



Living with FASD

Caring for someone with Foetal
Alcohol Spectrum Disorder

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What is FASD?

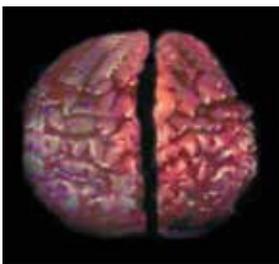
Foetal Alcohol Spectrum Disorder (FASD) is a term for a range of disabilities caused when a pregnant woman drinks alcohol. These include foetal alcohol syndrome (FAS), alcohol-related neuro-developmental disorders (ARND), alcohol-related birth defects (ARBD), foetal alcohol effects (FAE) and partial foetal alcohol syndrome (pFAS). Of these five disabilities, FAS is the only condition displaying the full set of the unique facial features.

When a pregnant woman drinks alcohol, the alcohol in her blood passes freely through the placenta into the developing baby. In the absence of a developed blood filtration system, the foetus is completely unprotected from alcohol circulating in its blood system. Alcohol can destroy brain cells and damage the nervous system of the baby at any point during the nine months of pregnancy.

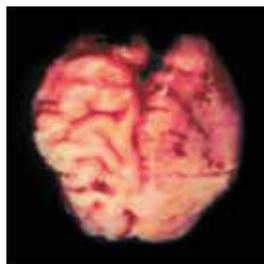
What are the effects of FASD?

The effects can be mild to severe, ranging from subtle changes in behaviour, reduced intellectual ability and attention deficit disorder, to physical defects such as heart problems and distinct facial features. It could also cause a miscarriage and increase the risk of sudden infant death. Many children experience serious behavioural and social difficulties that last a lifetime.

Alcohol can affect the developing brain, impacting all stages of brain development, from the birth of the cells to migration or myelination. It can cause significant changes in certain brain structures, such as the corpus collosum, the cerebellum, subcortical structures and frontal lobes. It can also have an effect on the viability of connections between brain structures. (Professor Ed Riley, scientist and FASD expert)



Brain of baby without FASD



Brain of baby with FASD

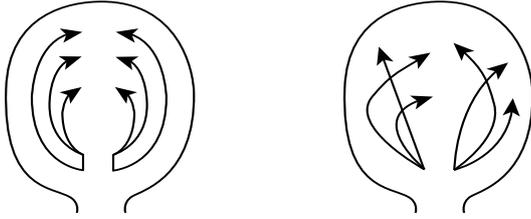
Photographs courtesy of Dr Sterling Clarren. Please note that the photograph on the right illustrates an extreme case of FASD.

FASD may cause visible physical effects as well as neurological damage.

Invisible characteristics	Physical effects
<ul style="list-style-type: none">• Attention and memory deficits• Hyperactivity• Difficulty with abstract concepts (eg maths, time and money)• Confused social skills• Poor problem-solving skills• Difficulty learning from consequences• Poor judgement• Immature behaviour• Poor impulse control• Lower IQ	<ul style="list-style-type: none">• Smaller head circumference• Heart problems• Limb damage• Kidney damage• Damage to the structure of the brain• Vision problems• Hearing problems• Specific facial characteristics, including a flat nasal bridge, upturned nose, thin upper lip and smooth philtrum (the vertical groove between the upper lip and nose)

People with FASD can become socially isolated because they are often not able to mature and maintain friendships with peers.

Understanding the FASD thought process



Non-FASD thought process

- Orderly, organised and sequential
- Many opportunities for links and interconnections.

FASD thought process

- Inconsistent growth, undergrowth, disorganised, gaps and clusters
- Clusters can appear as areas of strength eg in art, music, etc.

Diagrams courtesy of Diane Malbin

FASD at different ages

Infants may be irritable and sensitive to light, noise and touch.

Toddlers may exhibit poor memory, hyperactivity and lack of fear.

Primary school children may have short attention spans, be easily distracted, have poor coordination, have difficulty with motor skills and need one-to-one attention.

Older children and teenagers may have low self-esteem, be impulsive and need daily reminders of concepts.

Children, teenagers and adults frequently become frustrated by their own inability to remember information, or become angry because they are continually criticised for behaviour they may not be able to control. They may also be vulnerable to physical, sexual and emotional abuse because of poor judgement and lack of friends.

Adults can also have difficulty maintaining independence, keeping jobs or sustaining healthy relationships.

Care and management of FASD

It is important that parents and carers understand the needs of someone with FASD, so they can act as their advocate.

Knowledge is key

- Ask your GP for a referral for diagnosis to be able to get more support – early diagnosis means early intervention and treatment
- Find out as much as you can about FASD.

Everyday support

Make sure the person you support has structure and consistency:

- Same time, same location, same support providers
- Anticipate changes, avoid surprises
- Provide smooth transitions when making changes.

Use simple language and don't overload them with information:

- Use short sentences
- Minimise use of abstract concepts
- Use simple step-by-step instructions (written, illustrated, repeated, rehearsed or role-played).

Other considerations

- Consider special schooling and supported living
- Arrange supported social and recreational activities, and activities with groups like swimming, horse riding, art clubs, etc
- Avoid criticism. Reward works better than punishment
- Adjust your expectations to the person's developmental level, not their chronological age
- Provide support with paying bills, doing maths and money management
- Put them in contact with agencies for people with disabilities to provide a support network and links to understanding employers
- There are more suggestions in FASD: Strategies not Solutions. This booklet is available in the Links and Resources section at www.nofas-uk.org

Where can I get more help and information?

For more information about FASD and to watch case study videos, please go to www.mencap.org.uk/fasd or contact NOFAS-UK.

Call **020 8458 5951**

Go to www.nofas-uk.org

To access international online resources from outside the UK, use the international medical spelling 'fetal'.

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for Foetal Alcohol Syndrome UK
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Call **020 8458 5951**
Email help@nofas-uk.org
Go to www.nofas-uk.org

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