

Centacare Presentation

My name is Anne Russell and I am a member of an organisation that was founded to assist in the prevention, education of the community and support of people with Fetal Alcohol Syndrome.

The organisation is called the rffada – I'm trying to shorten it to the acronym as the full name is a bit of a mouthful – The Russell Family Fetal Alcohol Disorders Association.

Fetal Alcohol Spectrum Disorder is caused when a pregnant woman drinks alcohol. No one knows yet just how much alcohol can cause this problem but research suggests that the best course is no alcohol at all during pregnancy.

The full spectrum ranges from mild affects on the one hand to the full syndrome on the other. The full syndrome is usually caused when a lot of alcohol is consumed, but not always. There are cases where a pregnant woman has become drunk only once before she knew she was pregnant and did not drink after that and the child has now been diagnosed with the full syndrome.

A person with FAS has a brain injury that can't be fixed. That individual must live with the results of this injury all their lives.

There are two types of characteristics of effects: **Primary Characteristics** which are physical and mental disabilities with which a child is born and **Secondary characteristics** which are disabilities that may develop as a result of failure to properly deal with the primary disabilities and as a result of environmental influences.

The Primary characteristics of FAS are growth abnormalities, facial abnormalities, nervous system abnormalities and neuro developmental delays and deficiencies.

The secondary characteristics can occur in spite of appropriate supports with some FASD individuals. These characteristics or disabilities can be:

- Fear, anxiety, avoidance, withdrawal
- Victimisation of and by others
- Shutting down, lying, running away, dropping out of school, joblessness and homelessness
- Willingness to please and comply
- Mental illness, depression and self injury
- Violent or threatening behaviour, trouble with the law
- Addictions issues
- Suicide

The frustrations of dealing with a FASD child may even lead to family violence and shaken baby syndrome.

While everything I've said so far relates to women drinking alcohol, their partners, husbands, friends and relatives can play an important part in stopping this cycle. Many parents of children with FASD have FASD themselves. Any men in the lives of pregnant women also must accept some responsibility and assist in the

education and prevention of this condition. Anyone with an alcohol problem knows how difficult it is to give up or not drink when others in the room are drinking.

There is a great deal of discussion as to the degree that alcohol affects an unborn child. Many factors combine to produce FASD outcomes including:

- The amount of alcohol – binge drinking Vs social drinking
- The stage of the pregnancy
- The blood alcohol level of the mother – over a period of hours as the blood alcohol level rises with the mother, the level begins to multiply in the fetal system and may remain high for as long as 24 hours after consumption ceases.
- Genetics – women genetically susceptible to alcoholism have a higher risk of giving birth to an affected child
- Environment – attitudes of partners and family around drinking
- Poly drug use – the use of many different types of drinks reduce fetal capacity to recover
- Health of the mother – balanced diet and prenatal care

Alcohol is a teratogen and a poison. A teratogen is any substance that changes how the unborn baby develops, disrupts the development of body organs and in extreme cases causes death. Stopping drinking any time during the pregnancy will improve the outcome.

Why do pregnant women drink alcohol?

- Women may be unaware that they are pregnant
- Alcohol use may be the social norm
- Women may know other women who drank during pregnancy and who have children who appear outwardly to be healthy
- Alcohol use is common when celebrating festive seasons or special events
- Women may not know how much harm alcohol can cause
- Women may use alcohol to cope with difficult life situations such as poverty, violence, isolation, despair or depression
- Women may be struggling with addiction

There are many people in Australia struggling with this condition. Unfortunately because of the lack of understanding in Australia by our medical professionals, this condition is rarely diagnosed. It is more likely that a child with FASD will be misdiagnosed with ADHD or some other condition. While it is difficult to find a doctor prepared to diagnose this condition, it is crucial for the child that they know they HAVE a problem rather than they ARE the problem.

Once this condition is diagnosed there are many supports that can be put into place for the child. Supports at school, at work - many of the resources already in place in our society can be used to assist, but their workers and people who look after them MUST know about this condition to be able to help them properly.

This is a serious condition and in Canada it is estimated that it affects 1 in every 500 people. Please take these brochures and pass this information along to friends and relatives.

If there has been anything in this presentation that concerns or upsets you, please feel free to discuss with either myself or any of the support staff here.

Thank you
Elizabeth (Anne) Russell