

Common description of FASD

FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than 400 conditions can co-occur, FASD is at its core a lifelong neurodevelopmental condition. All people with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning.



Source: FASD: Preferred UK Language Guide (Seashell, National FASD, 2021): <https://nationalfasd.org.uk/languageguide/>

Brain based but also displays physically

Muscle

Bones

Endocrine system

Kidneys and liver

Gastrointestinal tract

Heart



428
conditions
can co-occur

Head

Ears

Eyes

Face

Brain

Mouth

GOVERNMENT POLICY HAS CHANGED.

Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile.

27% of children in care were diagnosed with FASD, but 75% had prenatal exposure to alcohol.

In Derby, 620 children are recorded as being in care. This means 167 LAC may have FASD.

2% of the population have FASD.

This means there are 1173 children who have or are likely to have FASD in Derby alone.



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Children with FASD are significantly different to children with other Special Needs.

Prof Raja Mukherjee et al.

Our expectations and the support offered needs to change with the stage the young person is at not their age

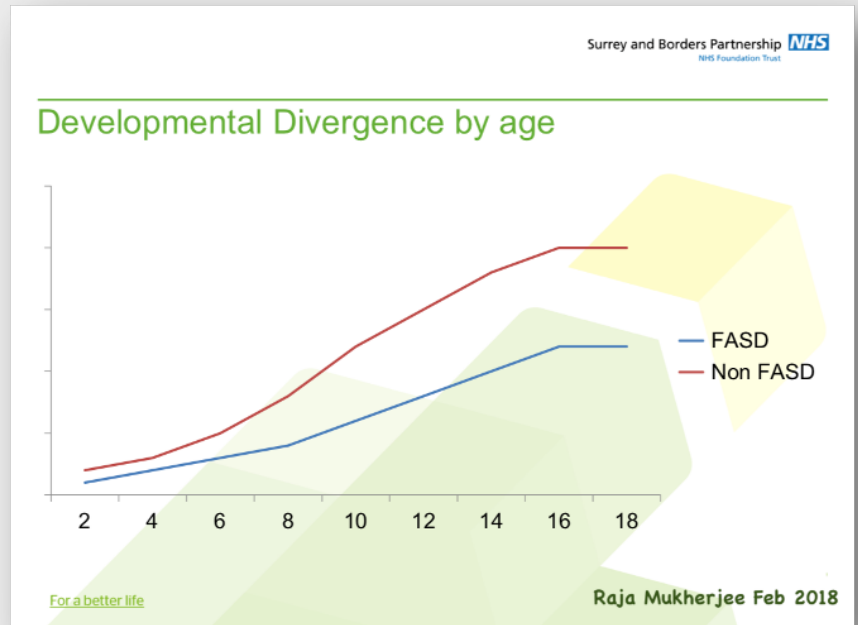
- Transition to secondary school is a particularly important time.
- Especially vulnerable if undiagnosed and there's no EHCP in place.

Environmental Support

- Minimise distractions.
- Trusted adult support to focus and explain.
- Think about visual information and cues.
- Pick the best time to do things and take the lead from the child or young person.
- Provide a soft zone for comfort not punishment.

Environmental Strategies

- A calm, nurturing environment is essential in boosting achievement and positive outcomes.
- Keep visual distractions to a minimum, including reducing the amount of visual noise.
- Only provide the items needed for each activity one at a time.
- Arrange for a quiet area to use when the child becomes over stimulated / dysregulated.



Communication Support

- Simple one step instructions and repeat as necessary.
- Chunk information (a maximum of 2 bits of information).
- Use positive concrete language.
- Check for understanding.

Communication Strategies

- Try not to use instructions that are based on imagination or unfamiliar stories.
- Try to personalise questions by including the young person's name or familiar information.
- Role play using real objects and names.
- Develop a range of visual and kinaesthetic learning opportunities.

Emotional Support

- Role models of trusted adults.
- Praise and correction and provide space and time for emotional regulation.
- Simple emotional scale and cues.

Emotional Strategies

- Pre warn the young person.
- Structure what you expect from the child.
- Teaching mind mapping will also help a young person to structure their thoughts before committing to a decision.
- Keep it short and simple (KISS).

Sensory Support

- Soft quilt
- White noise
- Headphones
- Den or tent
- Fiddle toys
- Personalised distraction techniques

Sensory Strategies

- Don't rely on one strategy, be prepared to use other strategies which achieve the same end point.
- Give the young person time to think about instructions.
- Use positive, direct language.

Resources that can help...

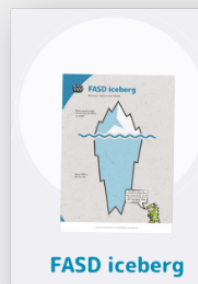
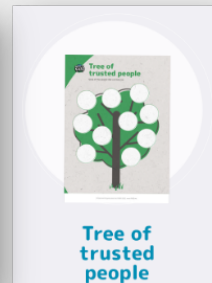
www.fasd.me



- An expert-reviewed website just for young people with FASD and those who support them.
- Contains coping resources that are printable and usable in wide range of contexts.

Coping resources

- Please have a look at the growing bank of resources on www.fasd.me.
- In collaboration with young people living with FASD, the National Organisation for FASD have created a range of materials which help young people to understand and navigate their diagnosis.



[FASD.me](http://www.fasd.me)



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Break It Down Board



The Break it Down Board has been a life changer. Mum to 7 & 8 year olds

Some things that happen can be confusing. This board can help you to break them down so you understand better what can help.

Interactive comic

This explains what FASD is, how it affects people and things that people with FASD have done to make their lives easier.



Calming Cards

A set of cards with suggestions from more than 70 young people with FASD about what helps them to stay calm. Use these cards to plan strategies that will help you too.



Mason is so proud of having his name on some of the calming cards



The game was suggested by Andy Jackson a young adult with FASD and its name came from our Adults and Young Adults with FASD Advisory Committee



We have lots more planned for the characters.

Now and Next Board

A set of cards with suggestions from more than 70 young people with FASD about what helps them to stay calm. Use these cards to plan strategies that will help you too.

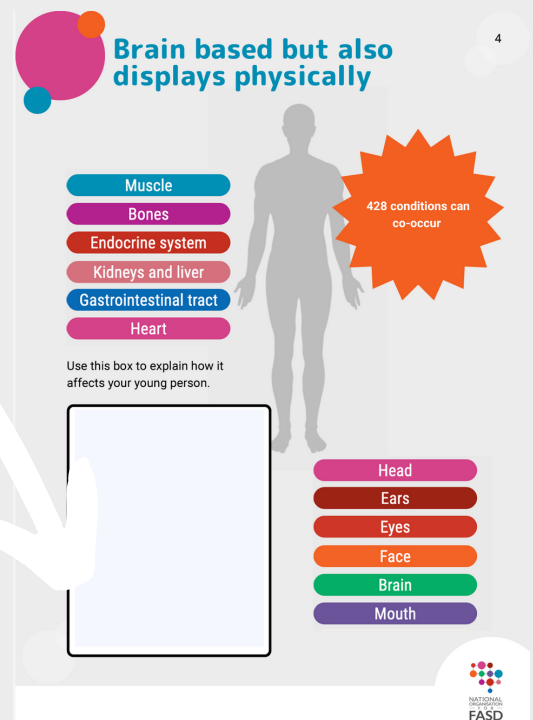


Advocating for your Young Person

At the National Organisation for FASD, we've developed a booklet intended for parents, caregivers, and guardians to complete and provide to professionals. Our primary objective is to simplify the advocacy process for your child. This fillable PDF booklet can be personalised and saved – it serves as a valuable tool for parents and carers to individually tailor with information about their young person, enabling professionals to gain a deeper understanding of the child and their diagnosis. We trust that this booklet, backed by the authority of our national organisation, will empower organisations supporting your young person to provide essential assistance and adjustments needed for your young person's success.

personalised for your young person

If you've met one person with FASD, you've only met one!



Key Official Quotes

- "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." Chief Medical Officers guidance (2016) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/545937/UK-CMOs_-_eprint.pdf
- "Drinking any alcohol can cause difficulties in pregnancy and can result in Fetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy." Public Health England, "Maternity high impact areas: Reducing the incidence of harms caused by alcohol in pregnancy" (2020) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_areas_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf
- 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. <https://www.nhs.uk/our-quality/our-children-and-young-people/exposed-or-possibly-to-alcohol/>
- "There is no 'mild' FASD." "FASD Health Needs Assessment for England" (2021) <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- NICE Quality Standard on FASD (2022) has five statements: 1) "Pregnant women are given advice throughout pregnancy not to drink alcohol"; 2) "Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded"; 3) "Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment"; 4) "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"; 5) "Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs." <https://www.nice.org.uk/guidance/qs224>
- "NHS England has a legal duty to take [NICE Quality Standard] into account in the discharge of its quality improvement duties. NHS organisations locally should take them fully into account in designing services that meet the needs of their local populations." Neil O'Brien MP, Parliamentary Under Secretary of State for Primary Care and Public Health, letter to National FASD, 8 Dec. 2022.
- "There is no known safe level of alcohol consumption during pregnancy." NICE, Fetal Alcohol Spectrum Disorder Quality Standard (2022). <https://www.nice.org.uk/guidance/qs224>
- "There is no known safe level of alcohol consumption in pregnancy. Even low to moderate levels of PAE [prenatal alcohol exposure] can negatively impact a fetus and these adverse consequences can persist into adulthood." SIGN 156, "Children and Young People Exposed to Alcohol" (2019) <https://www.sign.ac.uk/sign/156-children-and-young-people-exposed-to-alcohol>
- "The government recognises the importance of FASD." Department of Health and Social Care, "FASD Health Needs Assessment for England" (2021) <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- "Health assessments should... pay particular attention to health conditions that may be more prevalent in looked-after children (such as fetal alcohol syndrome or attachment difficulties) and which may otherwise have been misdiagnosed." Promoting the health and wellbeing of looked after children, statutory guidance, p. 18-19. (Note this uses the older diagnostic term but according to current diagnostic guidelines would read "FASD") https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/110108/Promoting_the_health_and_wellbeing_of_looked_after_children_August_2017_update.pdf
- The needs identified for this population group focus on a lack of robust prevalence estimates in England, the importance of multi-sector working to support individuals through the life course, better training and awareness for health professionals, better organisation of services to improve accessibility, a need to develop innovative approaches to support those living with the condition. "FASD Health Needs Assessment for England" (2021) <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- Definition of learning disability: The Health and Care Act (2022) refers to the Mental Health Act which states: "learning disability" means a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning." (There is no mention of IQ.) <https://www.legislation.gov.uk/ukpga/2022/31/section/18/1/enacted> <https://www.legislation.gov.uk/ukpga/1983/20/section/1> <https://www.legislation.gov.uk/ukpga/2007/12/section/28/section/2.3>

key official quotes

You have the support of a National Organisation and key policy documents.



Find it here.

More training?

- National FASD has been at the forefront of providing FASD training throughout its existence.
- We are pleased to remain at the cutting edge, with new offerings.
- Informed by lived experience and fact checked by a committee made up by the leading national FASD experts in the UK.
- Email training@nationalfasd.org.uk for more information.



www.fasd.me

For children and young people with FASD



eschool.nationalfasd.org.uk

For practitioners



www.preventfasd.info

For 15-25 year olds



www.nationalfasd.org.uk

For adults with FASD, families and practitioners



alcoholandpregnancy.info

For maternity teams