

# Living with People with FASD: A local perspective

Cambridgeshire VS  
06/03/2023

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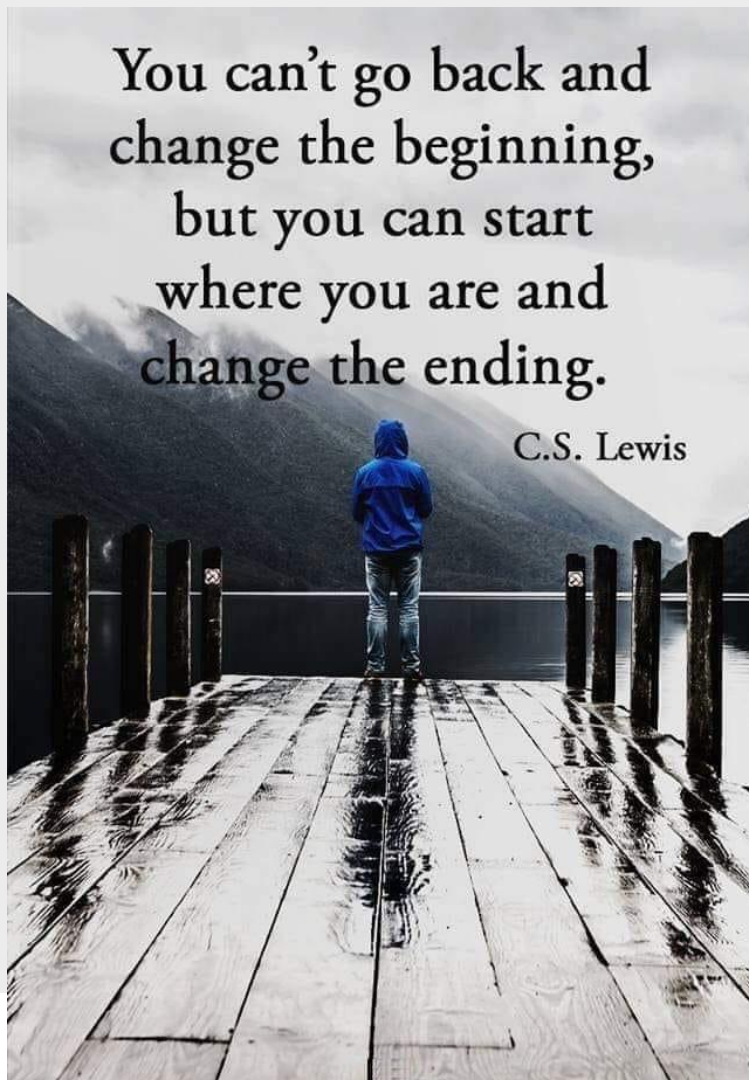


## INTRODUCTIONS

We can and  
must do  
better

You can't go back and  
change the beginning,  
but you can start  
where you are and  
change the ending.

C.S. Lewis





## WHAT WE'LL COVER – workshop

- Local issues, support information & Guidance
  - Time for personal reflection
  - Being a parent / carer (in Cambridgeshire)
  - Lessons for others in teams around the child
  - Partnership with school
- 
- Throughout the morning we will look to start to develop a plan to support children and young people with FASD and the families that they live with



**2 Years ago**

Cambridgeshire (& Peterborough) had

- 6 National experts working in the field (4 Health, 1 in education and 1 in Social care)
- Was the base for one unique national support organisation
- Hosted a regional parent support group
- Had published the only research papers on preverance in looked after and adopted children

But

- Had no pathway for Children & young people to obtain a diagnosis



Latest studies suggest that

2% – 4% of the mainstream population

Cambridgeshire

1.2 – 2.4 million  
population

with FASD  
101,031 (2021/22)

in the UK?



They are mostly undiagnosed and unsupported



## CARE EXPERIENCED

FASD is disproportional  
represented in the care  
experienced population

- The DHSC estimate that 27% of children within the care system are effected by FASD. In England alone nearly 22,000 children & young people. [DHSC FASD Needs Assessment September 2021](#)
- Research from Peterborough indicated that 75% of children assessed at adoption medicals had been subject to prenatal alcohol exposure

Gregory et al.:

<https://journals.sagepub.com/doi/abs/10.1177/0308575915594985>

## Cambridgeshire 2021 /22

597 children & young people looked after

**161** with FASD diagnosed or not

Adopted children 75% were prenatally  
exposed to alcohol  
(16% of adopted children EOTAS)

**Pupil Premium Plus funding ?**



## Cambridgeshire has it changed?

**2010 Cambridgeshire mainstream Primary 400 pupils  
5 diagnosed pupils (all in care)**

**2023 Cambridgeshire Special 60 pupils  
5 diagnosed pupils**

**Where are they?**







## FASD IS COMPLEX

- Most will have IQs in normal range
- We know that Mainstream and SEMH schools (esp secondary schools) are struggling to meet 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.”

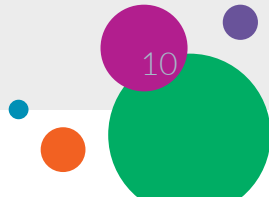
# Pen picture of a young person

Their strengths

The Challenges that they face and present

What their hopes and dreams are

What you wish to achieve



A green diamond-shaped road sign with a white border. The sign is oriented vertically, with the top point at the top. The text "CHANGE AHEAD" is written in white, bold, sans-serif capital letters, centered on the sign. The background of the sign is a solid green color. The sign is mounted on a post, and a small metal fastener is visible at the bottom center.

**CHANGE  
AHEAD**

**Things are changing - fast**  
Education 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 1<sup>st</sup> UK  
gold-standard  
prevalence study

2020-1<sup>st</sup>  
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>

[www.nationalfasd.org.uk](http://www.nationalfasd.org.uk) • [www.fasd.me](http://www.fasd.me) • [www.preventfasd.info](http://www.preventfasd.info)

# 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”



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

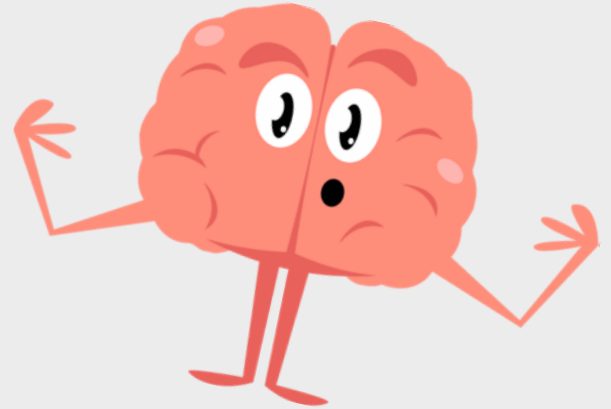
<https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol>



# 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



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

# NEW NICE QUALITY STANDARD ON FASD (2022)

Education 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”



**NICE** National Institute for Health and Care Excellence

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

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

# Parenting a child with FASD

BAAF Research Dr Raja Mukherjee et al April 2013

Lack of information

Lack of knowledge among professionals

Having to fight for things

Feeling misunderstood and blamed

Family stress and the benefits of one to one

Isolation

Concerns about the future

## These Children are different



# Educating a child with FASD

Lack of information

Lack of knowledge among professionals

Having to fight for things

Feeling misunderstood and blamed

Stress and the benefits of one to one

Isolation

Concerns about the future

## These Children are different



# What do teens think?

They fear growing up

They are confused and frustrated

They understand the challenges that they face

They worry about the future

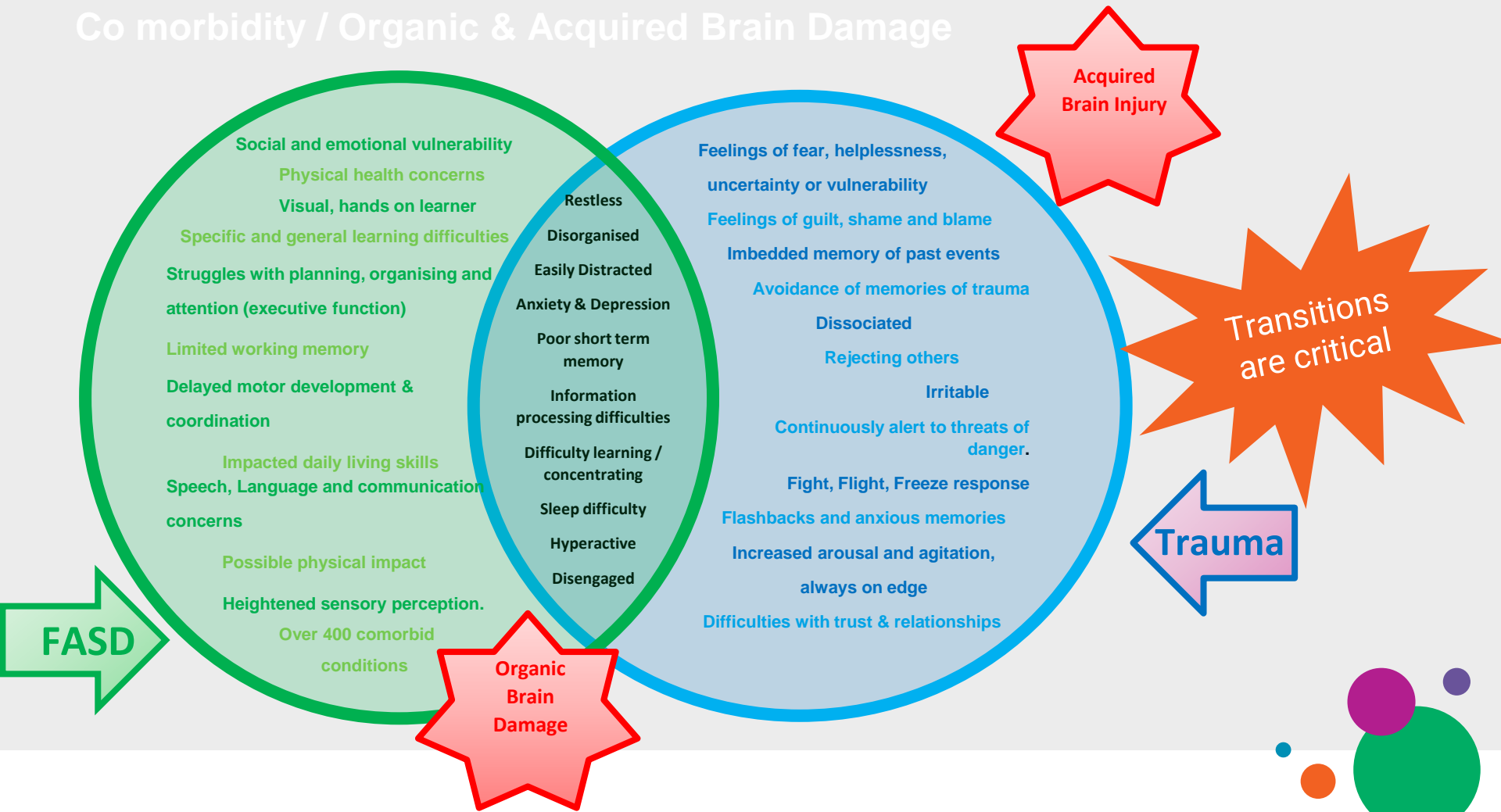
They know they can't cope and aren't in control



Bedford Borough Council  
Youth Service (Unpublished)



# Co morbidity / Organic & Acquired Brain Damage



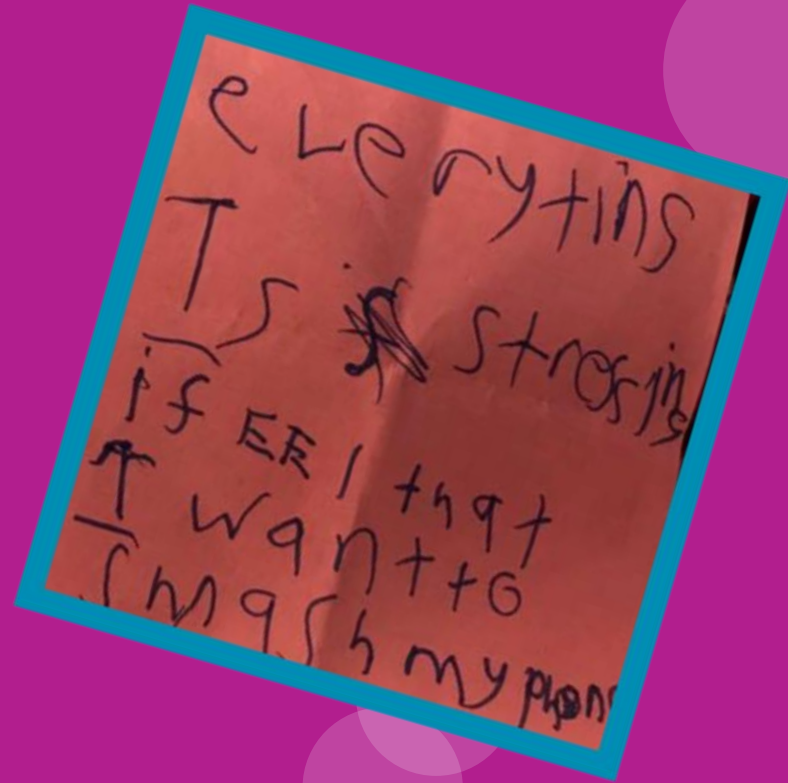


It's time for FASD to come into the sunlight, beyond stigma and blaming.

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.





**#HearOurVoices**





At 23 Full-time self-employed dog walker



# Jody

- Placed in care at 4 with siblings, un-met attachment needs and significant trauma
- Significant challenges in education but often un-noticed as always tried her best
- No knowledge of FASD in the community where she lived. Moved house at age of 10 and GP and Head Teacher both adopters of children with FASD
- Year 11 too much anxiety to take all examinations, Vocational BTEC was at Distinction
- Practical college courses for Year 12-13 in stable management and then animal care
- Passed driving test first time
- Various employments in stables & kennels and now self-employed dog walker



Now 20 but  
still life can be  
a challenge

# Georgia

- Placed in care at 15 months with older siblings, un-met attachment needs and trauma
- Significant challenges in Early years and Key stage 1. No speech until 3 years and no reading until 7
- No knowledge of FASD in the community
- Intensive work in Key Stage 2 to build friendships and basic skills
- Key stage 3 a challenge but GCSE marked a fresh start, diagnosis, EHCP
- Year 11 too much anxiety to take any examinations, but spoke to MPs in parliament 5 months later
- Practical college course for Year 12 achieved in 3 months then Apprenticeship with McDonalds where she was a part time worker
- Passed driving test first time
- Still struggles of conform to expectations mental health challenges





14 at  
Special  
School and  
football  
obsessed

# Callum

- Placed in care at 14 months un-met attachment needs and significant trauma
- Adopted at 2 but adoption broke down at 4 placed back with us in foster care now Special Guardianship
- Significant challenges in education but EHCP in Primary School
- Better knowledge of FASD in the community where he lives. Now year 10 in special school which understands his needs and is taking up most of the heavy lifting as far as FASD and education is concerned



## Others locally

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

Claire McFadden  
National FASD Advisory Committee



**What would help the young people we are considering today ?**

**What would they tell you?**

**Lets think about our next steps**





# Suggestions

ROUTINE

CONSISTENCY

RELATIONSHIPS

CHECKING FOR  
UNDERSTANDING

TRUSTED  
ADULTS

REPEATED  
INSTRUCTIONS

EMPATHY

WHAT ELSE?





**ENVIRONMENTAL  
SUPPORT**

## Minimise distractions

Trusted adult support to focus and explain

Think about visual information & cues

Pick the best times to do things & take the lead from the child / young person

A soft zone for comfort not punishment



# STRATEGIES TO TRY

A calm, nurturing environment is essential in boosting achievement & 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









## COMMUNICATION SUPPORT

Simple one step instructions and  
repeat as necessary

Chunk information (a maximum of  
2 key information carrying items)

Use positive concrete language

Check for understanding



# STRATEGIES TO TRY

Try not to use instructions that are based on imagination, an unfamiliar story or superfluous information.

**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.**

Demonstrate rather than tell children what to do and be prepared to repeat the demonstration.



# STRATEGIES TO TRY

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 becoming committed to a decision.

**Keep it short and simple (KISS) to build on what the child can already do.**





## **EMOTIONAL SUPPORT**

**Role models of trusted adult(s)**

**Praise & correction**

**Positive attitude**






**Provide space and time for  
emotional regulation**

**Teach emotional regulation and  
repeat**

**Simple emotional scale / cues**





5 Point Scale	
5	
4	
3	
2	
1	



Your emotional support plan





**EXECUTIVE  
FUNCTION  
SUPPORT**

**Trusted adult(s)**

**Supervision**

**Structure & consistency**

**Identity & Life Story**



# STRATEGIES TO TRY

Neurodevelopmental strategies - Exercise, Aerobics, resistance training, bouncing, spinning, martial arts, mindfulness

Warn of change frequently

Manage change and transitions

Break up activities, so that the affected child can have physical movement, making each activity brief







## SENSORY SUPPORT

Soft quilt

White noise / headphones/ earphones

Den or tent

Fiddle toys

Personalised distraction technics - Time on  
own interests

Occupational therapy



# STRATEGIES TO TRY

Don't rely on one strategy, be prepared to use other strategies which achieve the same end point with the FASD student.

**Give the young person time to think about the instructions you have given**

Use positive direct, consistent language in instructions and use the child's names to ensure that they understand that you are talking to them.






## Secondary Trauma

43

**‘Parenting’ an affected child is hard and we should strive not to make it harder.**

**Ensure that the parents / carers are adequately briefed about what strategies are being used and why**  
**What the realistic expectations are**  
**Good communication is vital.**

**Key people in the young persons life?**



Structured v  
Unstructured  
time

Remember .....

They can't remember

Your sensory support plan



**ME & MY  
FASD**

## “Resources and Training to Support Children and Young People with FASD”

Funded by first-ever  
Dept of Health  
grants for FASD



A special  
partnership  
Seashell and  
National FASD

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

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





# 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, FunBoards.co.uk. Design by crackajac, crackajac.com

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- 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](http://www.nationalfasd.org.uk) • [www.fasd.me](http://www.fasd.me) • [www.preventfasd.info](http://www.preventfasd.info)





## Calming cards

Created with input from more than 50 young people with FASD



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



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





We have lots more planned for the characters!

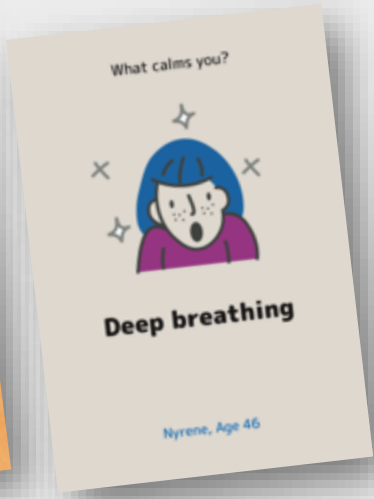
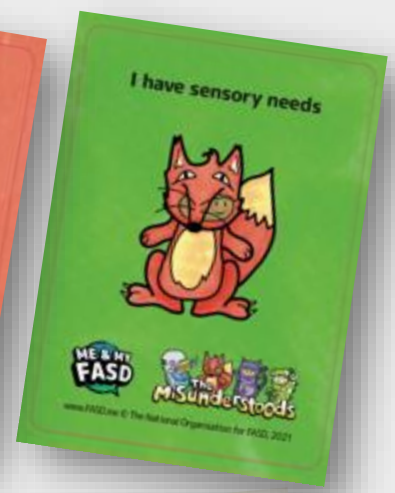


The game was suggested by Andy Jackson a young adult with FASD and its name came from our Adults and Young Adults with FASD Advisory Committee

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



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





## 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





NATIONAL  
ORGANISATION  
— F O R —  
**FASD**

