

# Fetal Alcohol Spectrum Disorder (FASD)

## FETAL ALCOHOL SPECTRUM DISORDER (FASD)

The Scottish Government estimates there are *at least* 172,000 children, young people, and adults affected by this lifelong, and life-compromising neuro-developmental condition. That averages more than 170 right now in every GP practice in Scotland.

How many people with FASD are you aware of being served by *your* practice? A recent survey revealed that the average number known to experienced community nurses (including GPNs) was 1. Roughly 99% of those affected by FASD remain undiagnosed, inadequately understood and unassisted. This has been an 'invisible disability' which should now be seen.

The UK is one of the top five countries in the world for the prevalence of alcohol consumption in pregnancy. A 2018 Glasgow study<sup>10</sup> suggested that 40% of pregnancies in the study group were exposed to alcohol with 15% at a level which in the non pregnant population would be classed as harmful (> 3.5 units per day or bingeing). It's estimated that at least 3 in every 100 babies born in the UK are affected by FASD.

## What is FASD?

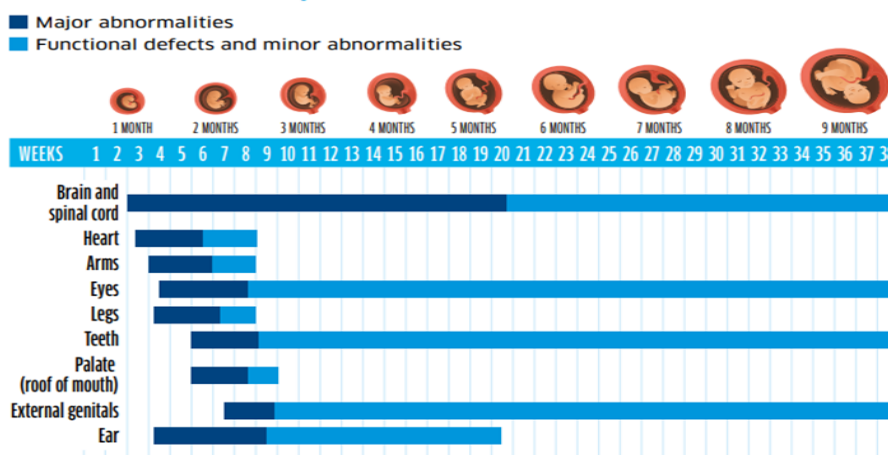
Fetal alcohol spectrum disorder refers to the lifelong effects caused when an unborn baby is exposed to alcohol. There is no way of being certain how alcohol may affect an individual unborn baby and no safe level. FASD is a hidden condition that can affect physical health, social skills, communication skills, memory and behavior.

## Assessment of FASD

Making the diagnosis in affected children is important. If appropriate and timely support is given, it is possible to prevent or mitigate potential mental health, behavioural and substance abuse problems. Children and adults with undiagnosed and unmanaged FASD are very often 'troubled' and 'in trouble' at home, in school and in the community.

## How alcohol in pregnancy can affect the developing baby

### Stages of fetal development



This illustration (from SIGN Parent and carer information booklet<sup>2</sup>) has been adapted from [www.slideshare.net/SDRTL/fetal-development-10766134](http://www.slideshare.net/SDRTL/fetal-development-10766134)

### Diagnostic criteria may include:

1. alcohol exposure prenatally.
2. impairment in neuro-developmental domains.
3. facial features.

**NB** It is important to be aware that FASD without sentinel facial features is the norm. Facial features affect less than 10%.

Alcohol consumption history taking should be normalised for ALL women of child bearing age (40% of pregnancies are unplanned).

There is a **SIGN booklet**<sup>2</sup> for parents & carers. This is a clear guide which professionals may also find useful.

### Referral

If FASD is possible as a cause of the child or adult's neuro-developmental problems, then referral should be made for a comprehensive diagnostic assessment.

For children and young people, this should be done through the normal route for any child with neuro-developmental delay, with information about maternal alcohol intake included.

FASD has a high degree of association with other neuro-developmental disorders including ADHD.

FASD should be considered as a potential factor in assessment and referral for adults.

## FASD requires **multidisciplinary assessment**

**FASD is a whole body diagnosis, and can affect the brain, central nervous system and physical development.**

**Features include:**

- A 'patchy' cognitive profile with a 'disorganised' brain.
- 3 or more affected brain areas of assessment/domains indicating CNS impairment. (>2 SD below the mean)
- **High variability from individual to individual.**



This is an **example** of how varied a profile might emerge and what life might be like for someone with this FASD profile:



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*I might appear to be very articulate but have problems understanding what you had just told me, as well as keeping track of what I was asked to do to correct my behavior.*

*I might be dreadful at keeping appointments and generally organizing my life, including poor money concepts and an inability to either plan or follow through on other's plans for me.*

*I might be very impulsive without thinking of the consequences; and, even if punished, I may do it again because I have great difficulty learning from experience.*

*I might be anxious and developing mental health issues because I am being bullied or misunderstood so often.*

*I might have real skills and talents I am unable to demonstrate consistently because my life is so disorganized and stressful.*

*I might drink alcohol, take drugs, and engage in other risky behaviours (including sexual ones) because I have a very hard time controlling my impulses.*

*My sleep pattern will have been poor from an early age*

## How To Help

Virtually no one drinks during pregnancy with the intention of harming their baby or making their lives as parents more difficult. This can become the starting point for effective, compassionate, person-centred, non-judgmental conversations and help parents take actions that will improve their, and their children's, lives.

- When seeing female patients of childbearing potential having alcohol problems, explore the underlying causes for their unhealthy drinking, and what can be done to ameliorate their anxieties and adverse life circumstances.
- There are two 100% successful ways to prevent FASD: No alcohol during pregnancy or no pregnancy while continuing to drink. Encourage positive contraceptive choices, e.g. long acting reversible contraceptive (LARC), until such time as they are well-prepared for a safe pregnancy and a healthy baby.
- Recognise that your patient may already have a child or children affected by FASD when you ask and they express concerns about behavioural and learning difficulties
- Know how, and to whom, you can refer children whom you suspect might have FASD, and what supports are available for you and the parent/carer to tap.
- Be aware that adults with FASD (the group least likely to be diagnosed) often have substance misuse and addiction problems. This happens not only because of diminished brain 'executive functions' (such as poor impulse control), but also because of mental health stresses from not understanding why they seem unable to 'fit in' and make healthy life choices.

## Useful Resources

1. SIGN 156 [CG 156](#)
2. Parent and carer information booklet [https://www.sign.ac.uk/assets/pat156\\_fasd.pdf](https://www.sign.ac.uk/assets/pat156_fasd.pdf)
3. The NES eLearning resource on FASD - <https://learn.nes.nhs.scot/>
4. Fetal Alcohol Advisory Support Team [The FAAST Team](#)
5. National FASD UK <https://nationalfasd.org.uk/>
6. FASD Hub Scotland - Information service, advice, support, and training for all parents/carers (adoptive, biological, foster and kinship) of children, young people, and young adults with a history of prenatal alcohol exposure (PAE), with or without a formal diagnosis of Fetal Alcohol Spectrum Disorders (FASD). Visit [FASD Hub | Home | Adoption UK Charity](#)
7. FASD e-learning course for GPs (need to sign up for free RCGP account) <https://elearning.rcgp.org.uk/course/info.php?id=483>
8. Public Health England report: [FASD Health Needs Assessment](#)
9. Alcohol-free Pregnancy - <https://www.drymester.org.uk/>
10. [Abernethy C. et al. Arch Dis Child Fetal Neonatal Ed. \(Glasgow study group\) 2018](#)

*Your comments, criticisms, questions and advice are welcome. Please contact:*

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