Foetal Alcohol Spectrum Disorders

Drinking alcohol during pregnancy increases the risk of preventable long-term harm to the baby.

Alcohol is a powerful teratogenic agent, and there are lots of studies which have increased our understanding of how alcohol impacts on the developing foetus. Foetal Alcohol Spectrum Disorder (FASD) is a preventable condition caused by prenatal exposure to alcohol, causing a diverse range of effects that can impact the individual throughout their lifetime. Health visitors are ideally placed to ensure that prospective parents are made aware of the benefits to the baby of avoiding alcohol during pregnancy, including preventing FASD and reducing the risks of low birth weight, preterm birth and the baby being small for gestational age.

Drinking anytime during pregnancy carries a real risk of creating a life-long, life-limiting neurodevelopmental condition, and is linked with adverse consequences across the lifecourse[1].

There is no known safe level of alcohol consumption during pregnancy. The UK Chief Medical Officers' low-risk drinking guidelines state that the safest approach is not to drink alcohol at all during pregnancy, to minimise risks to the baby[2]. Alcohol consumption has a significant impact on people's health and on the health and care system[3], with an estimated annual cost to the NHS of £3.5 billion. The Children's Commissioner for England published data[4] on the scale of vulnerability among children in England, highlighting that approximately 308,000 children live in families with at least one high risk drinker.

In September 2021, the Government confirmed that it does not have plans to introduce a standalone alcohol strategy and that alcohol will be considered within a forthcoming UK-wide cross-government addiction strategy[5]. Health visitors (HVs) can keep up with NHS guidance at: https://bit.ly/39tW7w9

Health visitors need to be aware that:

The Chief Medical Officer (CMO) Guideline[2] is that:

- If you are pregnant, or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.
- Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk.

  The current CMO guideline takes account of the known harmful actions of alcohol on the foetus, the evidence for the level of risk from drinking, the need for clarity and simplicity in providing helpful advice for women, and the uncertainties that exist about any completely safe level. It is not possible to say that low level drinking carries no risks of harm to the foetus at all. It is plausible scientifically that alcohol, even at such low levels, could cause some harm. Current evidence supports a 'precautionary' approach with clear guidance that it is safest to avoid drinking alcohol in pregnancy.

What are Foetal Alcohol Spectrum Disorders (FASD)?

- FASD is a broad term describing the range of disabilities that can occur in individuals as a result of alcohol exposure before birth.
- FASD are brain-based, neurodevelopmental disorders that require appropriate diagnosis, assessment and support across the lifespan.
- FASD is an umbrella term that covers Foetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Foetal Alcohol Effects (FAE) and partial Foetal Alcohol Syndrome (pFAS).
- Alcohol can affect any organ or system in the developing foetus including the central nervous system (brain), vision, hearing, cardiac, circulation, digestion, and musculoskeletal and respiratory systems, among others. One large systematic review identified more than 400 co-occurring conditions. Quite often people with FASD have multiple diagnoses.

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The information in this resource was updated on 01/06/2022.

- The severity of FASD appears to relate to the pattern of drinking during pregnancy, specifically the frequency of drinking high levels of alcohol – the more alcohol that is consumed in pregnancy, the greater the risk.
- Every person with FASD is affected differently. A common misconception persists that someone has to have specific facial features to have a diagnosis. This is incorrect. By some estimates, it is less than 10% of those on the FASD spectrum who have these distinctive facial features.

FASD may not be detected at birth but sometimes becomes apparent later in life and carries lifelong implications. FASD, especially if unrecognised and unsupported, can contribute to serious social and behavioural problems.

How common is FASD?

- FASD affects communities worldwide. However, there is limited international research on the prevalence of FASD and, therefore, estimates of prevalence need to be treated with caution.
- The first UK-based prevalence study[6] conducted by researchers at Bristol and Cardiff Universities was published in 2019. In this study, more than 6.0% of children screened positive for FASD. FASD occurs in the population as a whole – the UK has the 4th highest rate of drinking alcohol in pregnancy and FASD should be considered when working with all families. A positive FASD screen was more common among children in lower socioeconomic groups and children from unplanned pregnancies. However, other studies have found that older, more educated women are also more likely to drink during pregnancy.

What causes FASD?

- Alcohol is a teratogen - teratogens are substances that may produce physical or functional defects in the human embryo or foetus after the pregnant woman is exposed to the substance. Exposure to alcohol affects the foetus in a variety of ways. The severity of symptoms vary, based on how much and when alcohol was consumed. Symptoms are also influenced by genetic and environmental factors and the body's ability to break down alcohol, in both the mother and foetus.
- Alcohol crosses the placenta, enters the foetal bloodstream and interferes with foetal development. A baby's liver is one of the last organs to develop and doesn't mature until the later stages of pregnancy. As a result, they are unable to process alcohol and filter out toxins in the same way as the mother can. Instead, the alcohol circulates freely in the foetal bloodstream which can damage their developing brain and nervous system throughout pregnancy. Drinking alcohol, especially in the first three months of pregnancy, increases the risk of miscarriage, preterm birth and low birth weight.

How does Foetal Alcohol Spectrum Disorder (FASD) present?

- Symptoms of FASD are very individual and cover a broad range of features in children that may include:

  - attention and memory deficits
  - hyperactivity
  - difficulty with abstract concepts (e.g. maths and time)
  - confused social skills
  - poor problem-solving skills
  - difficulty learning from consequences
  - poor judgement
  - immature behaviour
  - poor impulse control
  - smaller head circumference
  - heart problems
  - limb damage
  - kidney damage
  - damage to the structure of the brain
  - eye 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)

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Moving beyond stigma

- Most people do give up alcohol once they know they're pregnant or when they're planning to become pregnant.
- If the pregnancy was unknown, and alcohol has already been consumed in early pregnancy, then the advice is to stop further drinking. They should not worry unnecessarily, as the risks of their baby being affected are likely to be low.
- There are many reasons why they might continue to drink alcohol in pregnancy. Often they do not know they are pregnant or do not understand the risks involved.
- It is important to move beyond stigma and help prevent and reduce the harm of alcohol-exposed pregnancies through improved preconception care for all women and people who are planning a pregnancy, particularly those in high risk groups (see Public Health England (2018) Making the Case for Preconception Care[7] and the Office for Health Improvement and Disparities (previously Public Health England) 2020 report: No child left behind: Understanding and quantifying vulnerability[8]).
- Once an alcohol-exposed pregnancy is identified[9], it is important that support is provided early to mitigate risk and ensure that the child's possible future needs are identified as soon as possible.
- Pregnant women and people with complex needs, including problem alcohol and drug use, can face barriers in accessing and maintaining contact with antenatal care and may require additional information, care and specialist support from agencies working with people with alcohol misuse issues – follow your local safeguarding procedures. The National Institute for Health and Care Excellence[10] has published a clinical guideline on a model for service provision for pregnant women with complex social factors.
- Early diagnosis and support can improve outcomes for affected children and their families.

  "The good news is that there are known strategies that can help someone with FASD to build upon their many strengths and to lead happy and fulfilling lives. FASD is often called a 'hidden disability'."

- More information on FASD can be found on the National Organisation for Foetal Alcohol Syndrome - UK website[11].

Best practice guidance - the role of the health visitor

- In March 2022, The National Institute for Health and Care Excellence (NICE)[12] published a new comprehensive quality standard designed to improve the diagnosis and assessment of foetal alcohol spectrum disorder (FASD). The NICE guidance says midwives and other healthcare professionals (including health visitors) should give clear and consistent advice on avoiding alcohol throughout pregnancy, and explain the benefits of this, including preventing FASD and reducing the risks of low birth weight, preterm birth and the baby being small for gestational age.
- The NICE quality standard highlights five key areas for improvement:
  - Pregnant women are given advice throughout pregnancy not to drink alcohol.
  - Pregnant women are asked about their alcohol use throughout their pregnancy, and this is recorded.
  - Children and young people with probable prenatal alcohol exposure and significant physical, developmental, or behavioural difficulties are referred for assessment.
  - Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.
  - Children and young people with a diagnosis of FASD have a management plan to address their needs.
- Where a health visitor has concerns that a baby or child may have FASD, particularly in situations where this has not been previously diagnosed, health visitors should refer to the GP for assessment. The GP may refer onward to a Community Paediatrician, or as required to a Psychologist, Psychiatrist, Speech and Language Therapist, and other specialists.
- FASD is one possibility when prenatal alcohol exposure is being considered as a cause of neurodevelopmental disorder. A neurodevelopmental assessment is needed to confirm, or rule out, a diagnosis of FASD. The neurodevelopmental issues associated with FASD are complex and varied, so the specific aspects of the assessment and the professionals involved will vary.

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Personalised support:

- Health visitors should work in partnership with families to ensure they have access to the right level of information for their individual needs. All parents are different and will respond to the diagnosis/ or suspected diagnosis in an individual way. It is therefore extremely important to take your lead from the parents.
- Instead of guessing how a parent might be feeling, ask them how they are feeling. Do not offer unsolicited advice, instead follow the parents' lead. Ask open questions like, "Do you have any questions? Is there any information that would be helpful for you now?"
- Some families will want lots of information straight away, whereas others may need more time and emotional support to work through different feelings that may include anxiety, confusion and possible feelings of shock, distress or guilt.
- Acknowledge concerns and respond to questions, including those that might appear unimportant or trivial – this does not mean that they are unimportant to the family asking them.
- Continuity of health visitor is important – families value "being known" and receiving personalised care.
- Don't forget to include all the usual universal health visiting support and advice – sometimes these can get overlooked (e.g. safer sleep advice, accident prevention, oral health, immunisations, etc).
- Make sure you are familiar with your local pathways and support available in your area. You can also signpost parents to the National Organisation for Foetal Alcohol Syndrome – UK for further advice and support if they ask for more information: https://bit.ly/39wmodl
- Whilst a helpful response to support an alcohol-dependent parent will impact positively on children within the family, it can be very easy to lose sight of children's health and wellbeing needs in the face of the parental difficulties[13]. However, children's needs, and the impact of living in a family with alcohol-dependent parent on their safety and wellbeing, should always be addressed as a priority in line with the 'paramountcy principle' of the Children Act 1989. Follow your local safeguarding procedures if you are concerned that a child is at risk of significant harm.
- More general advice can be found in the linked **iHV Good Practice Points: Reducing Alcohol Harm: Early intervention and prevention:** http://bit.ly/2ZNk64X.

Further information

- **Public Health England (2021) Guidance**: Parents with alcohol and drug problems: adult treatment and children and family services. https://bit.ly/3awul7l
- **National Institute for Health and Clinical Excellence (2021)** Antenatal care NICE guideline [NG201]: https://bit.ly/3ugveZa
- **Popova S et al (2017)** Estimation of national, regional and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. https://bit.ly/2QEbjOJ
- **Scottish Intercollegiate Guidelines Network (2019)** Children and young people exposed prenatally to alcohol. Network Guideline SIGN 156. https://bit.ly/3L5yBY1

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13. Public Health England (2018) Safeguarding and promoting the welfare of children affected by parental alcohol and drug use: a guide for local authorities. https://bit.ly/39wV8eO

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