

## What is different about the way adults with FASD may behave?

The following problems emerge in childhood and adolescence. By the adult years, there are often difficulties with:

- mathematics
- understanding time
- thinking things through / reasoning / planning / decision making
- learning from their past experiences
- understanding the consequences of their actions
- memory
- getting along with others
- generalising learning

Because of these life difficulties, activities in everyday life can be affected.

Advocacy and supportive assistance may be needed to assist them to:

- handle money – budgeting, paying rent and shopping
- make & keep appointments (doctor, counselling, criminal justice; income, employment)
- make changes to behaviours (they need someone who cares about them and can act as a mentor/life coach - reminding, making sense of circumstances in concrete language and ensuring comprehension and understanding)
- interact with other people
- complete their education
- secure and maintain employment, income and accommodation
- handle court related issues
- ensure income security

## Secondary issues and FASD

When individuals whose lives are affected by FASD have not been diagnosed, or are mis-diagnosed, anger and frustration towards self and the community can be an understandable reaction. Criticism and punishment for behaviours they are unable to control is a very common experience for this group, and can lead to the development of secondary issues such as incompleteness of schooling, mental health problems, trouble with the law, unemployment and homelessness, alcohol and drug problems and a heightened vulnerability to physical, sexual (victim and/or offender), financial, social and emotional abuse. Isolation and loneliness can lead to a range of other behaviours such as unsafe partnering and violent and unsafe relationships.

Too often, unplanned pregnancies combined with alcohol and other drug use feature among this group resulting in another generation of alcohol exposed children. Many mothers who have children with FASD are possibly themselves affected by fetal alcohol exposure. Parenting children is a risk because of FASD disabilities and this group of parents should not be subjected to family re-unification unless the full range of long term supports are in place. The risk to their children and the re-affirmation of parental failure is too high. This is a group who do not choose to fail at parenting but will struggle to gain the skills to be effective parents.

## support

For support and/or further information on diagnosis and interventions please contact:

NOFASD (National Organisation for Fetal Alcohol Spectrum Disorders) Support/advocacy for parents/carers/individuals with FASD  
– [www.nofasd.org.au](http://www.nofasd.org.au)

RFFADA (Russell Family Fetal Alcohol Disorders Association)  
– Information and support/advocacy for birth mothers of children with FASD  
[www.rffada.org](http://www.rffada.org)

## other useful contacts

DEN (Drug Education Network) Prenatal Exposure to Alcohol Clearing House  
[www.den.org.au](http://www.den.org.au)

NICFASEN (National Indigenous Corporation Fetal Alcohol Syndrome Education Network) [www.nicfasen.org.au](http://www.nicfasen.org.au)

ADAC (Aboriginal Drug & Alcohol Council (S.A.) Inc) Indigenous FASD resources  
<http://www.adac.org.au/>

Telethon Institute for Child Health Research –  
<http://www.ichr.uwa.edu.au/alcoholandpregnancy>  
[www.ichr.uwa.edu.au/fasdproject](http://www.ichr.uwa.edu.au/fasdproject)

# Fetal Alcohol Spectrum Disorders (FASD)

## the preventable disability



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## Fetal Alcohol Spectrum Disorders (FASD)

In 2014-2015 clinicians across the country trialled a FASD Diagnostic Instrument for Australia that had been developed by an Australian FASD Collaboration led by Professor Carol Bower from Telethon Kids Institute and Professor Elizabeth Elliott from the University of Sydney. As the Australian Diagnostic Instrument was finalised, a revised Canadian guide on the diagnosis of FASD was published. The Australian FASD Diagnostic Instrument was reviewed and modifications made.

In early 2016 the FASD Diagnostic Instrument Trial and Implementation Expert Review Panel decided to harmonise the Australian Instrument with the diagnostic subcategories recommended in the Canadian Guidelines and to accept the overarching diagnostic term of FASD and the diagnostic subcategories relating to the presence or absence of the three sentinel facial features.

Australian Diagnostic subcategories

- **FASD with three sentinel facial features** (similar to the previous diagnostic category of Fetal Alcohol Syndrome)
- **FASD with less than three sentinel facial features** (which encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed)

## How much alcohol is safe during pregnancy?

Alcohol is a teratogen – a substance that is known to cause birth defects and brain damage. The level of risk from alcohol use to the developing fetus or a breastfeeding baby is highest when there are high risk patterns of maternal alcohol use. The risk is likely to be low if a woman has consumed only small amounts of alcohol (such as one or two drinks per week) before she knew she was pregnant or during pregnancy. Because everyone is different, the risk varies considerably.

No alcohol at all during pregnancy is the best and safest choice for the health of the unborn baby.

## How can alcohol affect the fetus?

When alcohol is consumed in pregnancy it passes from the mother's blood stream into the baby's blood stream and the baby will have the same blood alcohol level as his/ her mother. Different parts of the unborn baby's developing body, cells and organs are vulnerable at different stages during the pregnancy. The first trimester when major organs are being formed, is a sensitive time when fetal alcohol exposure can result in a smaller head circumference, heart defects, limb damage, bone formation defects, kidney damage, eye problems, hearing problems and facial abnormalities. Throughout the pregnancy the developing brain is particularly vulnerable to alcohol exposure. The alcohol destroys brain cells and this can affect the growth, structure and function of the developing brain. The effects can range from mild to severe. Although Fasd cannot be caused by the father's alcohol consumption, research has linked a father's drinking with poor behavioural outcomes in children and changes in the DNA of the sperm that could lead to other birth defects. The father's drinking is also a risk factor for maternal alcohol use.

Almost half of pregnancies are unplanned and parents may have used alcohol during this time without realising. If small amounts have been consumed the risk to the baby is low. Cutting down or stopping alcohol use at any time during pregnancy increases the likelihood of having a healthier baby. Women who don't think they can stop drinking need additional support throughout pregnancy and the postnatal period. Good antenatal care, folic acid and a healthy diet are also important.

## FASD Diagnosis & Prognosis

FASD is a lifetime disability. Early diagnosis begins the process of explaining to parents how their child's behaviour and development is affected and helps families and other supportive people understand the brain damage rather than focus attention on behaviours. Behaviour is the window to understanding brain damage and should not be understood only as a signal of child naughtiness, laziness or defiance. Behaviours caused by alcohol related brain damage are not a consequence of poor parenting but a sign that parents need help to manage behaviours differently. Early diagnosis of the child is essential for the mother, the primary carer and the family because it allows for early intervention, appropriate treatment and support for everyone.

FASD is not curable; however individuals affected by prenatal alcohol exposure can do their best with appropriate management. Effective support includes special education programs; vocational programs and tutors; structured environments without unnecessary change; lifelong care and sometimes 24/7 supervision. Individuals living with FASD have strengths. They may be intelligent, affectionate, friendly, artistic and musical and show a great determination to succeed in life. With special assistance they can achieve at school; find paid employment; and have successful and safe relationships.

## What are some of the signs that might indicate that a child has FASD?

FASDs are sometimes confused with developmental and behavioural problems. Misdiagnosis can occur.

**Infants** may have a low birth weight but not be premature; they might experience irritability, sensitivity to light, noises and/or touch, feeding problems and a failure to thrive.

**Toddlers** may exhibit memory problems, hyperactivity, a lack of fear, a poor sense of boundaries and impairment in gross or fine motor skills, which may result in poor balance or clumsiness.

**Children** may develop more slowly and have a difficult time learning and controlling their behaviours. Most children with Fasd have developmental delays and they may also have intellectual impairment, although their IQ can cover the normal range (70 - 130). They may master a new task one day, and not remember the next day. They may also have problems with attention span and/or hyperactivity (ADD/ADHD), have limited and/ or appropriate communication skills and experience difficulties with learning such as the concepts required to do maths. A minority of children with FASD may also be small in stature, their faces may look different and they may have vision and/or hearing problems.

**Older children** may have low self-esteem because of an awareness of "difference", or because they have trouble keeping up or fitting in at school. Teenagers may exhibit the social skills of a 6-8 year old; show poor impulse control; may not distinguish between appropriate public and private behaviours; and may not follow rules. Concepts must be re-taught on a daily basis. Most become isolated because they find it difficult to sustain friendships with their peers and truanting from school, mixing with 'unsafe' individuals and groups, criminal behaviours, higher risk of alcohol and other substance use, and separation from family support can result.

