



FETAL ALCOHOL SPECTRUM DISORDER (FASD): A NEURODEVELOPMENTAL DISORDER

This resource sheet has been kindly written by FASD South West



What is a neurodevelopmental disorder?

Neurodevelopmental disorders are conditions that impact how the brain functions. The impact of alcohol on the developing brain can lead to a range of impairments from mild to severe—additionally, ongoing trauma and adversity compound vulnerabilities. FASD is more common, yet less recognised than other neurodevelopmental disorders, including autism spectrum disorder, cerebral palsy, Down's syndrome and other developmental disabilities.

Alcohol is a neurobehavioral teratogen, a substance that through prenatal exposure affects the body and (most importantly) the brain of a developing foetus.

Fetal Alcohol Spectrum Disorder (FASD) refers to the lifelong effects caused when an unborn baby is exposed to alcohol. The baby in the womb can't process alcohol, which means it can limit the growth of brain cells and damage the baby's central nervous system and other organs. It is classified as a

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neurodevelopmental disorder resulting from Prenatal Alcohol Exposure (PAE) which causes irreversible brain damage.

Individuals with FASD can experience complex behavioural and intellectual problems that persist throughout the lifespan, and can become increasingly complicated, if unsupported. The need for early and accurate diagnosis is critical for improving outcomes and quality of life.

Because FASD may impact multiple areas of the brain, providing comprehensive, personalised care and support that considers the individual needs of patients is crucial for their wellbeing.

Why look for a diagnosis for Fetal Alcohol Spectrum Disorder?

What we know?

- With appropriate support and scaffolding of learning at school, children with FASD can succeed and indeed thrive at school.
- Children with FASD have many strengths and are high functioning in some areas.
- Most children with FASD are born without any identifying features of a disability. Under 10% of children will be born with the identifying facial characteristics of FASD, which can change over time.
- FASD is commonly referred to as a “hidden disability”, increasing the vulnerability of the child not being assessed for FASD or misdiagnosing their condition.



- The most common signs of children having FASD are delays in reaching developmental milestones and complex behaviour problems that are challenging for parents or caregivers to manage.
- Children who have FASD may present to health services with developmental delays, difficulties adjusting to school, learning problems, ADHD and symptoms of poor social and adaptive functioning.
- FASD is the most common known cause of neuro-developmental disability and birth defects in the western world. The prevalence of FASD is such that up to 1 in 20 people could have FASD. In comparison, Autism Spectrum Disorder is thought to affect 1 in 94.
- *With early diagnosis, positive relationships and the right support, individuals can achieve positive outcomes. Early recognition of FASD and early emphasis on the prevention of secondary disabilities may decrease demands on families. Moreover, a diagnosis of FASD may indicate the need for specific interventions and parenting supports such as respite care, peer-support groups, treatment for parental alcohol misuse and education of other professionals who care for people with FASD'. Fetal Alcohol Spectrum Disorders 2023*
- Fetal Alcohol Spectrum Disorder FASD is often referred to as the 'invisible disability' as it often goes undetected, whether it be overlooked, ignored, attributed to another cause or even simply blamed on parenting or the environment the child is living in. Assessment and



diagnosis of FASD is important as it may provide answers for families and improve access to services that can improve life outcomes.

- Research has found that early diagnosis of FASD is a 'protective factor'. A protective factor is anything that stops one problem from causing another to develop. A written medical diagnosis of FASD will help anyone who is supporting your child to better understand that their learning and behavioural issues are a symptom of FASD and this helps when making plans to help your child with the challenges they face.
- If children or adults have no visible facial features their problems may be wrongly diagnosed, blamed on poor parenting or other disorders or trauma.
- FASD is a complex disability that is quite unlike all others, interventions that work are often specific to the disability.
- The quality and type of interventions truly matters. International studies tell us that early diagnosis and interventions for FASD are linked with better long-term outcomes for the child and the family who support them.

If FASD is suspected, an accurate diagnosis can:

- Help parents/carers better understand their child and their behaviour
- Help the older child/adolescent or adult better understand themselves
- Be a guide to the most appropriate and best support and services
- Aid communication among clinicians, caregivers, educators, and families.



Children with FASD are very different from each other. One child might have only a few characteristics and another might have many.

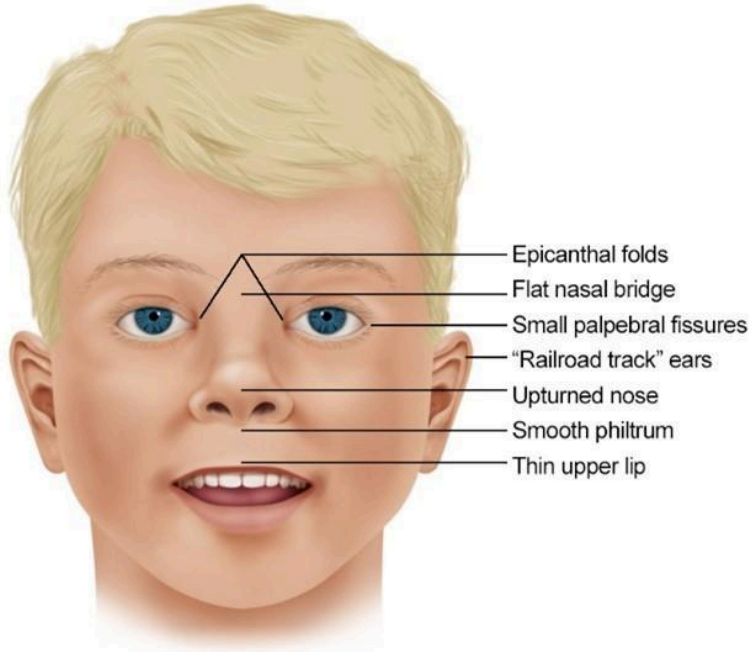
In very young children, it can be hard to detect the early signs unless the child has very obvious facial features and developmental delay. FASD is often not evident until they start pre-school or school. It's best to get advice and support early if you're worried that your child may have FASD.

It is important to consider having your child evaluated for FASD if:

- There is a maternal history of regularly drinking prior to pregnancy being confirmed.
- There is a maternal history of regular drinking during pregnancy or drinking heavily on an occasion during pregnancy.
- Your child is not growing or developing as expected. For example, they may have developmental delays, such as not learning from their mistakes or they may be smaller than other children of the same age (this is not the same for every child with FASD as it is a spectrum).
- They are having problems learning, behavioural problems and problems getting along with others.
- Your child may have distinctive facial features of FASD. Some of the features include a small face, narrow eye openings, a short, upturned nose, and a flattened groove between the nose and the upper lip. These features are often not noticed as less than 10% of children with facial



features have FASD or they may have been present at a younger age.



Some children may have a mixture of physical, behavioural and thinking difficulties:

What behavioural and thinking difficulties:

(Remember FASD is a spectrum where different needs are displayed in each child)

- Disturbed sleep
- Speech and language delay or advanced language skills above peers
- Mood, behaviour and attention difficulties
- Being easily led
- Poor short-term memory



- Difficulties in school, which become more noticeable as the child gets older
- Difficulties with social communication, particularly with their emotions; they may be sociable but don't understand the rules to maintaining relationships
- Difficulties with daily living (*for example dressing, or travelling independently*)
- Difficulties making and keeping friends
- Poor judgement skills
- Depression
- Sensory difficulties (*for example dislike of light, sound, smell, feel or touch of certain things, need to bump into things, curve over things*)

What physical difficulties may exist?

(Remember FASD is a spectrum where different needs are displayed in each child)

- Premature birth
- Sucking difficulties in babies
- Not growing as expected for their age
- Small head size
- Small eyes
- Poor fine motor skills (*for example, this may make handwriting difficult*)
- Vision or hearing challenges
- Movement, balance and co-ordination difficulties
- Thin upper lip



- Smooth philtrum (the ridge that is usually seen between the nose and upper lip)

People affected by FASD can have many strengths:

(Remember FASD is a spectrum where different needs are displayed in each child)

A child may have a hyperfocus in one thing, they may or may not be:

- creative
- musical
- active
- eager to please
- good at remembering visual information although may piece bits of information together to form one memory which they believe to be true (*confabulation*).

FASD can exist alongside other developmental conditions:

These include Autism and Attention deficit hyperactivity disorder (ADHD) which can be up to 60% more likely to co-occur with FASD.

Some behaviours are common, known as overlapping or 'comorbid conditions' to FASD in all these conditions where it is vital the clinician has the experience of looking at ADHD & Autism through understanding FASD.

Assessment will consider an overall profile of strengths and difficulties.



Parent observations are important to the assessment, diagnosis and planning process; we recommend you keep a note of existing and emerging needs where you will be asked what you notice now and what patterns you might see forming.

You can refer to [FASD Hub South West](#) to help you gather this information.

You will be asked to fill out forms before you go to the appointment, if you need assistance with this do please ask.

The multi-disciplinary team will meet with you over several appointments and usually do the following:

- Look at the documents you have brought with you, these can include any previous assessments or hospital reports.
- Ask about the birth mother's pregnancy and the baby's birth
- Examine your child
- Test your child's ability to communicate and move
- Will look at their face and may take measurements of it

The signs of FASD are complex and vary from person to person, so several professionals who are skilled in different assessments will be involved; known as a multidisciplinary team.

What will happen after the assessment?

The assessment team lead will talk with you about the results as soon as they can.



Within a few weeks you will receive a written report summarising what the assessment found and the team's decision about your child's condition.

After Diagnosis of FASD or likely FASD:

"It is vital carers, parents and especially professionals understand this is irreparable brain-based damage where very specific support and scaffolding is required, most importantly support from other families makes the biggest difference" FASD UK Alliance Conference 2023, Prof Raja Mukherjee, Consultant Psychiatrist, Clinical UK and International Lead for NDD & FASD

FASD Hub South West: supporting carers and parents alongside a network of professional colleagues nationally and internationally who specialise in FASD. Members of the FASD UK Alliance.

Facebook: Hosted by FASD Hub Friends Facebook pages give immediate support from others who face challenges and celebrate success together:

- [FASD Friends; South West UK](#)
- [FASD Friends; Home Education](#)
- [FASD Friends; Ideas for Supporting & Teaching FASD](#)

Online: The group runs a monthly Online Friends session where carers & parents chat and share stories, they offer subject specific topics with '[Ask the Expert](#)' guest speakers from a range of subjects that are relevant and chosen by carers & parents.



Drop in: 1:1 confidential online support & family support

Events: The group host weekend & holiday events in discrete safe venues that are tailored to children's needs

Other Support:

National FASD - The National Organisation for FASD provides support to people with Fetal Alcohol Spectrum Disorder (FASD), their families and communities.

Recommended reading by local carers and parents:

Free Downloadable Resources:

- [FASD Strategies not Solutions](#)
- [Primary Curriculum Framework for FASD](#)
- [Secondary Curriculum Framework for FASD](#)
- [Making Sense of Sensory Needs](#)
- [Booklet for Parents, Carers & Families](#)
- [FASD Language & Terminology](#)
- [FASD Summary for EHCP](#)
- [FASD Health Needs Assessment](#)
- [Masking in School](#)

Books:

- [Understanding Fetal Alcohol Spectrum Disorder: A Guide to FASD for Parents, Carers and Professionals](#) *Author Maria Catterick*
- [Fetal Alcohol Spectrum Disorders: Parenting a child with an invisible disability](#) *Author Mary Mather & Julia Brown*



- [Essential FASD Supports: Understanding and Supporting People with Fetal Alcohol Spectrum Disorders](#) *Author Nate Sheets*

Videos:

- [FASD & ME](#)
- [6 Things Educators should know about FASD](#)
- [Sensory Processing](#)
- [Other free resources, up to date research and further reading](#)