



# An Information Leaflet for Parents and Carers of Children who Have Received a Diagnosis of Foetal Alcohol Spectrum Disorder FASD

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## Living with and Supporting a Child with Foetal Alcohol Spectrum Disorder (FASD)

Foetal Alcohol Spectrum Disorder is an umbrella term, under which several related diagnoses sit. At the more severe end of the spectrum is Foetal Alcohol Syndrome (FAS), which means that a child has physical and cognitive markers associated with alcohol exposure. Physical markers can mean characteristic facial features, and also deformities of various organs associated with alcohol exposure, such as heart or kidney problems. Children who do not display any physical traits of FAS but who demonstrate many of the associated cognitive difficulties are often reported to have Alcohol Related Neurodevelopmental Disorder (ARND) or Foetal Alcohol Effects (FAE). For the purposes of this leaflet the term FASD will be used, to encompass all forms of this condition.

Parenting a child with FASD can be challenging. You can probably tick off a number of items from the list below in terms of some of the difficulties you may notice in your child:

### **Children with FASD**

- Often struggle to regulate their behaviour and can 'jump' from one extreme emotion to the other in a matter of moments.
- Can find it difficult to separate reality from fantasy.
- Have a tendency toward fabrication and not telling the truth.
- Have difficulty planning and completing projects independently as they tend to get stuck on certain parts of tasks without seeing the bigger picture.
- Find independent problem-solving very difficult without support.
- Struggle to communicate details in an organised and sequenced manner.
- Have problems initiating activities and organising themselves in order to begin.
- Struggle with planning their actions, or implementing plans that they have made.
- Usually have working (short term) memory problems, although long term memory can be much better.
- Have difficulty with abstract concepts such time and money.
- Tend to struggle significantly with maths in school.
- Can become quite obsessive or 'stuck' on certain issues or topics.
- Struggle to follow instructions – particularly if there are several steps to the instructions all at once.
- Can appear impulsive in their behaviour, with a lack of social awareness.
- Can behave socially inappropriately without recognising this .

- Can be over-familiar with others, and unaware of personal boundaries .
- Are often socially immature and gravitate toward younger children rather than their peers.
- Find it difficult to adapt their behaviour from one setting to another.
- Have significant problems with sustained attention and can be highly distractible
- Can have sensory issues such as problems with loud noises, lighting, touch, and textures.
- Find it difficult to learn from past mistakes and so often repeat these time and time again with little insight or learning.
- Struggle to fully understand and reason through consequences of actions.
- Have little danger awareness and therefore require higher levels of supervision than would be expected for their age.
- Can be extremely hyperactive, which in some warrants a diagnosis of attention deficit hyperactivity disorder (ADHD). (This is a fairly common manifestation of FASD).

### Why does my Child with FASD have these Problems?

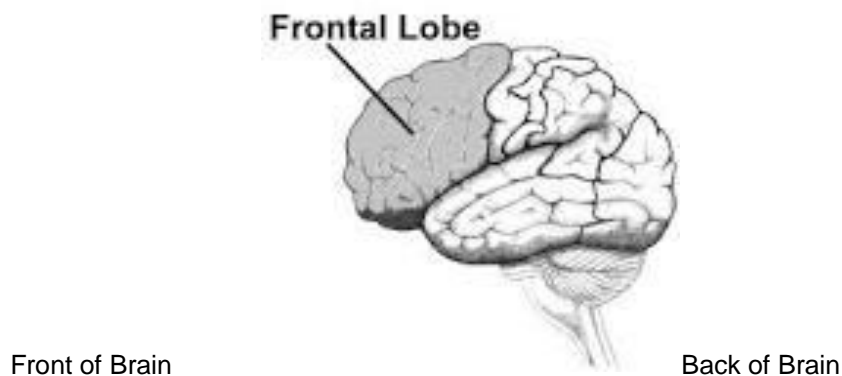
When a baby is exposed to significant quantities of alcohol in the womb, it causes organic brain damage. It can also damage other parts of the central nervous system and vital organs, but this sheet will focus on the effects that alcohol has on the developing brain. Many children who have FASD have been exposed to other harmful substances in pregnancy also, such as cigarette smoking and other drugs. While these have their own set of adverse effects on a baby, none are as severe as the effects of drinking alcohol. Alcohol is known to be the most damaging substance of all to a baby's developing brain.

Alcohol damages the developing brain in a number of ways:

- It damages the frontal lobes, causing what is known as an 'executive functioning impairment'. This will be explained below, but is the cause of many of the behaviours on the list above.
- It causes working memory problems, which means that a child frequently struggles to 'hold' information in the short term, for example to solve a mental arithmetic question, or follow a set of instructions such as 'go upstairs, put your pyjamas on and bring down your reading book'.
- It causes disorganisation in the way different parts of the brain connect and 'talk' to each other, which can mean that the speed of thinking and problem-solving in a child with FASD is slower and often disorganised. This means that the brain of a child with FASD needs to work so much harder than the brain of an unaffected child at just about everything. This causes them to become a lot more tired and over-stimulated.
- It causes problems with understanding language. Often children with FASD have reasonable expressive language (the words they use), but their understanding of what others say to them is more problematic, especially when people use sarcasm, irony, or abstract language. This can cause confusion and misinterpretation, and can mean others believe they are more able than they really are.

- It can cause a general learning disability for some children, while others will have a normal IQ, but still have impaired executive functioning.
- It can cause difficulties with sensory processing
- All of these problems together can make for an anxious, confused and overwhelmed child, who then will 'act out' as a result, and therefore behavioural difficulties are very common in children with FASD. These behavioural difficulties must be understood within the context of brain damage.

### What is an Executive Functioning Impairment?



Executive functioning predominately, but not exclusively, is controlled by the frontal lobes of the brain; that is the front part of the brain behind your forehead. Children with FASD invariably have an executive functioning impairment because their frontal lobes are damaged.

Executive functioning difficulties are also present in other diagnoses such as autism and ADHD, and this can lead to confusion and misdiagnoses in some cases prior to arriving at an FASD diagnosis. There are however, subtle differences which mean experienced professionals should usually be able to tell them apart. FASD is a greater 'mimicker' of other neurodevelopmental disorders, which is why it is so important to have an accurate history of your child's neonatal experience as well as their current difficulties. This is not always easy if your child is adopted or fostered. There are cases of course, where a 'dual diagnosis' of both autism and FASD is appropriate.

The term 'executive functioning' describes a set of cognitive abilities that control and regulate other skills and behaviours; both socially and academically. Executive functions are necessary for goal-directed behaviour; they are the self-monitoring system of the brain, much like the hard-drive of a computer.

Executive Functioning Includes:

- The ability to initiate and stop action appropriately
- The ability to monitor and change one's own behaviour when necessary
- The ability to plan future behaviour when faced with novel tasks and situations, drawing on past experiences and imagined consequences.
- The ability to think in an abstract and theoretical way about things.
- The ability to behave in an appropriate manner as a result of knowledge of the subtle nuances that make up the social world, and our ability to regulate our behaviour accordingly.

Normal executive functioning is vital for successful adaptation and performance in day to day life. It is often split into two discreet parts for easy understanding, called 'hot' and 'cold' processes. Sometimes children can have impairments in both areas, and sometimes one area can be significantly more impaired than the other.

*Cold Executive Functioning Problems Include Difficulties with:*

- Planning
- Sequencing behaviours and routines
- Working memory
- Switching between tasks
- Inhibiting action
- Attention and concentration
- Initiation
- Organisation

*Hot Executive Functioning Problems Include Difficulties with:*

- Social immaturity
- Hyperactivity
- Emotional regulation (hence aggressive and angry outbursts)
- Socially inappropriate behaviour/disinhibited behaviour
- Social naivety and vulnerability

Many of the problems associated with FASD are the result of this executive functioning impairment.

### Common Difficulties

FASD is a lifelong condition which is caused by organic brain damage. The best way to help your child to reach his or her full potential, is to understand that because of their executive functioning deficit and other difficulties, you and trusted people around them (for example teachers in school) will need to be their 'external' brain, in order to help them to remain organised, regulated, and safe. Building up a repertoire of compensatory strategies to support your child will enable them to be as independent as possible.

### *Dealing with Behaviour Problems*

A common question asked by parents who have a child with FASD is, why does my child keep repeating the same mistakes over and over? Why do they not seem to learn?! The short answer to this is that FASD is essentially an inhibitory control disorder. Children with FASD largely live and act on the here and now; not what went on before - and hence their impulsivity which tends to land them into trouble. They frequently fail to draw upon previous experience in order to calculate the possible consequences of their present and future actions, and in novel situations their difficulty with flexible and abstract (theoretical) thinking means that they also struggle to imagine what might go wrong!

Given that we cannot change this impulsivity and inflexible thinking as it is a part of your child's FASD, what we need to do instead as far as possible, is adapt the environment around them in order to minimise the chances of the undesired behaviour from happening or having a significant impact when it does. When we can, we need to remove the impulse

that causes the negative behaviour, and use compensatory strategies to manage it – rather expecting the negative behaviour to stop all by itself.

One of the key reasons for meltdowns in children with FASD is over-stimulation. This is often why children struggle with their behaviour in a busy classroom setting at school. Children with FASD are often hyper-aroused from the outset due to the noise and general activity level because of their sensory sensitivity, which makes it even more difficult to concentrate on their work with so many distractions. They are then expected to listen and remember lengthy instructions and to be able to initiate and plan out independent work as an outcome of these instructions, and/or to solve mathematical problems independently; all of which they will find extremely difficult because of their executive functioning deficit. It is then not surprising that something seemingly small may then at times push your child into a behavioural outburst, which again their executive functioning deficit means that regulating and being able to interpret their own emotions is extremely difficult for them, as is being able to calm down following an outburst. Other's interpretations of this behaviour may create and reinforce a very low self-esteem, especially if they do not have much understanding about FASD.

Below are some suggestions to help minimise over-stimulation:

### *In school*

- It is important that teachers recognise that children with FASD often have sensory difficulties similar to children with autism and where possible, adapt the environment accordingly.
- Many children with FASD benefit from being taken into a smaller group situation to learn when this is possible, in which it is easier for them to concentrate and participate.
- Keep rules and expectations as consistent as possible as a child with FASD may struggle when behavioural expectations are different from one lesson or setting to the other. This is true of home life also.
- Positive reinforcement is really important in terms of helping a child to remain on task without giving up, and to feel good about what they are achieving.
- For many children with FASD there will be times in the classroom when everything becomes too much. Having a 'calming down zone' (which is qualitatively different to 'time out'; i.e. not a consequence for negative behaviour) where they know they can go when over-whelmed can be helpful in terms of helping children begin to recognise when they need to retreat a little before things become more difficult. A child may perhaps be given a number of 'calming down' cards at the beginning of the day for example, which they can use when needed. This can help to prevent more dramatic meltdowns in the long run.
- For some children who perhaps do not require this or are too aware of appearing 'different' to their peers by using such support aids, teachers may begin to recognise when they are becoming fidgety or agitated and assign them a little 'job' which may involving a quick walk to the office and back if this is appropriate, or even just something at the back of the classroom sorting out equipment – anything that enables a subtle break from the situation.

### *At Home*

- A 'calming down zone' works equally well at home too. It is especially successful when your child has had a hand in creating it just how they want it, with their own cushions or soft toys inside, which feels comforting. Many children with FASD appreciate feeling

'contained' within a small space, which helps them to calm down and feel safe. It is important that your child's 'calming down zone' is not confused with a 'naughty step' or 'time out'. The key aim with the 'calming down zone' is to help children begin to recognise when they are becoming dysregulated and to arm them with strategies to use in order to learn how to better self-manage. This does not happen overnight of course.

- Keeping expectations about your child's behaviour predictable is extremely important, as for at school.
- Using visual timetables and planners can be a good means of helping your child to feel less anxious about what is going to happen next and to feel a sense of control over their day.
- Using appropriate strategies as detailed below for the various difficulties associated with FASD will all serve to minimise stress for the child, and thus minimise behavioural meltdowns over time.

### *Dealing with Working Memory and Attention Problems*

Children with FASD frequently have problems with their working memory. Working memory is a form of short term memory that allows us to do things such as maths tasks in school, or to remember instructions in our heads as we carry them out. It is a means of holding information in mind while simultaneously manipulating that information to create a response before it is forgotten. Mental arithmetic and learning to read both rely heavily on working memory ability, which is why both skills can come slower to children with FASD. Maths is often a life-long weakness.

Closely related to working memory, is attention. Again children with FASD invariably struggle to sustain attention, and are frequently described as distractible, fidgety, and inattentive.

It is worth noting that some FASD children have such significant attention difficulties together with hyperactivity and distractibility, that they warrant an additional diagnosis of ADHD, and can be medically treated for this. An ADHD-like presentation is a fairly common feature of FASD, and in most cases it is appropriate to regard this as an associated rather than primary diagnosis. The primary diagnosis is FASD, which has brought about the ADHD.

Below are some strategies to help with working memory and attention problems day to day:

- Provide visual schedules and review them during the day. This will help with memory and executive functioning problems, and reduce anxiety. This can be done discreetly for older children, either on a tablet, on a phone, or on a small laminated sheet to carry around in a school bag for term times.
- Use planners for homework and other jobs, which need to be overseen by you as a parent/carer, and your child's teacher at both ends. Do not assume that a child with FASD will have taken in and written down homework tasks fully themselves – this needs to either be checked by the teacher, or be provided directly to their parents in the form of a printed handout.
- Try to keep routines relatively predictable.
- Create checklists and "to do" lists for jobs at home, hobbies, etc, which can be ticked off when completed.

- When asking a child with FASD to do something or giving them instructions, keep to one step at a time and praise each completed step.
- The key to your child's learning is repetition. They are likely to need to 're-learn' new facts and processes repeatedly in order to optimise the chances of them being committed to long term memory. If new information is not rehearsed regularly, do not be surprised if this new information is 'lost', which then necessitates the need to start over. It is better to plan time during each week to repeat newly learned information and facts (for example, mathematical rules, times tables, spellings) to optimise the chances of these being committed to long term memory.

### *Managing Difficulties with Planning and Organisation*

Difficulties with organisation and planning are very common. Many children struggle to sequence their daily routines such as toileting and dressing, and find themselves in a muddle by missing out steps, doing them in the wrong order, and so on.

This can be difficult in school also, particularly as a child moves into secondary school, when they are expected to work on larger projects independently. Some children are able to verbalise an appropriate plan to a teacher or parent, but their executive functioning deficit means that they cannot necessarily follow this through, and instead they 'lose' the thread of what they are doing.

Below are some suggestions to manage planning and organisation problems:

- For children who can make a good plan of work but are not able to initiate beginning it, or lose what they are doing half way through; they will need support in terms of creating a structure with concrete steps and frequent prompts, as opposed to just leaving them to it.
- Many FASD children's problem-solving ability is described as 'perseverative' in medical reports, which essentially means it becomes repetitive and 'stuck', so that in spite of having an awareness that what they are doing is not working, they are unable to move their thinking on. They therefore repeat the same actions over and over. This is where the idea of requiring an 'external brain' comes into effect; they will need external support in moving their problem solving on. This 'stuckness' is a direct consequence of executive functioning impairment. Giving clear step-by-step instructions for work, with visual aids if possible can help with this. Children with FASD often struggle to make logical leaps to know what to do by themselves.
- A common misconception in school is that if a child can verbalise what they need to do, then it follows that they can put it into action. Please refer to the points above!
- Shifting rules can also be difficult for children with FASD. This is important to bear in mind during maths tasks, where a child may struggle to remain on the current rule without lapsing into previous ones. Similar issues can happen when learning to read.
- Be as explicit as possible with expectations, with visual prompts and clear language.
- Coursework in secondary school will require extensive support. Breaking long assignments into smaller tasks with mini-time limits for the completion of each one systematically is important. If this support is not provided, a child with FASD is likely to feel extremely over-whelmed and unable to know where to even begin.
- Simple things such as working at a clutter-free desk or table with minimal background noise can make a big difference.



- Difficulties with sequencing routines such as washing or dressing, can be helped with visual time tables in the bathroom, in the bedroom and so on.

### *Speech and Language Problems*

It is common that a child with FASD can present as outwardly capable and articulate, which often leads people to assume they are more able than they actually are. This is why FASD is so frequently coined an 'invisible disability' as the lay person would often not see a child with additional needs when they look at and even speak with many children with this condition. Beneath this outward appearance however, is a child who frequently struggles to understand what is said to them, as they have difficulties processing complex and abstract language such as pragmatics, irony, and other abstract concepts that we use day to day. Much like children with autism, children with FASD will often struggle to translate the little sayings we take for granted; 'how many times have I told you...' and 'Christmas is just around the corner' as two examples.

The more concrete thinking seen in children with FASD can be one of the causes of misinterpretation within a classroom setting too, which can cause the already hyper-alert and anxious child to become further dysregulated, and subsequently react in an aggressive and defensive manner.

It is therefore important to speak as clearly as possible to a child with FASD, avoiding abstract phrases where possible, and keeping instructions to as few key words as possible. For example, rather than saying 'Alice, you need put your shoes on before you go outside to play, otherwise you will get dirty socks'.. A simpler instruction: 'Alice, first shoes, then play' is likely to get better results and bring about less frustration all round.

For schools, all autism-friendly language strategies will work well for children with FASD too.

### *Managing Social Immaturity*

Children with FASD are invariably rather immature when compared with their peers, such that they behave like a younger child. Because of this they are often more comfortable playing with younger children. This social immaturity is a manifestation of their executive functioning difficulties. A suggestion for all parents and carers of children with FASD is to halve your child's chronological age in your mind - this is where they are functioning socially. Therefore a child of 10 probably has the social skills and social understanding more in-keeping with a five year old, and so on. Reminding yourself of this when a child is 'acting up' and tantruming well beyond the age one might expect them to, can help reduce frustration all round. It is important to keep your expectations at this level, rather than at the level their chronological age might otherwise dictate. This 'half age' level is the level at which a child with FASD is able to respond to you socially, and at which they are able to understand.

Another factor to keep in mind is that children with FASD may not generalise one social rule across different situations, such as from one birthday party to another or from one meal out to another. Therefore again repetition in different circumstances is key. It can be useful to reiterate what behaviour is expected prior to entering social situations. Give your child cues about how to behave in different circumstances in order to help them to be better prepared. You are their external brain and scaffolding and can help them to function appropriately. Children with FASD require significantly more supervision than their peers in order to remain on task and safe. This is discussed in more detail in the section discussing independence below.

Having said all of this, it is also worth remembering that inconsistency in behaviour and performance is normal for all children!

### ***Lying and Fabrication – and the difference between them!***

It is common for parents of children with FASD to report that their child frequently makes things up or lies to them. It is important to understand why this is, and also to differentiate the difference between lying and fabrication.

One important factor to keep in mind is that many typical 4-5 year olds make up stories and stretch the truth as a normal part of their developmental level. Many children with FASD may not progress much beyond this level socially for a long time. Therefore some of the truth-stretching is in-keeping with their social developmental level.

Another factor to keep in mind is that because many children with FASD have poor memories, there are often gaps missing in their histories or memories of events. Often what your child may then do is to fill in the gaps! This is not lying with intent to deceive; it is an attempt at making better sense of their worlds – even when the blanks are being filled in with some quite elaborate tales.

Children with FASD tend to struggle to completely differentiate between fantasy and reality, and may even merge what actually happened with what they thought about in relation to the event, so this can further make it seem as though your child is fabricating rather a lot. A real life example could be your child swearing point blank to you that they have cleaned their teeth that morning, while you are fully aware that they have not. Sometimes for children with FASD, because of this reality/fantasy muddle, just thinking about doing something can then create a ‘false memory’ that they have already done so. Bearing all of these possibilities in mind can help to reduce your own frustration in terms of these day to day issues and to think about fresh ways of dealing with it, perhaps using visuals, close supervision, and so on.

This problem is all a part of your child’s executive functioning disorder caused by their FASD. They cannot change it, and so we as their ‘external brains’, must enlist strategies in order to help them to manage. Sometimes it can be useful to speak with your child about this, that because their brain works in a different way they might need to ‘use’ other people’s brains to answer some questions for them. Encourage your child to ask themselves questions such as, ‘who can help me remember whether I have done that or not?’ or ‘who can remind me of what homework I have to do?’ This approach removes the shame out of the situation and instead encourages children use the support systems around them.

### **Looking to the Future: The issue of Independence**

While puberty will come at roughly the same time for your child as it does for all children, because of their executive functioning disorder they will remain socially less mature than their peers, and need a lot more supervision in order to keep them safe.

Life demands us to be able to switch focus between tasks, hold lots of things in mind all at once, sustain and alternate our attention, all of the time as adults. Even driving a car, with all of the simultaneous processes that involves, demands high levels of executive functioning ability. For those who do not have impairment in this area, we can do this largely automatically. For those who do, such as in FASD, they can often do one of these

tasks at a time, but when multiple functions are required all at once, this is when it begins to fall apart.

As children with FASD move into adulthood they will continue to struggle with abstract concepts and understanding some of the subtleties of the social world, which means they are more vulnerable to being taken advantage of, be this financially, socially or otherwise. FASD means that young people can be more suggestible and naïve compared to others, and therefore are more vulnerable to being led into troublesome situations and behaviours, simply because someone has told them to do something. Your child is likely to need support with these issues to some extent throughout their life, and with matters that rely on a high level of executive functioning, such as money and income management, general routine, cooking, and time keeping. The executive functioning deficit that creates these problems is a life-long deficit and not something which they will grow out of.

It is difficult to predict the extent to which these issues will pose a problem for individual children. Those with FASD will still need to rely on their 'external brains' – i.e. their support network around them, in order to manage. If they have a good support network, then they can of course lead a positive and fulfilling life. Some will be able to live away from their parents eventually but with a support network overseeing them from a safe distance. Others will not be able to live alone, because it would not be safe for them to do so, and may require support from adult services.

The most important step for you and your child, is that you now know the diagnosis, and are therefore informed and prepared. This is the most protective factor of all for your child, as you know what the issues are, and how to compensate for those. Make sure your child's school is also aware of their diagnosis, even if it is just their main class teacher if you are concerned about the diagnosis becoming more widely known. It is helpful to try not to see an FASD diagnosis as a label, but rather to see it as a means of understanding the difficulties that that your child has, and therefore knowing how best to support them moving forward. It is useful for school and other important people in your child's life, to have a copy of this leaflet for that very reason.

### ***Stay Positive!***

FASD is a diagnosis which brings about lots of emotions for all involved. Birth mothers do not generally set out with the intention of harming their unborn child. Many women who drank excessively during pregnancy may have done so without understanding the consequences of this, or possibly not even knowing they were pregnant in the first place. For others, it was their only way of coping at the time due to difficult life circumstances. Some parents and carers may experience feelings of guilt or anger at what has happened. While these emotions may well be part of the process of coming to terms with this diagnosis, a focus on the here and now and your child's needs, will be more beneficial all round, than dwelling on what may have been.

Parenting a child with FASD is difficult and exhausting at times. It can be easy during tough weeks, to focus on all the negative aspects and the things your child cannot do, and to worry. It is important to remember that your child can achieve, and they will master skills, albeit at a different rate to children who are not affected. This is why adjusting your expectations as a parent is important and helpful, for your sake as well as your child's. It is also important to look after yourself as a parent too, and to make sure that you get a break every so often to take care of your needs as well.

Some of the characteristic behaviour associated with FASD can also be seen as strengths, which when recognised and reinforced, can help build your child's self-esteem. Many

children with FASD can be very creative when it comes to art and music and other outlets where creativity is key. Their vivid imaginations can make them great story-tellers! They are often loving children, who are tactile and affectionate. Many children with FASD get on well with younger children, and also animals. They have bundles of energy, which channeled correctly, can be great in certain vocations such as outdoor or other physical work. Finally, because they often rely on their visual memories to get by, this can be very well developed, and can again be a relative strength when looking at how to help a child with FASD to learn.

A final word: you are not alone; there are many parents and carers locally who are raising children with this diagnosis. There are local support groups that you are able to access, some of which are accessible on social media such as Facebook and Twitter.

Please refer to [www.nofas-uk.org](http://www.nofas-uk.org) for lots of information and support, including articles to read and print of for both parents and professionals about behaviour management, and also supporting children in school.

We also recommend a book, 'Foetal Alcohol Spectrum Disorders: Parenting a Child with an Invisible Disability' by Mary Mather, 2014, which is available on Amazon UK.

If you have any further questions about the content of this leaflet, please get in touch with Dr Cassie Hunt, Clinical Psychologist, at Woodbridge Clinic, 2 Pytches Road, Woodbridge, Suffolk, IP12 1EP.

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