

# FASD Ailly

This booklet is all about:  
Completed by:  
Relationship:  
Contact email:  
Contact phone:  
Date:



# I am an FASD Ally

- The purpose of this booklet is to empower families to tell their story and inform those working with their loved ones about FASD.
- FASD is different for everyone. This booklet relies on families being honest and filling out information relevant to their loved one. It's not easy to share the challenges and the strengths. We hope professionals take time to consider this input.
- The goal is to **help those working with people with FASD** to provide the **best support possible** to ensure that **young people with FASD can thrive**.
- This booklet has been generated to help parents & carers make the team around their child aware of FASD and how it affects their loved one. All the materials produced by the National Organisation for FASD have been informed by a committee made up of the leading experts in the field in the UK and an advisory committee of adults and young people who have FASD.
- *While the information that we have provided is currently the most up to date thinking on the subject, the National Organisation for FASD cannot be held responsible for material that is edited.*
- *This booklet is specific for one young person and provides support and strategies to support them and as such does not replace the nationally acclaimed training that the National Organisation for FASD provides.*

# What is FASD?

- Fetal Alcohol Spectrum Disorder is a lifelong condition, but the effects will change as the young person develops.
- With informed and consistent support, people with FASD can and do achieve.
- This booklet is to help you to understand what you can do to help our child.

## 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.

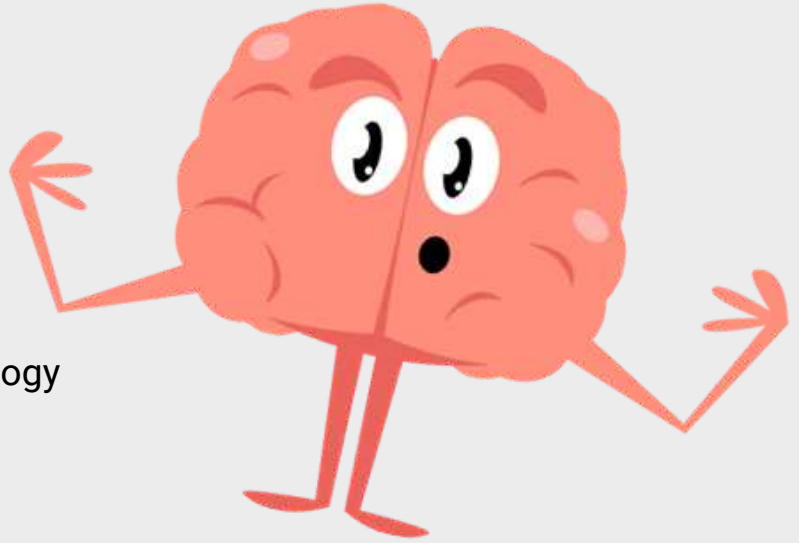


Source: FASD: Preferred UK Language Guide (Seashell, National FASD, 2021): <https://nationalfasd.org.uk/languageguide/>

# FASD is severe impairment

To have an FASD diagnosis there must be “**Pervasive and long-standing brain dysfunction**, which is **defined by severe impairment...in three or 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 behaviour, social skills or social communication



Healthcare  
Improvement  
Scotland

**SIGN**  
Evidence-based  
clinical guidelines

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

# Brain based but also displays physically

Muscle

Bones

Endocrine system

Kidneys and liver

Gastrointestinal tract

Heart

428 conditions can  
co-occur

Use this box to explain how it affects your young person.

Head

Ears

Eyes

Face

Brain

Mouth



# There is no 'mild FASD'.



Department  
of Health &  
Social Care

DHSC FASD Health Needs Assessment for England (2021)

<https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment#fnref:81>



## 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.**

SIGN 156

**SIGN 156**

Children and young people  
exposed prenatally to alcohol

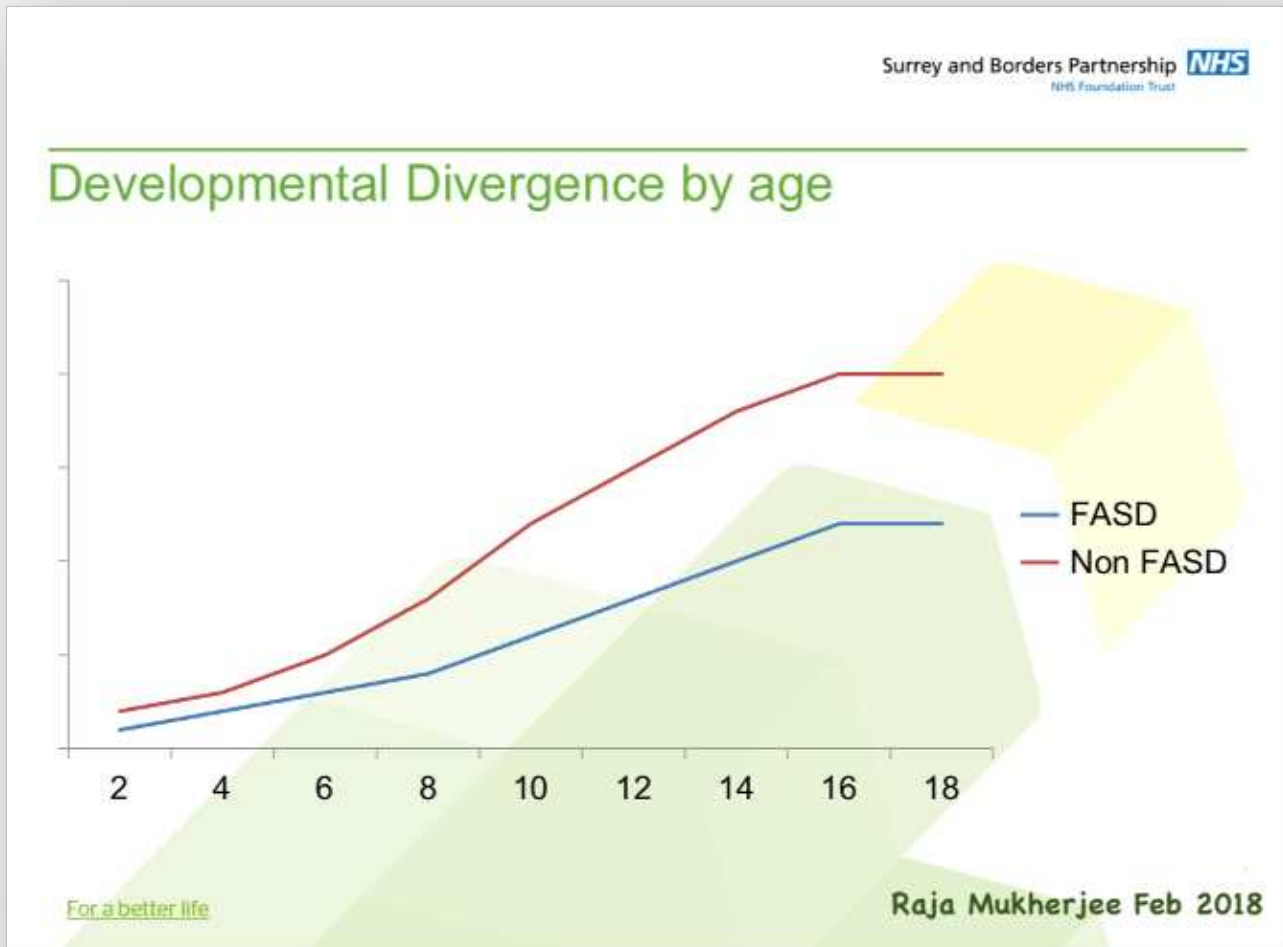
A national clinical guideline  
January 2019





**Latest studies suggest that  
Around 2 - 4% of the  
population has FASD. There is  
a much higher percentage in  
those with care experience.  
They are mostly undiagnosed  
and unsupported. With  
informed support, people with  
FASD can and do achieve.**

# 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.



# How people with FASD want to be treated

## #UKFASD MANIFESTO

<https://nationalfasd.org.uk/the-uk-fasd-manifesto/%20and%20https://fasd.me/uk-fasd-manifesto/>

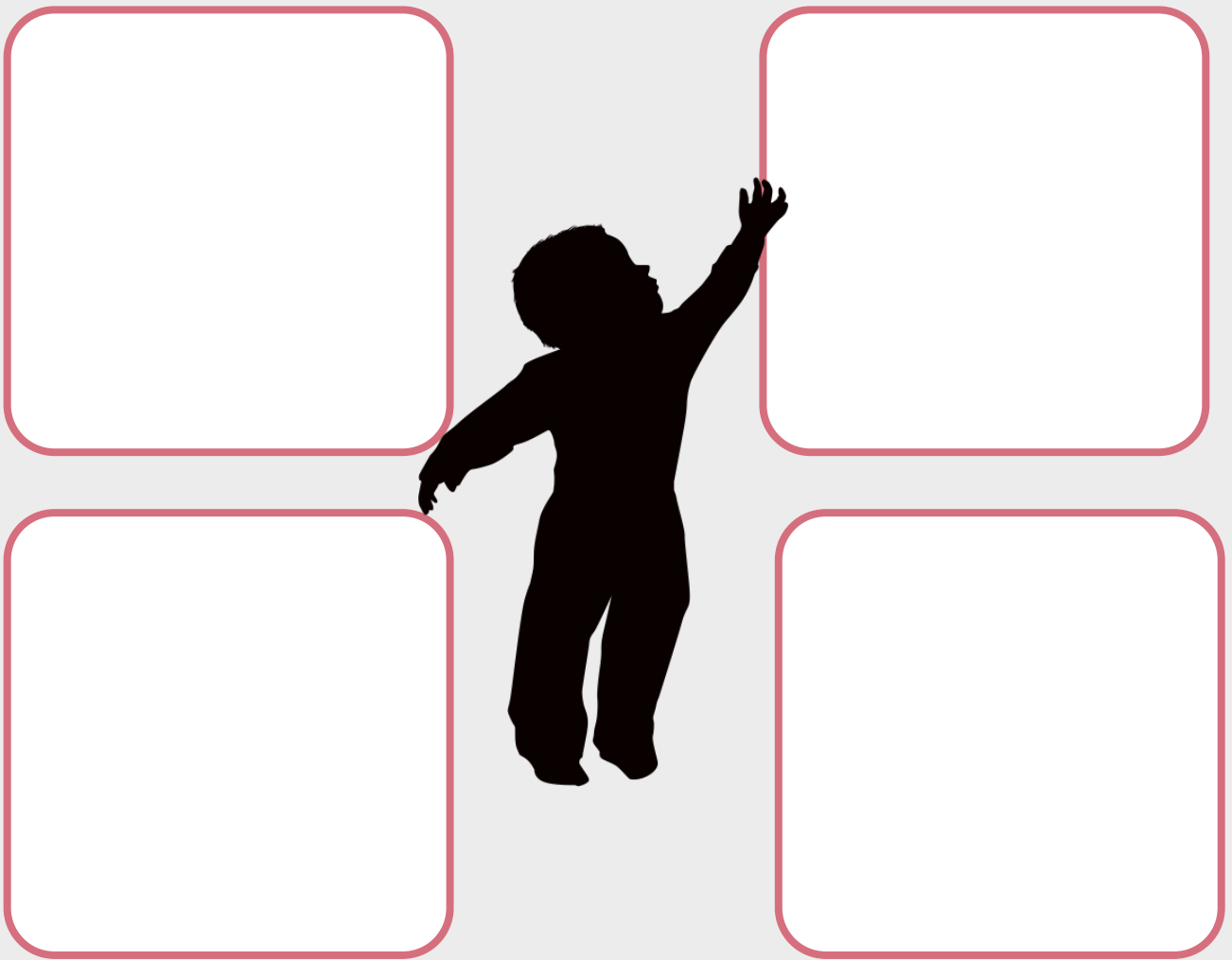


This is how \_\_\_\_\_ wants to be treated:



# What does FASD look like for \_\_\_\_\_?

Prenatal alcohol exposure affects everyone slightly differently. This is based on all of the variables that can occur through out pregnancy including the amount of alcohol present, environmental issues, epigenetics, the stage of development and more.



# What FASD is and is not...

## Traditional approaches may not work

### MYTHS

The naughty step, detentions and consequences will work to modify behaviour.

FASD means you have a low IQ.

### FACTS

Behaviour is affected by cognitive processing, emotional regulation and impulse control which are common difficulties for someone living with FASD. Coping and self-regulation strategies are needed.

Whilst some people with FASD have a low IQ, many will have an IQ within the normal range. However, it is typical to have need of support with executive functioning skills.

## The key is for the trusted adults to REFRAME EXPECTATIONS

original  
expectation

Acting like a child	↔	Is a child
Won't	↔	Can't
Lazy and does not try	↔	Exhausted with trying
Does not care	↔	Does not understand feelings
Refuses to sit still	↔	Over stimulated /needs contact
Forgets everything	↔	Can't remember
Fussy, demanding	↔	Hypersensitive
Steals	↔	Does not understand ownership
Does not get the obvious	↔	Does not learn from experience
Calculating and sly	↔	Does not understand social norms

reframed  
expectation

# Key milestones

Here are some key milestones of our young person's journey to help you understand their journey.





# Medical Tests

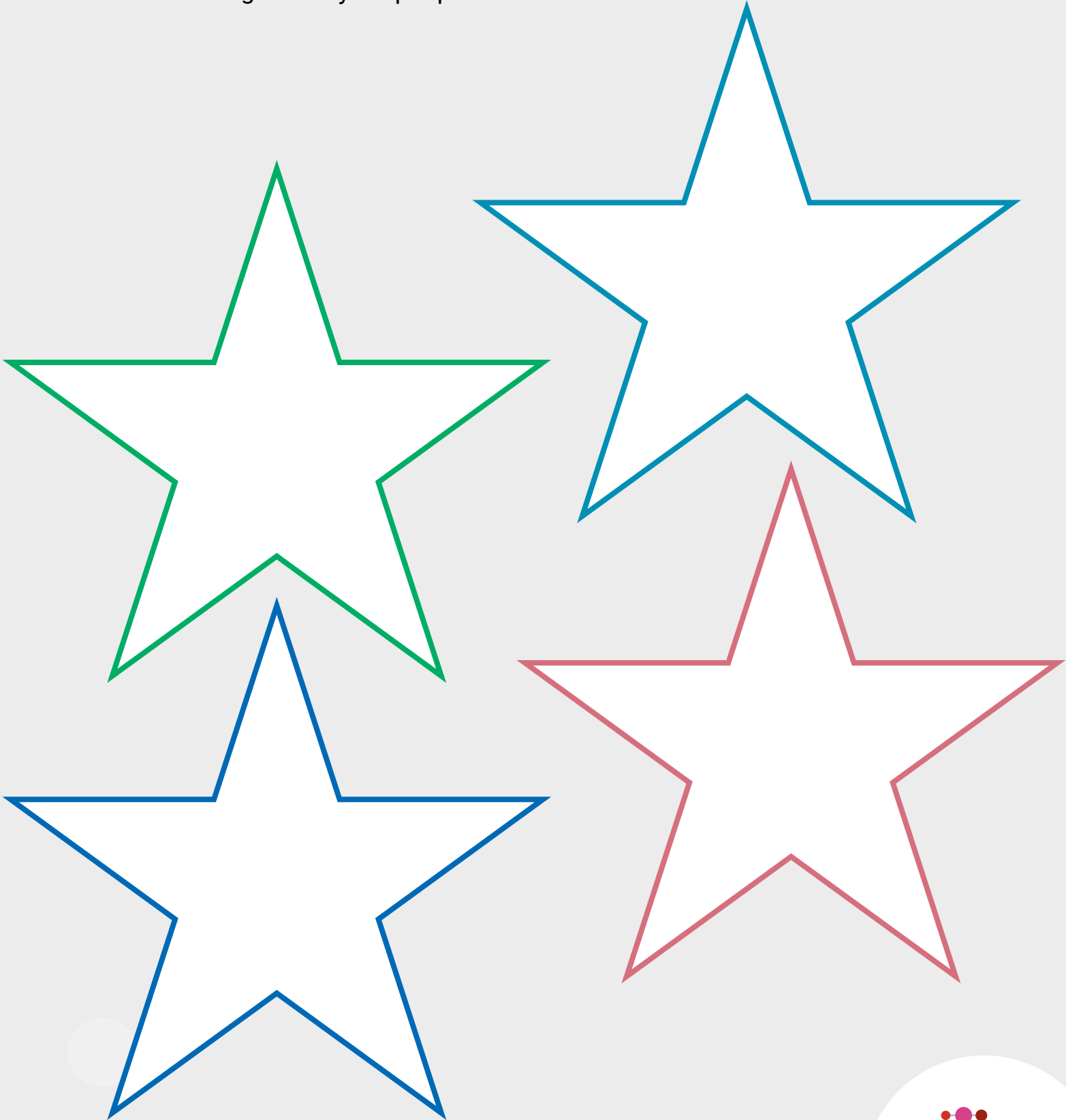
These are some key medical test results. It is recommended that individuals with FASD have up-to-date neurodevelopmental, speech and language and sensory integration assessments. Professionals have a key role in making sure these assessments are up-to-date and relevant.

test / date

score

# Personal Strengths

Everyone with FASD is different and has different strengths. All people with FASD have great strengths. Using individual strengths is a great way for people with FASD to achieve.



# Challenges

- Although alcohol can affect the development of all cells and organs, how the brain forms and functions is particularly vulnerable to the effects of prenatal alcohol exposure.
- As a result, children and adults with FASD often experience difficulties in processing information.
- This can be needing to take longer than their peers to appearing to miss chunks of information.
- In order to process information, the brain often has to work harder meaning that people with FASD might also be more tired.

This is what \_\_\_\_\_ finds  
most difficult.



This is what \_\_\_\_\_ finds helpful.

## Dysregulation

- People with FASD can become dysregulated.
- Dysregulation is the inefficient functioning of the brain networks that control behaviour and/or emotions and is caused by brain damage.
- This can lead to impulsive behaviours and emotional reactions – it is not intentional.
- When dysregulated, their brains are not able to process information efficiently. The more stress the worse this becomes.
- When dysregulated, people with FASD must first and foremost have help to self-regulate and calm.





# Recognising dysregulation

Because of the brain damage, dysregulation is common. They may not be able to tell you this, but this is what it may look like...





# What helps to decrease dysregulation...



# Resources that can help...

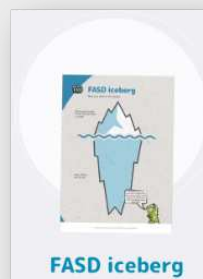
[www.fasd.me](http://www.fasd.me)



- 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](http://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**

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# Break It Down Board



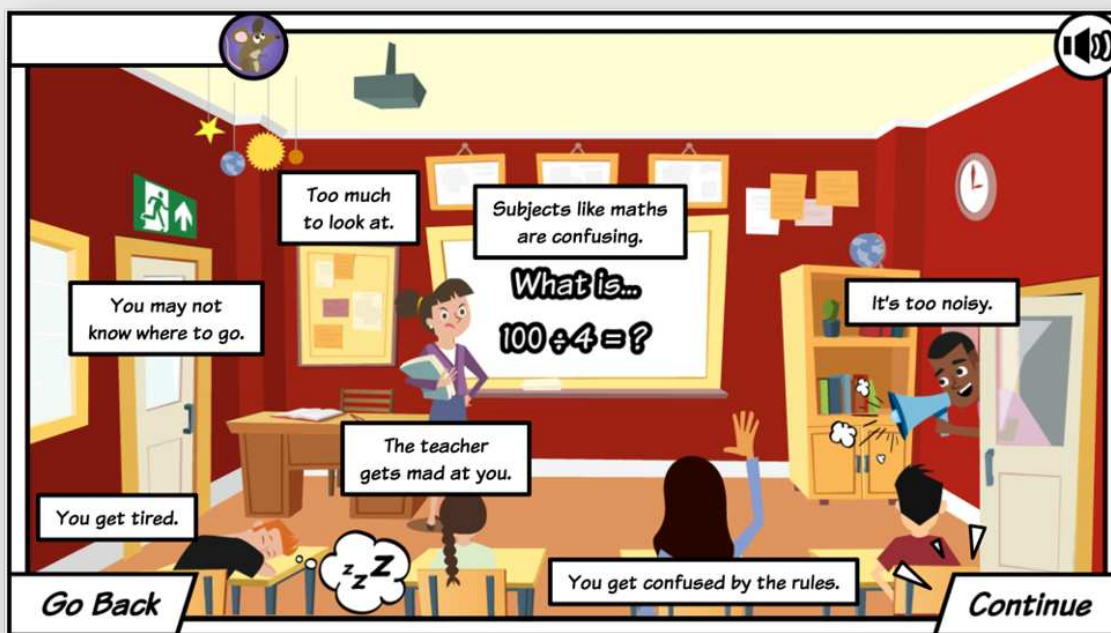
The Break it Down Board has been a life changer.  
Mum to 7 & 8 year olds



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.



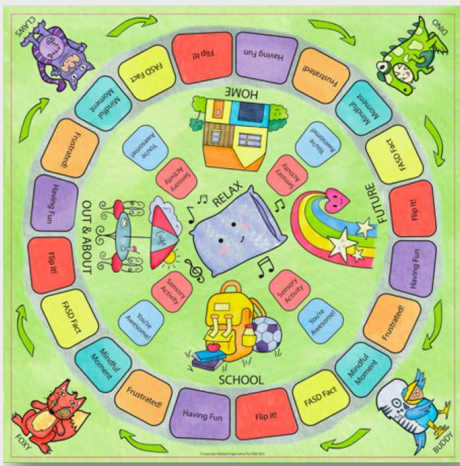
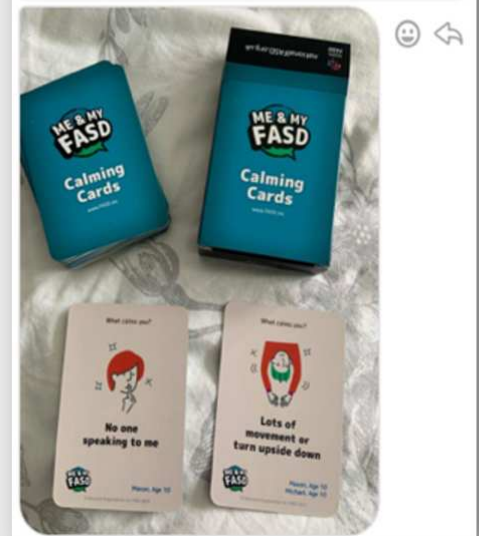


# Calming Cards

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.



# Get further training

- This is a very short snapshot. What works for one child or young person may not work for another. It is not intended to replace informed and up to date FASD training. Make your workplace FASD-friendly by undertaking 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.
- Scan the QR code to find out any further information.



## Thanks

## Any questions?

You can find more information about FASD  
at [www.nationalfasd.org.uk](http://www.nationalfasd.org.uk)

- “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\\_report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/545937/UK_CMOs_report.pdf)
- “Drinking any alcohol can cause difficulties in pregnancy and can result in Foetal 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 area: 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\\_area\\_4\\_Reducing\\_the\\_incidence\\_of\\_harms\\_caused\\_by\\_alcohol\\_in\\_pregnancy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_area_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.sign.ac.uk/our-guidelines/children-and-young-people-exposed-prenatally-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 204 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/qs204>
- “NHS England has a legal duty to take [NICE Quality s] 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 204 (2022). <https://www.nice.org.uk/guidance/qs204>
- “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 Prenatally Exposed to Alcohol” (2019) <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-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/1100188/Promoting\\_the\\_health\\_and\\_well-being\\_of\\_looked-after\\_children\\_August\\_2022\\_update.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100188/Promoting_the_health_and_well-being_of_looked-after_children_August_2022_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/181/enacted>, <https://www.legislation.gov.uk/ukpga/1983/20/section/1>, <https://www.legislation.gov.uk/ukpga/2007/12/section/2#section-2-3>

# National FASD's sister sites



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

For children and young people with FASD



[eschool.nationalfasd.org.uk](http://eschool.nationalfasd.org.uk)

For practitioners



[www.preventfasd.info](http://www.preventfasd.info)

For 15-25 year olds



[www.nationalfasd.org.uk](http://www.nationalfasd.org.uk)

For adults with FASD, families and practitioners



[alcoholandpregnancy.info](http://alcoholandpregnancy.info)

For maternity teams