FASD & Trauma

Parenting Tips for Carers

Why it matters

You can change a life

"When you are a kid you fear the invisible monster under the bed. You can't see or hear it, but you know it's there…waiting for you… every single night. The monster. But getting the FASD diagnosis named that monster. Once the monster is named it loses much of its power."

R J Formanek, Adult with FASD, Founder, Flying With Broken Wings Facebook Group, Feb 2020. Quoted with permission.

FASD is preventable. There is no proven safe amount of alcohol to drink during pregnancy. Those affected by FASD need and deserve varying levels of lifelong support. Diagnosis is key for their own wellbeing, acceptance, self-esteem and to allow them access to relevant support and benefits.

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Understanding FASD

Is the young person in your care showing extreme, unpredictable or unexplained behaviours, sudden outbursts and issues around development or learning? Is it possible they were exposed to alcohol in the womb?

Foetal Alcohol Spectrum Disorder (FASD) is permanent and unchanging brain damage caused when alcohol exposure in the womb affects brain development. Any part of the brain can be affected in varying degrees by any amount of alcohol. It is a spectrum disorder encompassing difficulties and challenges in health, behaviour and judgement, often accompanied by co-morbid lifelong conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD), Oppositional Defiant Disorder (ODD), mental health issues and concerns around sight, hearing, development and ongoing medical problems. It's a full body diagnosis, more than 400 conditions can co-occur. Early diagnosis and appropriate support are key to creating brighter tomorrows.

What is the difference between a brain affected by FASD and a brain affected by trauma?

A brain affected by FASD has permanent organic damage and neurological dysfunction. The struggles are life-long for the affected person. A brain affected by trauma has the neuroplasticity to form new neural pathways for better long-term outcomes. When trauma and FASD mix, the result can be very complex. This brief explains why support at home and school must be FASD-informed.

Every child with FASD is different. Care and behavioural plans must be individualised, strategies flexible and creative, nurture and boundaries consistent. It takes a whole community to raise a child with FASD. Together we are stronger!

If you suspect the child in your care is affected by FASD a diagnosis is paramount. Individuals who are aware of and can accept their condition are more likely to live their best lives.

Teamwork is crucial. Ensuring appropriate support for a child with FASD is critical to avoid negative outcomes. Foster carers juggle a complex mix - the impact of the organic brain damage caused by FASD as well as the damage caused by unmet attachment needs, trauma and neglect. This makes the work that foster carers do complex. They need support from an informed team around the child. This means that all of the various plans for a child must complement each other and provide consistent approaches to what is to be achieved. It also means social workers working with the family need to understand FASD.

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FASD affects children in care disproportionately, but it's little understood

FASD is believed to affect more people than autism. It's been called a "hidden epidemic." The UK is 4th globally for drinking alcohol in pregnancy, with more than 40% drinking in pregnancy*. One study** led by Dr Ges Gregory in Peterborough found a history of prenatal exposure in 55 out of 160 health assessments for looked after children (34%) and in 34 out of 45 medicals for adoption (75%).

That said, FASD affects individuals from all walks of life. Some international studies have found that older, educated women are more likely to drink in pregnancy.

NICE Quality on Standard on FASD

A NICE Quality Standard (January 2021) identifies areas where quality of care for FASD diagnosis and support should be improved. That mean's it's time to train up.

* See: Popova, DOI:https://doi.org/10.1016/S2214-109X(17)30021-9
**Gregory, https://doi.org/10.1177/0308575915594985

"As Foster Carers, understanding FASD empowered us to embrace new approaches, reach out to connect with other families and access our local support group to build our knowledge. Parenting our children 'traditionally' was not working; but by changing our views and environment and listening to the boys' needs made their lives, and ours, so much easier."
- Sue and Tony Sharp, Hertfordshire

Learning by doing
Role play may be a useful tool. Try practising appropriate behaviours, maybe before a specific situation or transition that may be challenging, or after a situation where behaviour was not appropriate. Try 'mirroring' the child's behaviour. Meet them 'where they are at' and show them the way out.

Can we talk about consequences?

Children affected by FASD often react badly to consequences and may not learn from them. Due to their brain-based issues and lack of understanding of cause and effect they will often make the same mistakes over and over and repeat them in different environments. Modelling behaviour rather than punishment is key. Natural consequences can be effective (if a toy is thrown and breaks, it goes in the bin and the child can't play with the toy).

In school, consequences must be concrete, immediate and simple i.e. - removal of an item in short bursts only; maybe aided with a visual timer to help allow for lack of concept of time. It is not advised to remove a treasured item like an electronic device that might also help self-regulation. Difficulties with memory and linking cause and effect means a child is not able to understand why they are being punished, which can lead to further challenging behaviour. Always be positive. Encourage and teach wise choices.

Cognitive effects

Executive functioning
Difficulties with planning, sequencing, problem solving, organisation, task initiation, flexibility control, prioritising, impulse control, emotion, self-monitoring, transition, consequences, abstract ideas and time. Choices can be difficult.

Sensory and motor skills
Hypervigilance, over/under sensitive to sensory input (noise, touch, smell, taste, and light/dark). May not be able to make sense of what is going on around them.

Living and social skills
May be vulnerable and easily taken advantage of. May not understand personal space, boundaries or approach strangers inappropriately. Lack of sense of danger. Often act half of chronological age. Will have poor judgement.

Focus and Attention
Often in 'fight or flight or freeze' mode. Impulsive, hyperactive, unregulated and overstimulated.

Cognition
Difficulties with reasoning, memory, planning and readjusting.

Communication
Delayed speech, slow processing, difficulties following instructions, may speak/read well but not understand content.

Memory
Difficulties with short or long term memory, unable to recall instructions and will learn better from 'visual memory'.

FASD & Trauma

Top Tips

1. Consider self-care and caregiver affect management. The better position you are in mentally and physically, the better placed you will be to help the child in your care. Be mindful of your wellbeing. Recharge your own batteries. Talk to others. Share your experiences with professionals. Investigate support groups and peer support. Eat healthily, exercise regularly and stay positive.

2. Use the 'halve their age' rule. Meet them where they are at socially and emotionally. Pitch expectations about behaviour and their need for supervision and support to that age rather than chronological age. Your child with FASD will need you to be their support person/coach. Fill in the gaps they cannot. Calm their insecurities. Guide and reassure them. 'Risk assess' each given situation for them.

3. Give constant supervision to keep them safe. Help them make the right decisions. Due to their cognitive challenges they need to develop habitual patterns of appropriate behaviours to keep them away from danger and help them to reach their full potential.

4. Be attuned. Pre-empt tricky, uncomfortable or overwhelming situations. New experiences need careful and therapeutic management. Listen to your child. if they tell you "I don't know," believe them. Don't jump to any conclusions around them 'lying'. They are probably filling gaps with confabulation. "I am bored" could mean they don't know what to do next. "Help me" could simply mean "stick around/be near me and guide me" rather than intervene/takeover.

5. Allow them time to process questions and instructions. It can take them 30-40 seconds to process and answer. Give them time to get ready to leave the house or go to bed. Give them limited choice. Ask them what they need to do before they can end one task to move onto another and help them do it. Use visual timers and planners.

6. Remember children traumatised and living with FASD are hypervigilant. They know your mood before you do! Always act calmly (even if you are not inside). Keep your voice lower than theirs. Smile more. They will also notice what is new or changed in their surroundings. Put away items you don't want them to see or that may tempt them.

7. Choose your battles! Does it really matter if they want to eat at a different time/place/setting? Or if they want more than one toy out? If they want to stay in all day on a weekend?

8. Build on their many strengths and use a rotation of strategies to bring distraction, patience, humour, positive reinforcement and reward of good behaviour into the daily care of your child with FASD.

9. Environment will influence how children with FASD behave. Adjust the surroundings to what they need. Provide sensory toys – many will have sensory issues. Less is often best. They may be easily overwhelmed and overexcited. Hyperarousal may suddenly cause high alert (fight/flight/freeze). When anxiety is up, impulse control goes down.

10. Teach your child to help themselves self-regulate. Breathing techniques. Crossover exercises. Deep pressure like pushing against a wall or jumping. Count backwards. Blow a harmonica. Engage all senses. Create a calm space. Have fun together.

Trauma

- Feelings of fear, helplessness, uncertainty & vulnerability
- Avoidance of reminders of trauma
- Emotional numbing, becoming withdrawn
- Feelings of guilt or shame
- Dissociated, feelings of unreality
- Continually on alert for threat of danger
- Unusually reckless or at risk behaviour
- Difficulty with trust & relationships
- Rejecting others before they have a chance to be rejected
- Flashbacks & anxious memories
- Physical sensations, pain, sweating, feeling sick or trembling
- Re-enacting traumatic events in thought or play

(Adapted from "Fetal Alcohol Spectrum Disorder and Complex Trauma", Marninwarntikura Women's Resource Centre, 2018. This excellent resource is available here: https://mwrc.com.au/pages/mwrc-blog. It cites "Trauma and ADHD" by the National Child Traumatic Stress Network as inspiration for the chart.)

Overlap

- Disorganised
- Difficulty concentrating
- Difficulty learning
- Easily distracted
- Difficulty processing information
- Hyperactive, restless, hyperarousal
- Negative thoughts
- Irritable, quick to anger
- Difficulty sleeping
- Disengaged
- Increased arousal
- Edginess & agitation
- Eating disorders
- Anxiety/depression
- Disruptive, destructive, difficult or controlling behaviours
- Regression
- Physical symptoms; headache or tummy ache
- Nightmares
- Low self-esteem, lack confidence

FASD

- Specific & general learning difficulties
- Difficulty with planning
- No understanding of cause & effect
- Poor executive functioning skills & mental flexibility
- Slow processing
- Trouble understanding abstract concepts (time, maths, money)
- Poor short term/working memory
- Social and emotional vulnerability
- Speech and language delays
- Behavioural difficulties/defiance
- Abnormal sensory perception
- Delayed co-ordination & motor development
- Poor adaptive skills
- Vision & hearing issues
- Autistic traits
- Difficulty with transitions
- No impulse control/inflexibility
- Unknown/invisible disorder
- Confabulation ('lying')
- Other related physical conditions

A trauma-informed care model for those with FASD builds on brain-based strategies

People with FASD are vulnerable to further trauma. They experience sometimes even small things with far greater subsequent impact. FASD-informed brain-based strategies protect against further compounding trauma.

FASD & Trauma

Parenting primarily for trauma or attachment may backfire

New research shows that, without overlooking trauma, using strategies for FASD might be best

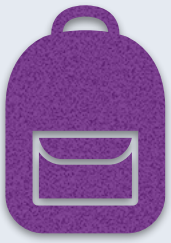
A recent study from Alan Price (Oct 2019) concluded that if a person has FASD and has experienced trauma, they tend to be functionally more similar to children with just FASD than they are to children with just trauma. Without overlooking trauma, it may be best to think of these children's difficulties as being caused primarily by prenatal alcohol exposure and to use strategies that are designed for FASD. Parenting should be mainly therapeutic and can be learned through relevant training groups and book publications but needs to be amended to suit each individual with FASD. Traditional parenting strategies for trauma or attachment may backfire on a child with FASD as these strategies concentrate more on rebuilding neuro pathways for different outcomes.

Source: Price, https://tinyurl.com/PricePhD

Education

Carers need to work closely with educators and professionals

Most children and young people with FASD will not have a learning disability (an IQ <70), but to achieve they will need considerable individualised support as if they had a learning disability. The older they get the more obvious this is likely to become. All children on the FASD spectrum learn in non-traditional ways. Their profiles are 'spiky'. They likely will have difficulties with maths, reading, time, money, organisation, abstract ideas and age appropriate tasks. Receptive language (what they understand) is often masked by strong expressive language (what they say). They will often learn better in a multi-sensory way. Music and movement helps. They will need learning tools, now/next boards, visual prompts and fewer spoken instructions. Information will need to be repeated.



Looked After Children with FASD will need therapeutic personalised education rather than following a normalised curriculum. The key tool will be the personal education plan - a formal educational assessment that is made each term and allows relatively rapid changes to take place. It must focus on and develop the student's learning needs and strengths rather than following what would be expected of a typical child of their chronological age. Specialist schooling is often more suitable due to therapeutic teaching practices, relaxed curriculum, smaller classes and easier transitions between lessons. Mainstream schools should have robust SEN support and designated virtual school teachers to help a student with FASD succeed. Children are likely to need an Education, Health and Care Plan. Schools are required to make 'reasonable adjustments.' Learning difficulties may lead to frustrations and unwanted behaviour. Challenging behaviours are a communication of an unmet need.

FASD-informed parenting

- **Think brain damage.**
- **Be curious and ask what is happening for that child at any given moment.**
- **Listen. They will be telling you what they need but it will not always be easy to ascertain. Adjust your expectations.**
- **Be ready to change the environment, you can't change the child's brain.**

Children with FASD do best when caregivers and educators use concrete terms and avoid phrases with double meaning, i.e. 'jump onto the computer', 'it's raining cats and dogs'. Say exactly what you mean. Keep instructions concise and broken down into achievable chunks. Social and emotional understanding is often less than chronological age so we often need to think younger. Consistency of boundaries and routines are imperative, chronic short-term memory problems bring the need to repeat, repeat, repeat instructions and knowledge for better understanding. Input should be short. Children with FASD are easily overstimulated leading to shutdown at which point they can take in no more information. When children are also living with trauma this shutdown effect is exasperated. Structure is the glue that enables a child with FASD to make sense of the world.

Adapted from https://www.sign.ac.uk/assets/pat156_fasd.pdf

For more information please see the National Organisation for FASD (www.NationalFASD.org.uk), the local support group in Hertfordshire (https://ehertsfasd.wordpress.com) or find other local groups via the FASD UK Alliance (fasd-uk.net). Online support can also be found on Facebook at FASD UK. To start the diagnostic process, contact your GP/CLA Nurse.