

The HUR



Lifelong problems are resulting from mothers who drink during pregnancy. A parliamentary committee draws attention to an issue too long hidden from public debate. Story: [Emma O'Sullivan](#)

Anne Russell will never forget the moment she realised her drinking habits during pregnancy were the cause of complex and traumatic problems plaguing both her sons.

She describes her feelings of devastation in a book she has written about her experiences: "My addiction had physically harmed my child! I knew I had to find out more, but just then I was paralysed with a sorrow so powerful there are no words to describe it."

Ms Russell, a former alcoholic, is talking about Foetal Alcohol Spectrum Disorder (FASD). While most people in Australia are generally aware that drinking alcohol during pregnancy is not recommended, many are unclear about the consequences.

If a child has FASD, they may suffer from a range of physical, behavioural,

mental and cognitive disorders because they have a brain injury.

Diagnosis is tricky, finding appropriate support is complex and the prognosis for adulthood is uncertain.

"There's not enough attention given to the fact that alcohol is a toxin."

Australia also stands accused of ignoring the issue over the past three decades, something federal MP Sharman Stone (Murray, Vic) is seeking to rectify.

Dr Stone was a key player in the formation of a bipartisan parliamentary group established to raise awareness of FASD. She is also on the House of Representatives Social Policy and Legal Affairs Committee which is holding an inquiry into prevention strategies,

It's inside

intervention measures and management of FASD.

"This problem is too big to play politics," she says. "It's about getting rid of our culture of denial in Australia and literally making sure that not one more child is born with this incurable, permanent, lifelong brain damage when the mother could have changed her use of alcohol if she knew better."

FASD children and teens are likely to be grappling with a complicated cocktail of overlapping issues such as learning difficulties, memory problems, suicidal thoughts and poor physical and mental health.

Without intensive support they may go on to struggle in adulthood with substance abuse, homelessness, unemployment and brushes with the law.

All these fears are still very real and ongoing for Anne Russell, who can't remember exactly how much she drank in each pregnancy while living in a north Queensland mining town.

She says she was never warned about the harms of drinking. Nor was she asked by her doctor if she had a drinking problem during her second pregnancy with her son, Seth, when her first child, Mick, was already displaying problems.

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"My youngest son has a significant disability. He can't live independently, he can't manage his money. Unfortunately what people see are the behaviours and until about 12 months ago he was just suicidal because he just couldn't seem to fit in.

"When he was growing up he would have birthday parties, give out lots and lots of invitations but nobody would turn up.

"[Mick] has temporal lobe epilepsy and he's very small for his genetic heritage. But he can live fairly normally and I'm very lucky that he's not as significantly disabled as my second son."

Over the years Ms Russell has watched both her sons suffer. While Mick's problems have been more physical, Seth has struggled with drug abuse, a patchy job record and trouble at school.

When they were young both were hard to handle at various times, but to her frustration she could never work out why. At one point Seth was diagnosed with ADHD, a common misdiagnosis among FASD sufferers.

Ms Russell has now set up the Russell Family Fetal Alcohol Disorders Association in the hope of educating more women about the dangers of

“Many people just cannot face the fact that their behaviour is directly behind their child’s problems.”

drinking during pregnancy and to find ways of supporting those already affected. But her quest for answers has not been easy.

Once she made the connection between her drinking and her children’s symptoms, securing an official diagnosis was difficult. According to Ms Russell, one doctor even asked her: “Why are you doing this to yourself?”

“I’ve heard this called an emerging problem but it’s not an emerging problem — it’s something that we’ve only just realised is a problem,” she says.

While countries like the US and Canada appear to be making inroads with FASD, critics here believe not enough is being done to get a national diagnostic tool up and running, establish more accessible intervention programs and better pinpoint its prevalence.

Recent research suggests the incidence of FASD could be up to 0.68 per 1,000 live births, however some say this number is underestimated. It is known that FASD is more prevalent in Indigenous communities with the incidence at somewhere between 2.76 and 4.7 per 1,000 births.

It is generally recognised that FASD is the commonest preventable cause of non-genetic intellectual disability, yet it does not have official disability status.

The implications of this are summed up by the National Council of Intellectual Disability (NCID) in its submission to the parliamentary inquiry: “It is of great concern to NCID that people with FASD are the single largest most undiagnosed, unrecognised cause of disability in the community which attracts no funding and no support or assistance.”

For many of the children community paediatrician Sue Packer sees, FASD is also not their only problem.

“This group of children is the group of children that are more prone to neglect, the parents take other substances as well as alcohol, there’s often malnutrition, there’s often domestic violence,” she says.

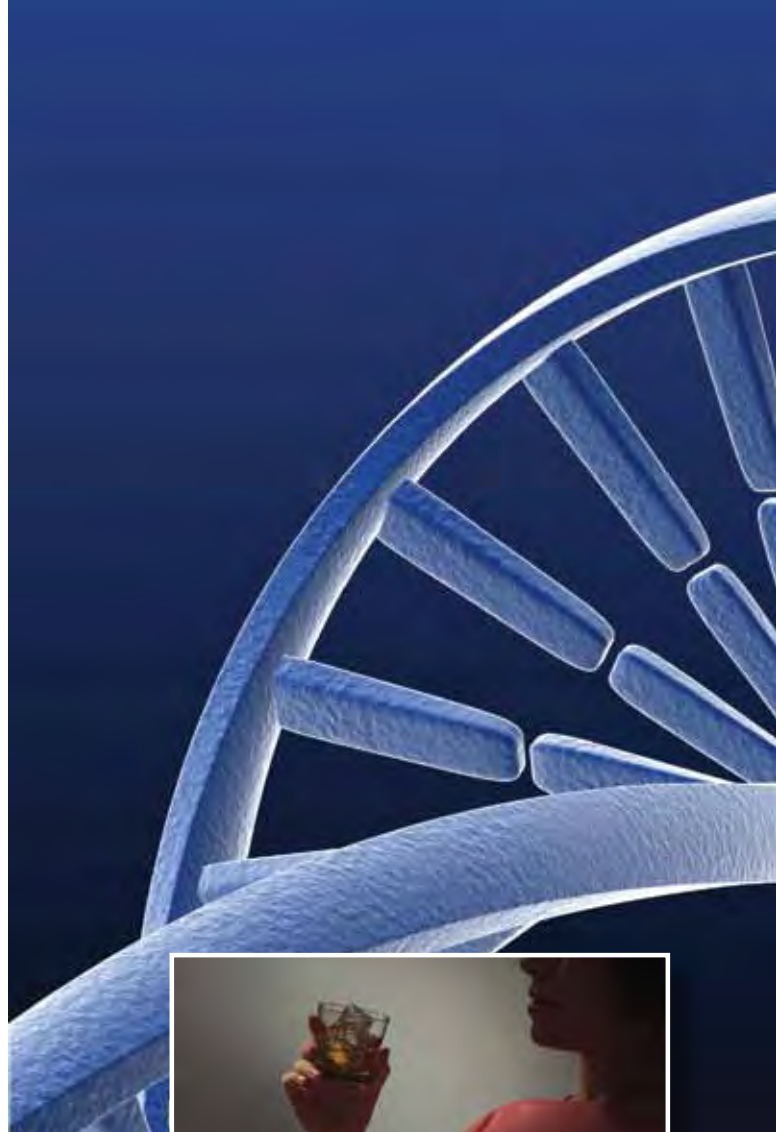
“All these things can interfere with a child’s development. So we’re not saying you take alcohol, it affects the foetus and this is the outcome — we’re saying you add alcohol to a very unsatisfactory mix, you’ve got a bad outcome and alcohol is one factor in that outcome.”

On top of these issues is how medical professionals and caregivers themselves handle the perceived stigma attached to FASD.

“It’s very, very hard when you think it is something being in your lifestyle which has caused your child’s problem,” Dr Packer says.

“It’s devastating. Many people just cannot face the fact that their behaviour is directly behind their child’s problems.”

While Anne Russell’s children are fortunate to have ongoing support and commitment from her, other children



CULTURE OF DENIAL:
Facing up to the effects of alcohol during pregnancy

from troubled backgrounds often find themselves in the care of the state.

In her submission to the inquiry, child protection manager Prue Walker details some of the startling results from studies conducted in the US and Canada, where she spent time researching FASD. She says research shows that children in care are 10 to 15 times more likely to have FASD than other children, stay in care longer and require greater attention.

Several foster carers have detailed to the inquiry the difficulties they have endured while caring for children with FASD.

“From the beginning, this child was in a too-hard basket — medically, socially, educationally and in every context imaginable,” writes one anonymous carer in a submission.



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“He had major learning disabilities, poor impulse control, poor memory and concentration, inability to understand or learn social mores and consequences, no empathy, poor gross and fine motor skills.

“The education system ascertained him as merely having a speech impairment, allocating a laughable two hours teacher aide time per week.”

Louise Voigt is CEO of foster care organisation Barnardos. She says those with FASD are hard to place and need a lot more time and attention from carers. Because they are such hard work, some families just cannot cope with the placement.

“People think, ‘if I love this child that will be good enough’, and it’s not,” she says. “It takes years and extremely skilled assistance to learn how to help the child to the maximum.”

Despite the lack of attention to FASD in recent decades, some believe progress is being made, such as paediatrician and clinical academic Elizabeth Elliott. She was part of a team invited to the Fitzroy Valley in the Kimberley region of Western Australia to map the prevalence of FASD and help the community progress a strategy for prevention and

management. The study is the first of its kind in Australia.

In 2010 she spent a year working in around 50 remote communities where she studied children born in 2002 and 2003. She also got a detailed history from their mothers about their drinking.

“What we were able to do was to come up with each of these children a list of strengths and weaknesses and we were able to develop a management plan for every child and to feed that back immediately to the parents, the health professionals involved in the care of that child and their school teachers,” she says.

“We came out of that project feeling that this sort of multi-disciplinary approach is a very good approach to be used in remote communities to get a very good baseline assessment of health and developmental problems.”

She is now analysing the data collected and hopes this work will contribute to a better understanding of how prevalent FASD is, especially in remote Indigenous communities.

Professor Elliott is also involved in the development of a diagnostic and screening tool which is being funded by the federal government.

“I guess what we need to do now is to make a decision nationally about what approach we’re going to take to diagnosis and how we’re going to enable access to diagnostic clinics for all children,” she says.

Establishing prevalence is one thing, but how do you go about a widespread social and community change that would work towards better preventing FASD cases in the first place? And why in this day and age, when pregnant women have access to more information than ever, are children still being born with FASD?

Sharman Stone believes Australia’s attitude to drinking certainly doesn’t help.

“We have alcohol in every element of our society,” she says. “We talk about it as a relaxant, we talk about it as a celebratory drink. We associate it with sophistication and having fun.”

According to the Australian Institute of Health and Welfare around 80 per cent of Australians over 14 drink alcohol. Figures also show that one in

BITTER EXPERIENCE:

Better information is needed on alcohol effects says Anne Russell



five Australians drank at levels that put them at harm over their lifetime.

“Alcohol in our society is a huge problem,” says Dr Packer. “If you don’t drink at all you’re a wowser and we’re not very keen on wowsers.

“There’s not enough attention given to the fact that alcohol is a toxin.”

Dr Packer, Professor Elliot and Anne Russell all agree there needs to be a coordinated national media and

education campaign about alcohol and pregnancy.

“Even though the National Health and Medical Research Council has stated that no alcohol is safest, medical professionals are still not giving that as a consistent message,” Ms Russell says. “It must be very difficult for people now to know exactly what’s right and what’s not.”



“Blanket warnings and recommendations for total abstinence by pregnant women serve little purpose other than to inflict fear or guilt in pregnant women.”

was thought to have some intellectual problem when he was six months old. If the doctor had asked me at that point whether I'd been drinking my young son may not have been affected.”

She and others in the field also support the use of warning labels on the packaging of alcoholic drinks as part of a coordinated campaign. However the issue is controversial for several reasons.

Voluntary consumer labels are being rolled out on various products over the next two years. They were launched last July as part of a broader campaign through the organisation DrinkWise, which is an independent body funded by industry.

The labels read ‘It is safest not to drink while pregnant’ and there is also an image of a pregnant woman, drink in hand, with a line drawn through it.

For some advocates and health professionals, however, this action is not enough. Groups such as the Foundation for Alcohol Research and Education (FARE) are in favour of more explicit warnings such as: ‘Drinking any alcohol can harm your unborn baby.’

FARE says the current labels do not describe the potential harms that can result from alcohol misuse and contain “ambiguous” and “weak” messages.

However industry is opposed to anything mandatory and argues while labelling may raise awareness it ultimately does not change behaviour.

“Blanket warnings and recommendations for total abstinence by pregnant women serve little purpose other than to inflict fear or guilt in pregnant women,” the Winemakers Federation of Australia says in its submission to the inquiry.

“The current effort and energies being expended by governments and

NGOs on population-wide responses would be [better] directed to address specific and targeted education through GPs, obstetricians, paediatricians and community health centres which will ultimately enable the women to make informed choices based on the best available evidence.”

While that prevention fight goes on, what is the prognosis for those who are already suffering? According to Dr Packer, that depends on what your other life circumstances are like.

Those most likely to thrive will have an extended support network, good health care and plenty of early intervention therapy. But without that, the story is very different.

“If they continue to live in an abusive, violent, chaotic, unpredictable, poorly nourished environment they are going to do very, very badly,” she says. •

Current labels do not describe the potential harms that can result from alcohol misuse

FOR MORE INFORMATION on the inquiry by the House of Representatives Social Policy and Legal Affairs Committee into the incidence and prevention of Foetal Alcohol Spectrum Disorder, visit www.aph.gov.au/spla or email spla.reps@aph.gov.au or phone (02) 6277 2358.

Professor Elliott also points out that health professionals have a bigger role to play early on.

“I think early recognition is the key so GPs particularly, but also obstetricians, gynaecologists, need to be aware of whether or not the woman they're seeing either prior to or during pregnancy has a problem with drinking.”

It's a point Anne Russell agrees with from bitter experience. “My eldest son