FASD IN FOCUS

DIAGNOSIS & ASSESSMENTS

Information is power. People with FASD benefit greatly from proper diagnosis and assessments to identify specific needs

DIAGNOSIS

Referrals

For a child: Ask the GP to refer you to a paediatrician. The paediatrician may conduct an array CHG blood test to rule out any genetic issues.

Note: a referral to a geneticist is not needed at this point and can delay things. If something shows positive, the referral can be made at that point. Even if there is a positive genetic test, this does not rule out that there may also be FASD.

For an adult: Sadly, it can be more challenging for adults to get a diagnosis. Discuss your concerns with your GP. Explain that you are concerned you might have FASD. Bring any proof you have (as above) and ask the GP to refer for a neuropsychological assessment or to a specialist clinic (see p. 2). Even if it doesn't lead to an FASD diagnosis, a neurpsychological assessment can identify any problems with processing and will be useful in supporting any claims for benefits or support at work.

SIGN 156

<u>Scottish SIGN guidelines</u> on "Children and young people exposed prenatally to alcohol" have been accepted by NICE as the basis for the NICE Quality Standard on FASD (January 2021). You can ask your doctors to look at this if they are unsure how to diagnose. SIGN 156 states: "The diagnostic /descriptive criteria for FASD are the same for adults as for younger individuals"

CONFIRMATION OF AEP

Was it an alcohol-exposed pregnancy?

These are the types of proof that can be provided re an alcohol-exposed pregnancy. Sometimes a review of the maternal records with a fresh set of eyes by the professionals can yield the proof needed. This is from <u>Scottish SIGN guidelines</u> that have been accepted by NICE as the basis for the upcoming NICE Quality Standard on FASD:

Confirmation of PAE requires documentation that the biological mother consumed alcohol during the index pregnancy based on:

- reliable clinical observation
- self report or reports by a reliable source
- medical records documenting positive blood alcohol concentrations, or
- alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy.

NOTE: a diagnosis of FASD is possible without confirmation of alcohol-exposed pregnancy in the <10% of instances when three sentinel facial features are present.

YOU MAY BE ASKED FOR THESE

- Proof from school or other professionals about developmental challenges.
- Baby pictures that show the face (not smiling)



RELATED SYMPTOMS

Also necessary for diagnosis

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
- Academic achievement
- Language
- Attention
- Executive function, including impulse control and hyperactivity
- Affect regulation, adaptive behaviours
- Social skills or social communication

OTHER ASSESSMENTS

- Neurodevelopmental or neuropsychological assessment – for adaptive planning and executive functioning;
- Speech and language assessment including receptive language;
- Sensory integration assessment a specially trained occupational therapist can give you a 'sensory diet'.

These assessments, if not done during diagnosis, can be requested during the Education, Health and Care Plan assessment process, through adoption/fostering processes, or at the time of transition to adulthood.

HELPFUL RESOURCES

SIGN 156

Scottish Clinical Guidance on children and young people exposed prenatally to alcohol has been accepted by NICE. <u>https://www.sign.ac.uk/our-</u> guidelines/children-and-young-people-exposedprenatally-to-alcohol/

BMA

Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders, 2016.

https://www.bma.org.uk/what-we-do/populationhealth/drivers-of-ill-health/alcohol-and-pregnancypreventing-and-managing-fetal-alcohol-spectrumdisorders

NICE Quality Standard

Every practitioner who interacts with your child should be made aware of the NICE Quality Standard on FASD (Draft currently available, the final will be out in January 2021)

https://www.nice.org.uk/guidance/indevelopment/gidgs10139/documents

Referrals/consultations

The National FASD Clinic in Surrey specialises in assessing and treating children and adults. If your doctors don't have local ability to diagnose, ask for a referral or consultation. https://www.fasdclinic.com

The Centre for FASD in Suffolk is a multi-professional service, providing full FASD assessment, diagnosis, and post-diagnostic support for children and their families. https://www.centreforfasd.co.uk

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