnormality or functional impairment of the central nervous system and may include defects in heart, kidney, bone development. The organic brain damage can include microcephaly, intellectual disability and seizures and can occur in the absence of other physical features. The neuropsychiatric features or Alcohol Related Neurodevelopmental Disorder (ARND) may also occur without identifiable physical features. The term Alcohol Related Birth Defects (ARBD) is used to describe physical effects of prenatal alcohol and can occur without ARND. FASD is the umbrella term that includes the three groups of fetal alcohol related abnormalities. First trimester alcohol exposure may cause facial dysmorphology and growth deficiencies, while 2nd and 3rd trimester effects on brain development include disruption to neurogenesis, neuronal differentiation, migration, arborisation, synaptogenesis and functional synaptic organisation, and neurotransmitter



system development. Animal models even show a transgenerational effect of maternal alcohol use, for example leading to offspring having an increased craving for alcohol or even a different coat colour. ARBD may account for approximately 20% of all birth defects.

Susan Rich, a child psychiatrist from Washington DC, highlighted the multidirectional interactions between multifactorial elements of FASD: the cognitive dysfunctions and learning disability, the poor academic and social performance, school failure, the adverse home and social environment and violent and persistent antisocial behaviours. She divides the neuropsychiatric deficits up into: 1. language and social skills deficits, 2. mood and autonomic arousal dysregulation, 3. multisensory functional and perceptual deficits, and 4. cognitive and executive dysfunctions. Identifying FASD helps professionals understand the co-occurrence of such a wide range of complex deficits. She classifies ARND severity: **Mild** - with evidence of complex learning disorder, with or without language disorder, psychiatric disorder and deficits in adaptive functioning or executive functioning or **Moderate** - with evidence of complex learning disorder with or without intellectual disability; chronic psychiatric disorder unresponsive to standard treatment approaches including medication; neuropsychological deficits in working memory, executive functioning, judgement and decision-making, and deficits in adaptive functioning. **Severe** ARND is also known as static encephalopathy, with evidence of structural brain damage, brain dysfunction or seizure disorder.

A practicing American lawyer, William Edwards, described his work with juveniles on death row, where many seem to have FASD. His work suggests that mothers will routinely deny use of alcohol in pregnancy and that discrete information from other informers is necessary. The major neuropsychiatric problems described in FASD are often seen in recidivist juvenile offenders, who do not have the insight to alter their own trajectory. The reports that they often end up in foster and institutional care are alarming, but difficult to substantiate without more longer-term studies. The Australian NHMRC health recommendations on alcohol use reports that there is no safe lower limit of drinking in pregnancy (NHMRC 2009). Prof Elliott reports that many young female drinkers don't heed this advice. The simplicity of the recommendation of "no alcohol in pregnancy" enables other members of the community to show concern and help women who continue to drink when pregnant. This mirrors the Surgeon General's warning in the USA (2005) that a woman who is pregnant or considering becoming pregnant should abstain from alcohol. Further, since nearly half of all births are unplanned, women of child-bearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure. Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy. The tragedy is that most women are unaware that drinking in pregnancy can do lifelong harm to their child. Public awareness and prevention is a most important intervention, but must

be supported by moves to restrict access to alcohol through pricing, taxation, availability of low strength options and limitation of the number of alcohol outlets and their opening hours.

Kieran O'Malley, an Irish child psychiatrist, said both the lack of recognition and treatment of FASD contributed to the grim long term outcomes (O'Malley, 2007). For example, in Ireland, which has as high a level of alcohol consumption as anywhere in the world (13 litres/person over 15 years old/year) and where 44% of women report an episode of binge drinking in the last month, national data report no identified cases of FASD! Australia has a similar and growing national level of alcohol consumption. An Australian study of case identification through reports by paediatricians only identified 92 new cases of FASD over 4 years (Elliott et al, 2008). O'Malley (2011) reports that ARND may be 10 times more frequent than FAS.

Streissguth and O'Malley (2000) reported on the dreadful long term outcomes of one cohort followed into adulthood: at 21 years 90% had mental health problems, 80% had dependent living and problems with employment, 40% had problems with the law, sexually inappropriate behaviour, and disrupted education, 30% had a period of imprisonment and 20% had drug and alcohol problems! Brain scan abnormalities include loss of cortical volume especially in frontal lobes (associated with problems of executive function), changes to the corpus callosum and hippocampus (affecting motor coordination and memory) and basal ganglia (affecting perseveration and executive function). Executive function skills can be classified as: complex cognitive functions, future orientated skills and integration of various perceptual processes. Deficits in the dopamine and noradrenergic neurotransmitter systems are found in those with attention problems. There is also disruption of the balance between the GABA inhibitory and the glutamate excitatory neurotransmitter systems. Phil Ray, Clinical Neuropsychologist, will report on the neuropsychological abnormalities in a later article.

Assessment of the child exposed to alcohol *in utero* should include evaluation of cognitive and language skills, behavioural and psychiatric problems, and sensory processing especially in the under 5s. Although IQ is, on average, impaired by 20 points, scholastic skills and adaptive functioning are more severely impaired, by 30-40 points. Problems of working memory, abstraction, planning, organisation, judgement and insight are critical, along with problems of emotion recognition and expression and social understanding and

interaction. Variability between domains of skills is the rule. O'Malley's summary of common psychiatric presentations highlights the complexity of these cases: regulatory disorder including hypersensitive or sensory seeking/impulsive behaviour presents in first 3 years of life; co-occurring PTSD and developmental trauma disorder; ADHD (40-60%) with co-morbid learning disorders of mathematics, reading and writing; and ADHD not uncommonly associated with social communication disorder or Autistic Spectrum Disorder. Other disorders secondary to alcohol exposure *in utero* include sleep problems, anxiety, mood disorders (40%) with suicide threats and attempts, intermittent explosive disorder, conduct disorders, psychoses (30%), drug and alcohol problems and personality problems. Infants and young children are prone to Attachment Disorders, Affect Disorders, Anxiety Disorders and Regulatory Disorders of Sensory Processing. O'Malley uses the diagnostic classification of mental health and developmental disorders of infancy and early childhood for Regulatory Disorders of Sensory Processing: 1. Hypersensitive: Type A fearful/cautious; Type B negative/defiant. 2. Hyposensitive/under responsive: withdrawn/difficult to engage; self-absorbed. 3. Sensory stimulation seeking/impulsive (Zero to Three, 2005). In summary these youngsters are vulnerable to neurodevelopmental disorders, neuropsychiatric disorders and drug and alcohol disorders which may be made worse by environmental contributors.

O'Malley describes the importance of a range of medications to reduce psychiatric impairment, with the caveat that applies for all youngsters with significant abnormalities of development of the brain: lower rates of success and greater sensitivity to side effects compared with a mainstream population, plus the added risk of syndromes related abnormal cardiac function

and seizures. More than one medication may be needed to treat attention with co-morbid conditions. There is control trial evidence in FASD on the use of stimulants, fluoxetine, valproic acid and risperidone. Other medications that may be useful are other treatments for ADHD, other mood stabilisers, SSRIs and major tranquillisers and others medication types include buspirone, clonidine, tryptophan, melatonin, longer acting benzodiazepines, and naltrexone. He also cites evidence for the role of neuroprotective agents for drinking mothers, such as vitamins, folate, magnesium, zinc and choline to diminish the harm of alcohol on the developing fetus.

Treatment needs to be multidisciplinary, multimodal and multiagency, tailored to the individual child and family. O'Malley lists: detailed diagnostic assessment followed by individual treatment, dyadic therapy, family therapy, group therapy, residential/housing, vocational/rehabilitation, dental care and advocacy. The individual therapy may include: sensory/motor training, non-verbal play therapy, cognitive behaviour therapy, reality-based therapy and trauma-based therapy. Speech and language therapy may be important, but recognition of special needs and appropriate support from the education system is a pivotal influence to the subsequent developmental trajectory. The criminal justice system also needs to be proactive in identifying and seeking treatment for such young people (Paley & Auerbach, 2011). A couple of new books on "Fetal Alcohol Spectrum Disorders: Interdisciplinary perspectives" and "Educating children and young people with fetal alcohol spectrum disorders: constructing personalised pathways to learning" by Blackburn, Carpenter & Edgerton, will be reviewed in subsequent editions.

Over the year I have met two youngsters in my clinic who are in good quality foster care and have an unfamiliar pattern of complex co-morbidities of learning and development and extreme psychiatric impairment, and who have been inordinately difficult to treat. We have made a putative diagnosis of FASD in the context of inadequate maternal history in pregnancy, supported by the neuropsychological and neuropsychiatric findings that fit the descriptions from the literature summarised here. This article highlights the breadth of challenge. Meeting their needs requires collaboration from paediatrics, allied health, child and adolescent mental health, education, welfare and the criminal justice system, and of course the community. The first challenge is for clinicians to think of the possibility of the diagnosis. Tristan and his community have shown us courage and leadership, bringing "Hope in the Valley" and are an example to all Australians (Elliott et al, 2012). The raising of awareness will be important for us all, as we come to appreciate the scale of this new silent epidemic of damaged and troubled youngsters and adults in our midst. As June Oscar says "the attitude of society to FASD has to change, since the children with the condition can't". ●

**Teratogenic*: adj. Of, relating to or causing malformations of an embryo or a fetus.

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Hope in the Valley

James Fitzpatrick, winner of Derby Bush Poetry Competition, 2011

*There's hope in the Valley, it flows slow and deep
a river of life floods the plains
It softens the tears that the grandmothers weep
like a desert refreshed by the rains
There's pride in the Valley, those women stood strong
to stop that damned river of booze
While businessmen, countrymen swore they were wrong.
But the women had too much to lose
See the children were damaged before they were born
the alcohol poisons the brain
The grandmother grew them up, tired and forlorn
while the parents went drinking again
Now the river of grog is a trickle out there
and the young people hunt through the skies
For the spirits of old men with wild untamed hair
and that wise patient gleam in their eyes
There's hope in the Valley, it flows deep and slow
like culture- where life finds its themes
The river of hope has a long way to go
but its flowing and so are their dreams.*



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