

Diagnosis and support change trajectories

“My son was diagnosed... after many years of referrals to paediatricians, OTs, therapists, speech and language, CAMHS, school support workers, children’s services and more... It’s only when you look back over the years that you realise just how many professionals it took, to finally get to the point of diagnosis and support. Yet, I have had to explain what FASD is to almost every single one of those professionals.”
SH, Birth mother (APPG on FASD, 12/2018)

“Diagnosis made me understand why I was the way I was and how to get on with my life now knowing.”
Adult with FASD (NFAC, 2018)

“I have a right to a diagnosis. It’s unfair it’s taken me six years just to be assessed.”
NC, Adult with suspected FASD (2019)

RECOGNISING FASD

Foetal Alcohol Spectrum Disorders

“I care deeply about the rights of those affected by fetal alcohol spectrum disorders. They must have access to services that deliver the best possible care.”

Professor Sheila the Baroness Hollins, BMA, Alcohol and Pregnancy (2016)

For more information

SIGN 156: <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html>

NICE Quality Standard on FASD: <https://www.nice.org.uk/guidance/indevelopment/gid-qs10139>

BMA, Alcohol and Pregnancy: Preventing and managing fetal alcohol spectrum disorders (2007, 2016)

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Note: The international and medical spelling is *fetal* but NOFAS-UK uses the more common British spelling *foetal*.

A new NICE Quality Standard on FASD is coming in January 2021, based on the Scottish SIGN 156 guidance on ‘Children and young people exposed prenatally to alcohol’

Listen, support, refer

FASD is more common than autism according to international studies. (May et. al, 2018)

A screening prevalence study here in the UK showed more than 6% may be affected. (McQuire et. al, 2018)

The UK has the 4th highest rate of alcohol in pregnancy in the world. (Popova et. al, 2017)

There is no proven safe amount of alcohol in pregnancy. The developing brain is particularly vulnerable throughout the pregnancy.

All levels of alcohol exposure should be recorded.

FASD is a full-body diagnosis; more than 428 conditions can co-occur. (Popova et. al, 2016)

Concerns? Refer for a neurodevelopmental assessment

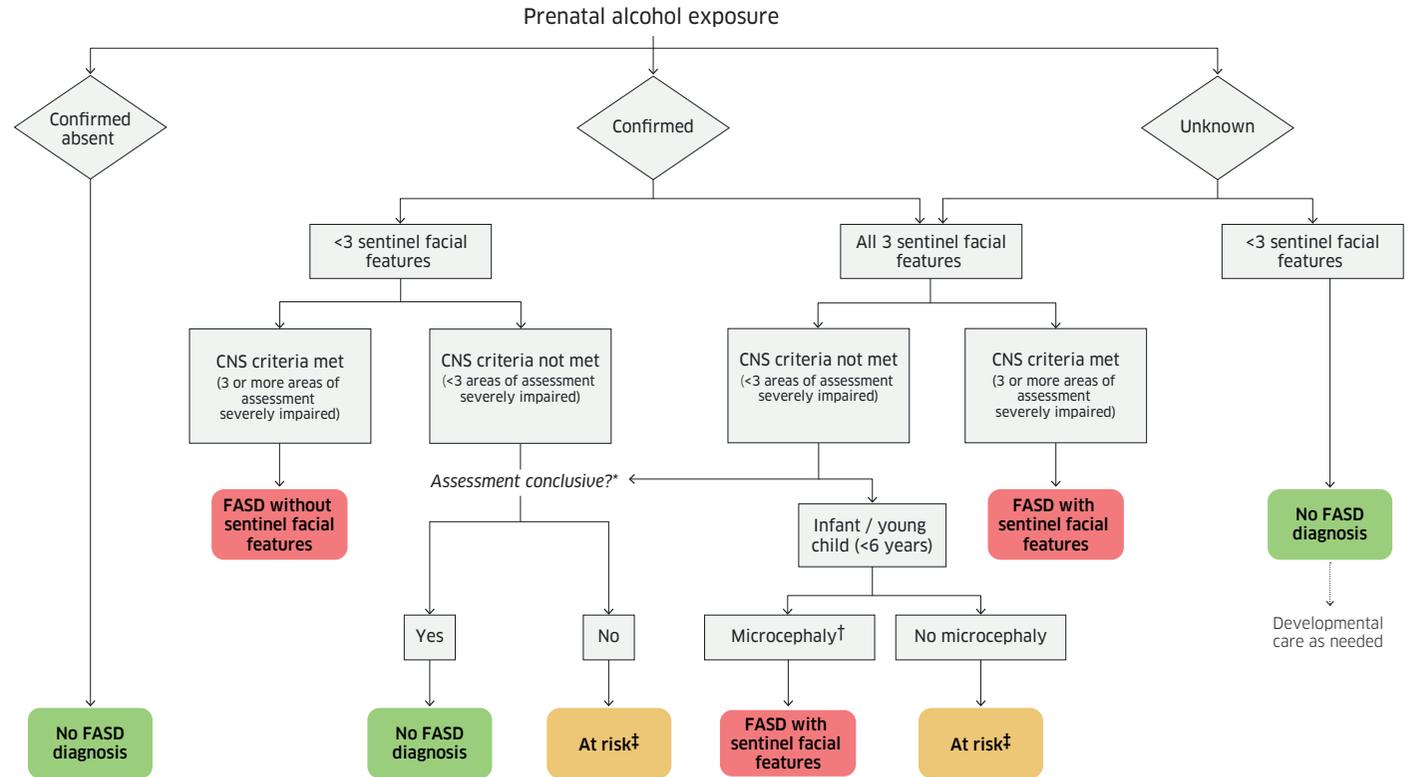
According to SIGN 156, "a diagnosis/descriptor of FASD is made only when there is evidence of pervasive and long-standing brain dysfunction, which is defined by severe impairment...in three of more of the following neurodevelopmental areas of assessment":

- motor skills
- cognition
- memory
- neuroanatomy/neurophysiology
- executive function, including impulse control and hyperactivity
- affect regulation, adaptive behaviour, social skills or social communication
- academic achievement
- language
- attention

SIGN 156 states: "The diagnostic /descriptive criteria for FASD are the same for adults as for younger individuals".

Diagnostic Algorithm

Found at: <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html>



* Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some areas of assessment cannot be investigated with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness.

† Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests.

‡ At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnoses. Clinical judgement is recommended.

Contribution of genetic factors should be considered in all cases and referral may be indicated in typical cases or where PAE is uncertain.

Diagnostic terms used by SIGN

Likely to be used more in England after the NICE Quality Standard on FASD

FASD without sentinel facial features, also known as:

- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Partial Foetal Alcohol Syndrome (pFAS)
- Neurodevelopmental Disorder-Prenatal Alcohol Exposure (ND-PAE)

FASD with sentinel facial features, also known as:

- Foetal Alcohol Syndrome (FAS)
 - palpebral fissure length ≥ 2 SD below the mean
 - philtrum rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide
 - upper lip rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide