

FASD: THE TIME IS NOW

Kingston Council
SEND Partnership Board
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WHAT WE'LL COVER

- Information about FASD
- Insights from people with FASD
- National changes
- Suggested local changes
- Resources

WHAT IS FASD?



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 A FULL-BODY DIAGNOSIS

428
conditions
can co-occur

Muscle

Bones

Endocrine system

Kidneys and liver

Gastrointestinal tract

Heart

Head

Ears

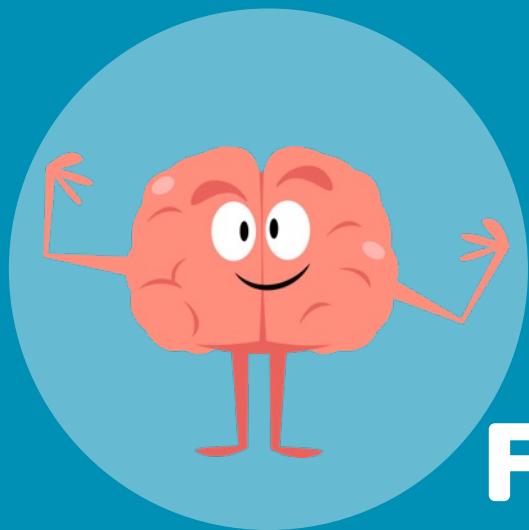
Eyes

Face

Brain

Mouth

Popova et al. (2016): <https://www.sciencedaily.com/releases/2016/01/160106091842.htm>
Interactive impact of alcohol tool: <https://preventfasd.info/impact-of-alcohol/>



FASD is preventable



FASD IS CAUSED BY ALCOHOL EXPOSURE IN PREGNANCY



"The safest approach is to not drink alcohol at all if you are pregnant or could become pregnant"
-UK CMOs (2016)

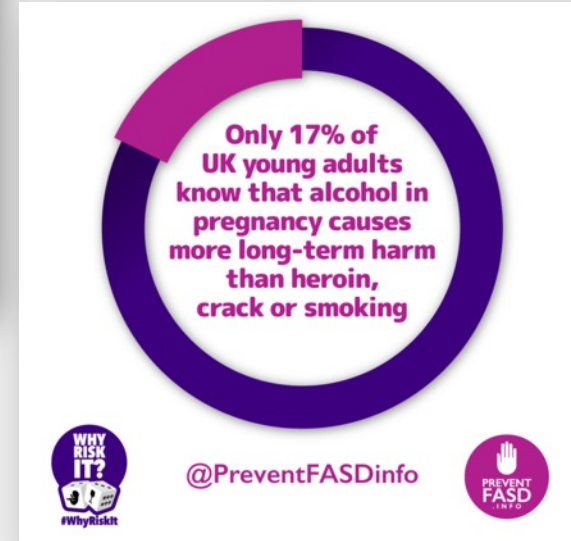
There's no safe amount of alcohol in pregnancy.

There's no safe time to drink alcohol in pregnancy.

There's no safe type of alcohol in pregnancy.

Info for 15-25 year olds: The Conceivables: <https://preventfasd.info/the-conceivables/>
RISK (an award-winning film): <https://preventfasd.info/risk/>

1/4 OF PEOPLE STILL DON'T KNOW CMOs GUIDANCE



- We have conducted polls over past three years
- Consistently ~25% do not recognise the CMOs guidance on alcohol in pregnancy
- Even more don't know WHY it's important

ALCOHOL IN PREGNANCY IS HIGH IN THE UK

- UK has 4th highest rate globally (2017)
- 41% of pregnant women drink alcohol in pregnancy (2017)
- ~50% of pregnancies are unplanned



Studies referenced in 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#fn:5>

**FASD IS MORE
PREVALENT
THAN AUTISM**

27% Looked
After
Children*

UK's 1st active-case ascertainment study
(Salford, 2021) matches international figures

2-4%

At least 1-2
students per
year group may
have FASD



University of
Salford
MANCHESTER

FASD

FETAL ALCOHOL
SPECTRUM DISORDERS

McCarthy, et al.: <https://onlinelibrary.wiley.com/doi/10.1111/acer.14705>

*Gregory et al.: <https://journals.sagepub.com/doi/abs/10.1177/0308575915594985>

Put another way, those stats may mean there are



**1.2 – 2.4 million
with FASD
in the UK?**

They are mostly undiagnosed and unsupported



FASD IS COMPLEX

- Most will have IQs in normal range
- Mainstream and SEMH schools (esp secondary schools) not meeting the needs of students with FASD

“Children with FASD were
considered exceptionally
different to other children
with Special Needs”
--Mukherjee et al.

“Mukherjee et al., “The impact of raising a child with FASD R. Mukherjee et al Adoption & Fostering BAAF April 2013.”



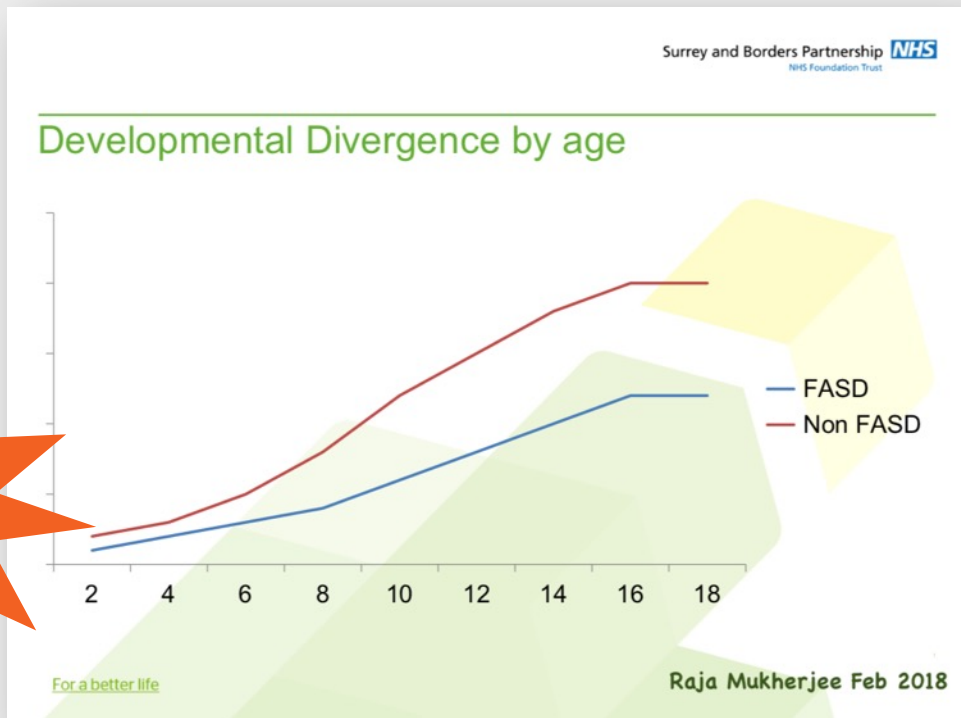
SCHOOLS NEED TO BE FASD- INFORMED

*"Too often the goal is to get
students with FASD to sit quietly
and watch other students
get educated"*
- Prof Barry Carpenter OBE CBE

- Students with FASD will present with a pronounced and complex set of needs that can make it difficult for teachers to know how best to support them
- We have lots of info for educators here:
<https://nationalfasd.org.uk/learn-more/practitioners/educators/>

The gap widens

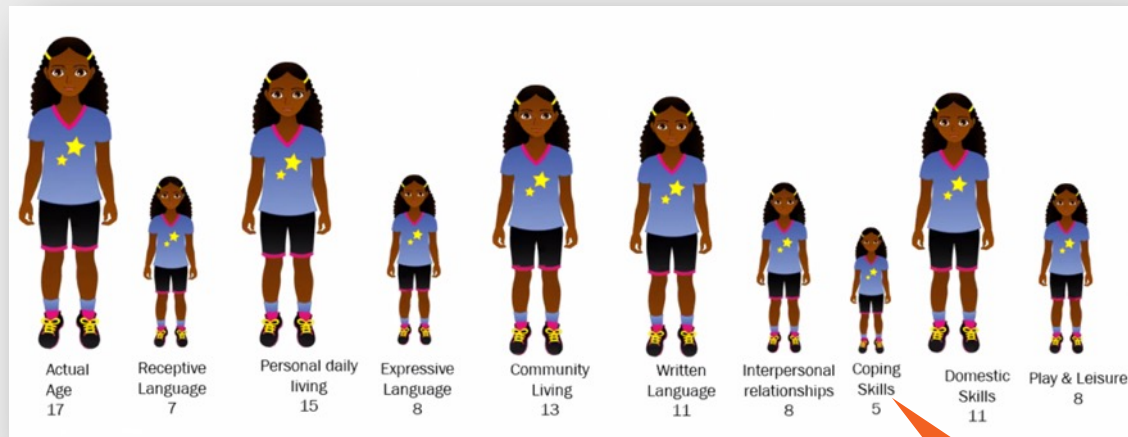
Transitions
are critical



- Transition to secondary school is a particularly important time
- Especially vulnerable if undiagnosed and there's no EHCP in place
- Can't reach age related expectations

Source: Dr Raja Mukherjee - used with permission

STAGE NOT AGE

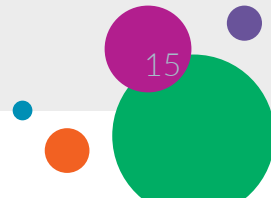


- Living in the moment – impulsivity
- Slower processing and actions
- Significant sensory issues
- Poor socialisation skills
- Poor executive function
- Need to reframe expectations in the classroom
- Need significant Trusted Adults (and peers) in all aspects of life, especially schools

Everyone with FASD is different but all are complex

Graphic source: National FASD based on real data

Slide with personal details removed



IT'S IMPORTANT TO LISTEN THOSE WITH FASD



FASD is lifelong
and people should
take it seriously
and learn more
about it



Bailie, 18





Learning can make
my body really
tired



Rebecca, 10





I can't listen to
two people at once

Teigan, 11





Sometimes my
friends don't
understand me



Peter, 11





My life is not easy

Lilly, 8

ME & MY FASD

22

Some parts of my brain don't always work or make sense of things but I've learnt how to manage things differently



Claire, 22



"I struggled at school.
My teachers didn't
understand me."

Claire McFadden
National FASD Advisory Committee



ME & MY FASD

I'm
caring

I like
singing

I enjoy
IT

I have a
strong imagina
tion

I'm
good at
baking

I'm
musical

I have
found ways to
cope

I like to
help

I'm a
good ballet
dancer

I take
care of
animals





A confusing journey

- Adopted 16 months
- Professionals all over the map due to his spiky profile, sensory/physical needs, dysmaturity,
- Increasingly struggled – behaviours escalated (violence, stealing, fire...)
- ADHD (meds help him immensely, not true for all)
- Autism diagnosis Great Ormond Street
- 100% facial features, FASD diagnosis from National Clinic when 9/10
- A constant battle to a) get into services & b) to not get booted out too quickly
- Only after EHCP, specialist school did things stabilise
- Now 18 in inclusive learning programme at college
- Musical, helping others with FASD
- We were the lucky ones, most don't get this far, even now

FASD
diagnosis
was key





**CHANGE
AHEAD**

A green diamond-shaped road sign with a white border. The words "CHANGE" and "AHEAD" are written in large, bold, white capital letters, stacked vertically. The sign is mounted on a green background.

Things are changing - fast

Schools will start to see more
with FASD diagnosis as a result
of national policy changes

2022 is the tipping point

Decades of
official indifference

2021 Local Govt &
Social Care
Ombudsman Ruling

2022 NICE Quality
Standard on FASD

2021 1st UK
gold-standard
prevalence study

2020-1st
DHSC
FASD
Grants

2021 DHSC
FASD Needs
Assessment
for England

Decades of advocacy

2020 PHE
Maternity
High Impact
Area Report

2019 Scottish
SIGN 156 Guideline

2016 CMO
alcohol-free
pregnancy guideline

BMA
2007, 2016

All major public health bodies
now on board...change is coming

<https://nationalfasd.org.uk/learn-more/policy/>

**FASD IS NOW
OFFICIALLY
RECOGNISED**

**“The government
recognises the
importance of FASD”**



Department
of Health &
Social Care

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

DHSC FASD HEALTH NEEDS ASSESSMENT FOR ENGLAND (2021)



Department
of Health &
Social Care



List of priorities to improve healthcare

1. A lack of robust prevalence estimates in England
2. The importance of multi-sector working to support individuals through the life course
3. Better training and awareness for health professionals
4. Better organisation of services to improve accessibility
5. **A need to develop innovative approaches to support those living with the condition**

“There is no
‘mild FASD’”

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



SIGN 156 (2019)

“Prenatal alcohol exposure should be
actively considered
as a possible underlying cause for
neurodevelopmental delay”



Healthcare
Improvement
Scotland

SIGN

Evidence-based
clinical guidelines

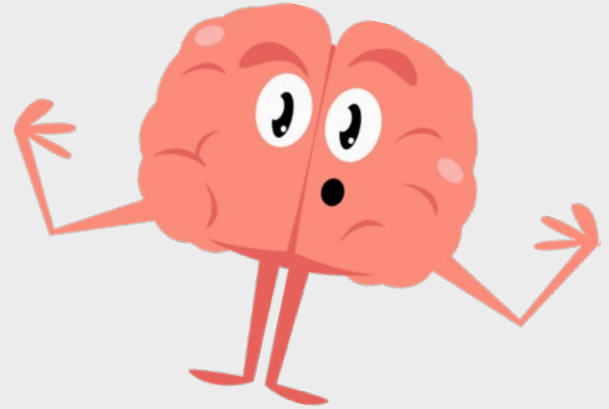
- Became the basis for 2022 NICE Quality Standard on FASD
- Now is guideline across Scotland, England and Wales

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

SIGN 156 DIAGNOSTIC CRITERIA

“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>

NEW NICE QUALITY STANDARD ON FASD (2022)

Educators take note!

Identifies areas for improving
quality of care re FASD:

- Advice on avoiding alcohol in pregnancy
- Prenatal alcohol exposure
- Referral for assessment
- Neurodevelopmental assessment
- Management plan

**"Game
changer"**

Health services will have to
show they have:



- FASD training for GPs, community paediatric services, child development centres and CAMHS.



- multi-disciplinary teams with expertise in FASD.

- referral pathways



NICE National Institute for
Health and Care Excellence

<https://www.nice.org.uk/guidance/qs204>

All CCGs (ICSSs/ICBs) and NHS Trusts have to 'have regard'
for NICE Quality Standards and report on progress



LOCAL GOVERNMENT & SOCIAL CARE OMBUDSMAN

“[W. Sussex] appears to be gatekeeping access to its services ...
The council has a duty to ensure there is sufficient educational provision available in its area to meet demand.
The lack of suitable placements for the boy in the council’s SEN schools suggests it is not meeting this duty.”

- Local area couldn’t exclude someone with FASD from services for those with “autism or severe learning disabilities”

Local Government &
Social Care
OMBUDSMAN

<https://www.lgo.org.uk/information-centre/news/2021/jul/disabled-boy-missed-out-on-education-and-support-because-of-poor-council-practice>

**THE TIME IS NOW,
ARE YOU READY?**



“There has been unprecedented work done by all major public health bodies in recent years. This work is ground-breaking...but what happens next will show just what sort of society we live in”

- 140 page report based on 9 roundtables with 60 leading paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from the Third Sector & those with lived experience

<https://nationalfasd.org.uk/learn-more/policy/innovation-best-practice/>

**YOU HAVE THE
ABILITY TO CREATE
BRIGHTER FUTURES**

**How it's been up to now
is not how it will be in the future**

are

You ~~can be~~ ^{are} part of the new wave





It's time for FASD to come into the sunlight, beyond stigma and blaming.

People with FASD have a right to understand their diagnosis. We've developed new tools to help them begin to become self-advocates.

Diagnosis is the starting point for creating brighter tomorrows.

**ME & MY
FASD**

"Resources and Training to Support Children and Young People with FASD"

A special
partnership
Seashell and
National FASD

Funded by first-ever
Dept of Health
grants for FASD



These have
been called
'world class' in
an external
evaluation

Guided by
experts &
those with
lived experience

Couldn't have done
it without them

Experts Committee

Dr Carolyn Blackburn, Education Specialist, Birmingham City University

Joanna Buckard, Trainer, Red Balloon Training, Specialist Projects Coordinator National FASD

Sandra Butcher, National Organisation for FASD

Jan Griffin, birth mother to teen with FASD, member of the EU Birth Mums group

Brian Roberts, Foster Carer/adoptive parent/former Virtual School Head, Field of Enterprise Training

Dr Cassie Jackson, Psychologist, Centre for FASD

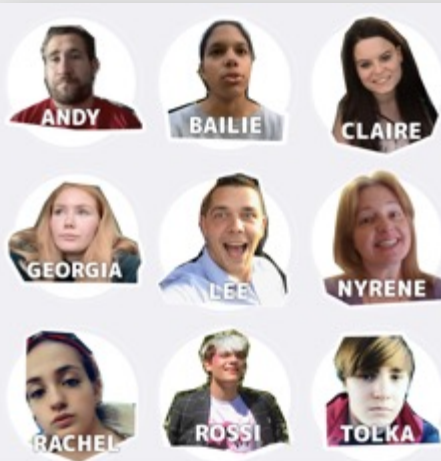
Sharon Jackson, Foster Carer/adoptive parent, Much Laughter: Standing Up for FASD, Trainer

Michelle Jones, Seashell

Susan McGrail, Foster Carer/adoptive parent, FASD Greater Manchester

Dr Raja Mukherjee, Psychiatrist, National FASD Clinic

Dr Inyang Takon, Paediatrician, E. Herts NHS



Adults and Young Adults with FASD Advisory Committee

AT THE CORE

- A new website just for young people with FASD and those who support them
- Website and all materials intentionally branded throughout with FASD – a UK first

Filling a gap, bridging loneliness, featuring positive peer-to-peer strategies & hope



www.fasd.me

**WHAT
A YEAR
!!!**

60,000
pageviews
22,000
sessions



happy 1st birthday
fasd.me

**ME & MY
FASD**



"FASD.me is such a great
resource. We now routinely
recommend it to families at our
FASD clinic"

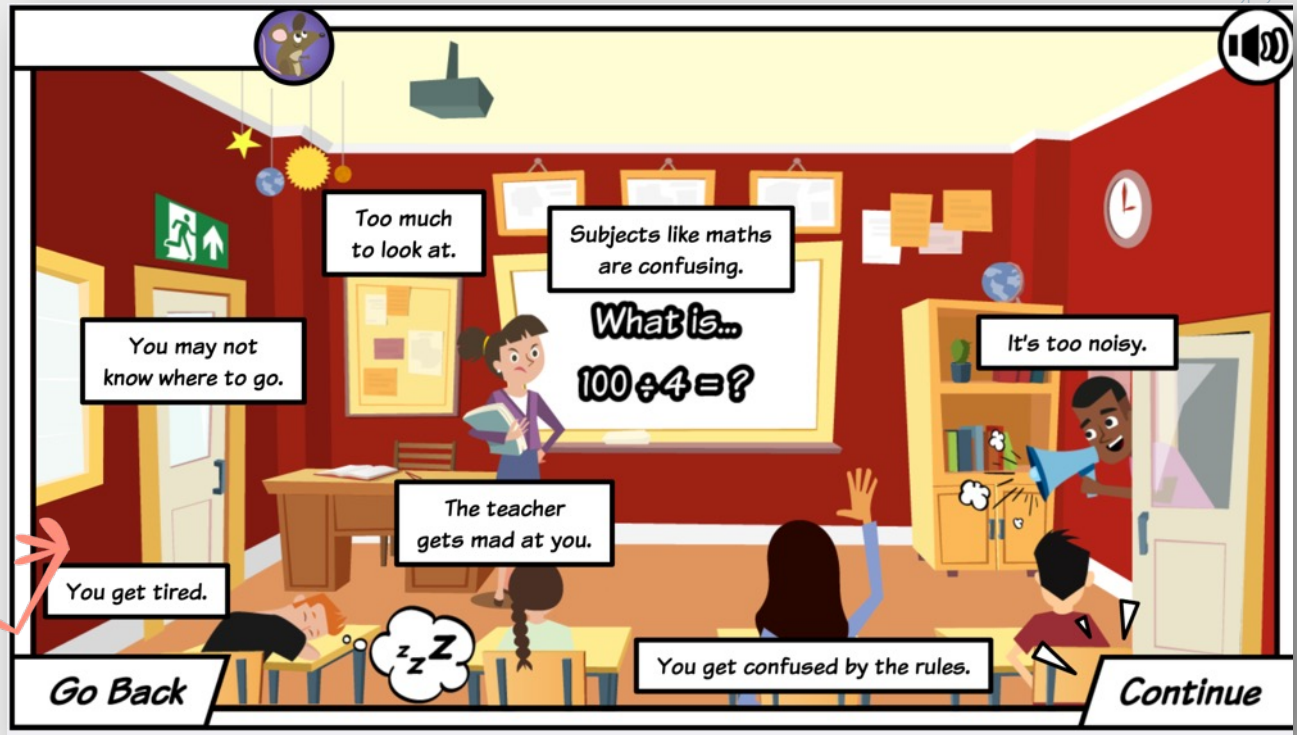
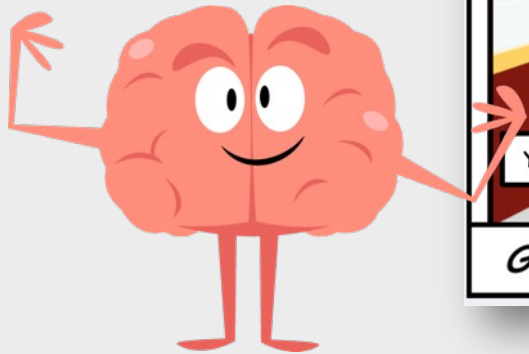
Leading International
Researcher

Quote source: Rachel Flood & Associates, [External Evaluation](#), 2021



ME & MY
FASD

INTERACTIVE COMIC



<https://fasd.me/me-and-my-fasd/interactive-comic/>

(Has personalised printable pages)



Break it down!



Where was I?



Home

© National Organisation for FASD 2021



What happened?



I shouted and swore

© National Organisation for FASD 2021



What was the cause?



What I heard

© National Organisation for FASD 2021

How did it affect me?



Angry

© National Organisation for FASD 2021



What helps?



Being left alone

© National Organisation for FASD 2021



My strengths



I can use coping strategies

© National Organisation for FASD 2021

Produced in collaboration with OurBoards OurBoards.co.uk. Design by crackajack crackajack.com

© National Organisation for FASD 2021 - nationalfasd.org.uk

- Created at suggestion of a mum
- Named by an adult with FASD



<https://fasd.me/me-and-my-fasd/coping-resources/break-it-down-board/>

www.nationalfasd.org.uk • www.fasd.me • www.preventfasd.info





Calming cards

Created with input from more than 50 young people with FASD



<https://fasd.me/funzone/games-and-activities/calming-cards/>

www.nationalfasd.org.uk • www.fasd.me • www.preventfasd.info

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





We have lots more planned for the characters!

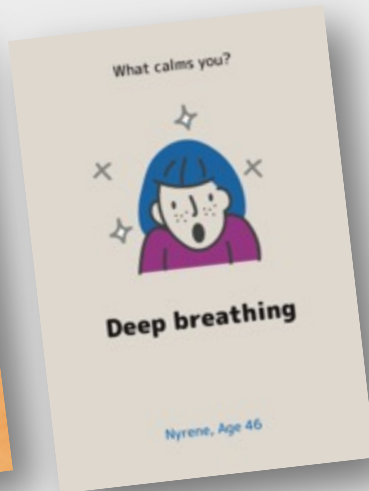


The game was suggested by Andy Jackson a young adult with FASD and its name came from our Adults and Young Adults with FASD Advisory Committee

<https://fasd.me/funzone/games-and-activities/misunderstoods-the-game/>



3 card sets to
help explore
different
aspects of
living with FASD





“... it’s amazing. The children enjoy it. It’s the first time where there’s been a game where it’s interactive, where the children can actually express themselves.”

– Dr. Inyang Takon
consultant paediatrician





Overwhelming response

Pilot and scoping exercise funded by Pears Foundation (via Contact), as part of Government's COVID response.

Seeking funding to expand it in a sustainable manner

<https://fasd.me/club/>



Everything has FASD branding





Just as we were leaving the house this morning for the school bus, he ran back into the house to get his Me & My FASD bag ... shouting as he ran "I need to show it to my teacher and I can explain what is going off in my head".

That's what it's all about!

**BULK LICENSES
ARE AVAILABLE
FOR OUR
E-LEARNING**

Introduction to FASD



NATIONAL FASD **eSCHOOL**

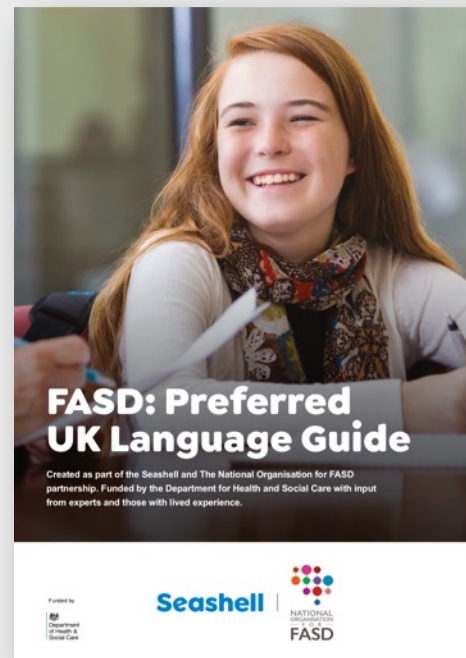
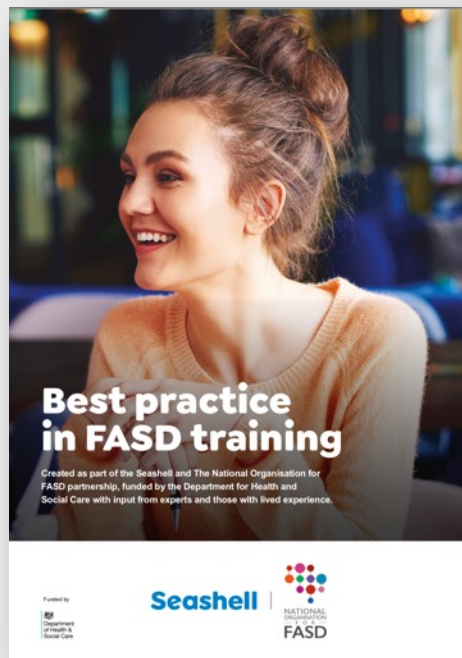
Help create brighter futures.
Bring insights about Fetal Alcohol Spectrum Disorder to your work.

☐ CPD accredited

<https://eschool.nationalfasd.org.uk>

www.nationalfasd.org.uk • www.fasd.me • www.preventfasd.info

1st step: establishing best practice



<https://nationalfasd.org.uk/learn-more/resources/publications/>

Trainings for professionals

“The 3-day training is the most child-centred I have come across”

1-day

Introduction to Supporting Children & Young People with FASD

Developed under a Department for Health and Social Care funded partnership

Seashell



Me and My FASD

Developed under a Department for Health and Social Care funded partnership

Seashell



“Walking the walk” based on the best practice

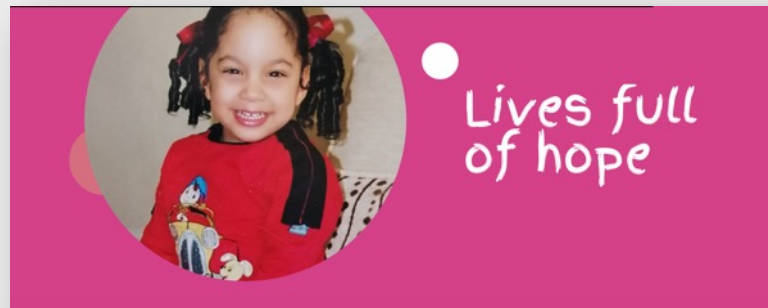
3- day – to help individuals with FASD understand and own the diagnosis (all who attend get the full tool-kit plus access to special portion of the website)

<https://nationalfasd.org.uk/learn-more/training/>

National FASD website – full of information & resources



NATIONAL
ORGANISATION
— FOR —
FASD



54



**I'm an adult
with FASD**

[VIEW](#)



**I care for
someone with
FASD**

[VIEW](#)



**I'm pregnant
and want to
know more**

[VIEW](#)



**I'm a
professional
looking for
info**

[VIEW](#)

Wellbeing

Adults with FASD

- > FASD and you
- > Diagnosis for adults
- > Health
- > Coping strategies
- > Adulthood
- > Relationships
- > Work and volunteering
- > Easy read resources

Know your rights

- > Legislation
- > Education
- > Benefits
- > Legal issues

Supporting loved one

- > Caregiver wellbeing
- > Parenting tips
- > All shapes of families

- > Birth mothers
- > Foster carers
- > Adoptive families

- > Kinship
> carers/special
guardians

- > School years
- > Transition to
adulthood
- > Medical
- > #HearOurVoices
- > Getting support

Training

- > Face to face
- > E-learning

Policy

- > NICE
- > CCGs & NHS Trusts
- > Department for
Education
- > Department of
Health and Social
Care
- > Parliament
- > APPG on FASD

Practitioners

- > Midwives
- > GPs and healthcare
professionals
- > Educators
- > Social care workers

Resources

- > Easy read
- > Research
- > Publications
- > Reports from
roundtables
- > Posters
- > Videos
- > Social media assets

www.nationalfasd.org.uk

www.nationalfasd.org.uk • www.fasd.me • www.preventfasd.info

National FASD's sister sites



NATIONAL
ORGANISATION
FOR
FASD

www.nationalfasd.org.uk

Adults with FASD
Families
Practitioners

www.preventfasd.info

15-25 year olds



**PREVENT
FASD**
.INFO



www.fasd.me

Children and young
people with FASD



<https://eschool.nationalfasd.org.uk>

Practitioners

IN SUMMARY WHAT 'S NEEDED

1. Specialist workforce training on FASD (multi-agency)
2. Diagnostic pathway for children
3. Diagnostic pathway for adults
4. FASD-informed practice
5. Prevention work
6. FASD-informed assessments (social care, education, MCA)
7. FASD support options/ management plans

“There is a need to develop services that support diagnosis and management. These can utilise existing resources, to make them more accessible to those in need. A strong economic case can be made to illustrate how cost-effective future investment could be.”



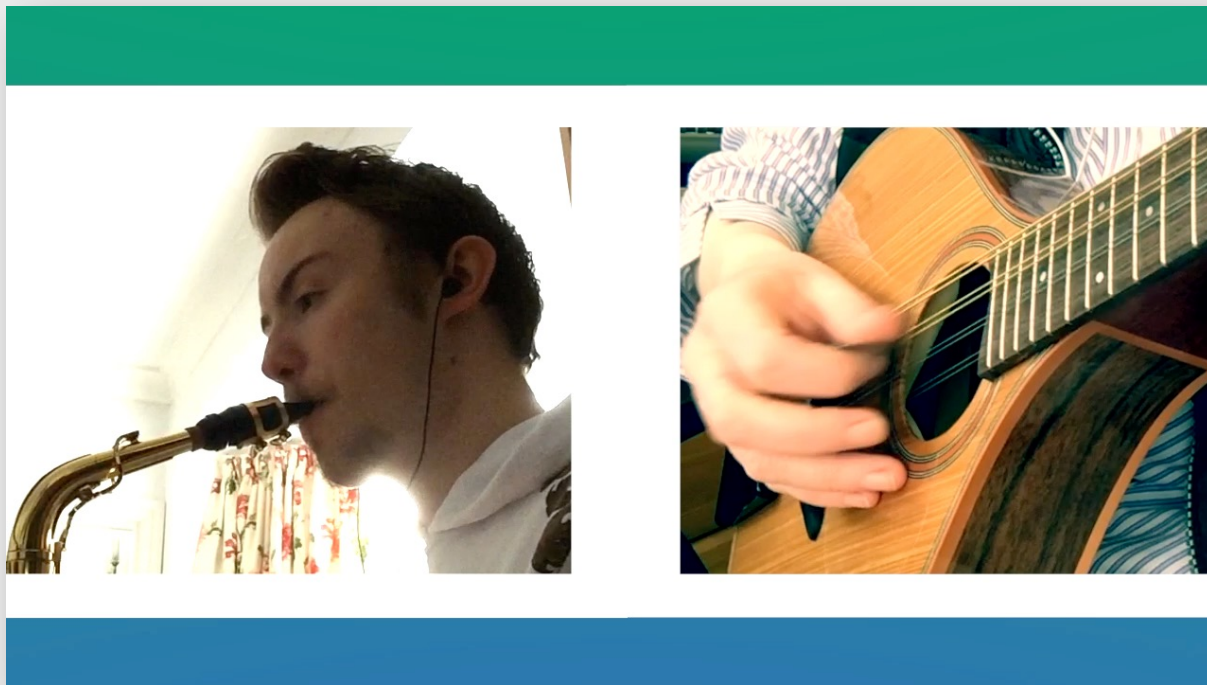
Department
of Health &
Social Care

(The National Clinic is right next door to you in Surrey...)

<https://www.fasdclinic.com>

We asked people with FASD what they want others to know about living with FASD...

#HearOurVoices
#WalkAlongWithMe



<https://fasd.me/funzone/music/walk-along-with-me/>



NATIONAL
ORGANISATION
— F O R —
FASD

