Fetal Alcohol Advisory Support & Training Team

THE UNIVERSITY of EDINBURGH

Understanding Fetal Alcohol Spectrum Disorder (FASD)

Information for parents and carers



November 2023

"I want to do my best for my parents.
I want everyone to be proud of me.
I look the same as the other kids of my age
but I know my brain is different!"

"Children with FASD are 10-second children in a 1-second world"

(Diane Malbin)



understanding FASD

Fetal Alcohol Advisory Support & Training Team

THE UNIVERSITY of EDINBURGH

Contents

Acknowledgments 5

Introduction 6

What is FASD? 7

Strategies for parents & carers 13

- Strengths
- Structure, Routine and Consistency
- Sensory Processing and Everyday Activities
- Transitions
- Learning
- Impulsivity
- FASD and sleep
- Your Environment
- Ownership
- Storytelling/Filling in the Blanks
- Getting along with Others
- Communications

What doesn't work and why 45

Finding Support 47

Helping your teenager with FASD 54

Talking with children and teenagers about FASD 60

Grief and Loss 62

Taking care of yourself 63

FASD resources 66

Acknowledgements

With thanks to ***Healthy Child Manitoba Office, Winnipeg*** for permission to reproduce resource materials for this document.

Special thanks to the ***Parents, Carers and Young People*** who contributed to the production of this resource by sharing their experiences to help others.

With thanks to ***members of NHS Ayrshire & Arran's Fetal Alcohol Advisory and Support Team*** for compiling and producing this resource.

Introduction

1

This resource is for parents and carers of children and teenagers who have a Fetal Alcohol Spectrum Disorder (FASD) to provide ideas and suggestions to help ensure that they have the best lives possible. This booklet refers to anyone who is caring for, or involved in the care of a child with FASD, as a parent or carer.

Parenting, in general, is hard work but also challenging and rewarding. When caring for a child with FASD, you will require information about the disability as well as support and strategies to help you understand what this means for you and your child.

This booklet provides information about FASD. Some helpful strategies will be discussed although not all of them will be suitable for your child or family. Every child is unique and will experience different challenges. You may want to try one or two of the strategies and build on these the more you understand your child's disability. You will also see some quotes and comments from parents who live with the challenges of FASD and want to share some of their experience.

"I am still trying to find my way of learning. I have to learn how to learn"

What is FASD?

The term Fetal Alcohol Spectrum Disorder (FASD) describes a range of physical, emotional and developmental difficulties that may affect a person when they were exposed to alcohol during pregnancy.

Diagnosis of FASD involves assessments by a Paediatrician, Clinical Psychologist, Occupational Therapy and Speech & Language Therapist.

Fetal Alcohol Syndrome

also referred to as FASD *with* facial features*

- Result of exposure to alcohol during pregnancy
- Affects how the central nervous system works
- Distinctive Facial Features:
  - Small head
  - Small eyes
  - Thin upper lip
  - Smooth philtrum *(area between nose and mouth)*

** Cook et al (2016)*

Fetal Alcohol Spectrum Disorder

also referred to as FASD *without* facial features*

- Result of exposure to alcohol during pregnancy
- Affects how the central nervous system works
- Absence of Distinctive Facial Features
  - FASD is often referred to as a 'hidden disability'

** Cook et al (2016)*

Every child is unique and has individual strengths and challenges!

Nine brain domains affected by FASD

There are 9 brain functions that can potentially be affected by alcohol during pregnancy.



Executive Functioning

- May have trouble with planning, sequencing, problem solving and organisation.
- May be impulsive.
- Difficulty controlling emotions.
- Challenges with transitions and change.
- Often repeats mistakes and has difficulty understanding consequences.
- Difficulty with abstract ideas/concepts.
- Difficulty managing time.

Sensory and Motor

- Maybe unable to make sense of what is going on around them.
- May under or over react to sensory input, for example, light, noise, touch, smell and/or taste and movement.

Academic Skills

- May have difficulty in school particularly with maths, reading, time and money.
- May have difficulty with comprehension, organisation and abstract concepts.
- May have difficulty with age appropriate tasks.
- May have normal IQ.
- Learn better with visual or 'hands on' approach.

Brain Structure

- Brain and head circumference may be small.

Living & Social Skills

- May not understand personal boundaries and have difficulty reading social cues.
- May be socially vulnerable and easily taken advantage of.
- May have difficulty seeing things from another's point of view
- Socially and emotionally immature... may behave younger than actual age.

Focus & Attention

- Can be easily distracted, over-stimulated or impulsive.
- May have difficulty paying attention and be over active.
- 'Can't sit still'.

Cognition *(Reasoning & Thinking)*

- Difficulty with attention, learning, memory, planning and organisation.
- Difficulty with understanding complex ideas.
- Wide range of IQ.

Communication

- May speak well but not always understand the full meaning.
- Delayed language milestones for age.
- Difficulty with lengthy conversations.
- Difficulty following instructions.
- May be able to repeat instructions but not able to follow them through.

Memory

- Difficulty with long and short term memory – may seem forgetful.
- Difficulty recalling sequences or complex instructions.
- Relatively better visual memory.
- Easily forget steps in normal daily routine.
- Appear to lie but are really 'filling in the blanks'.



'The degree of damage to the unborn baby will depend on its stage of development at the time of exposure to alcohol because different parts of the brain develop at different times during pregnancy'

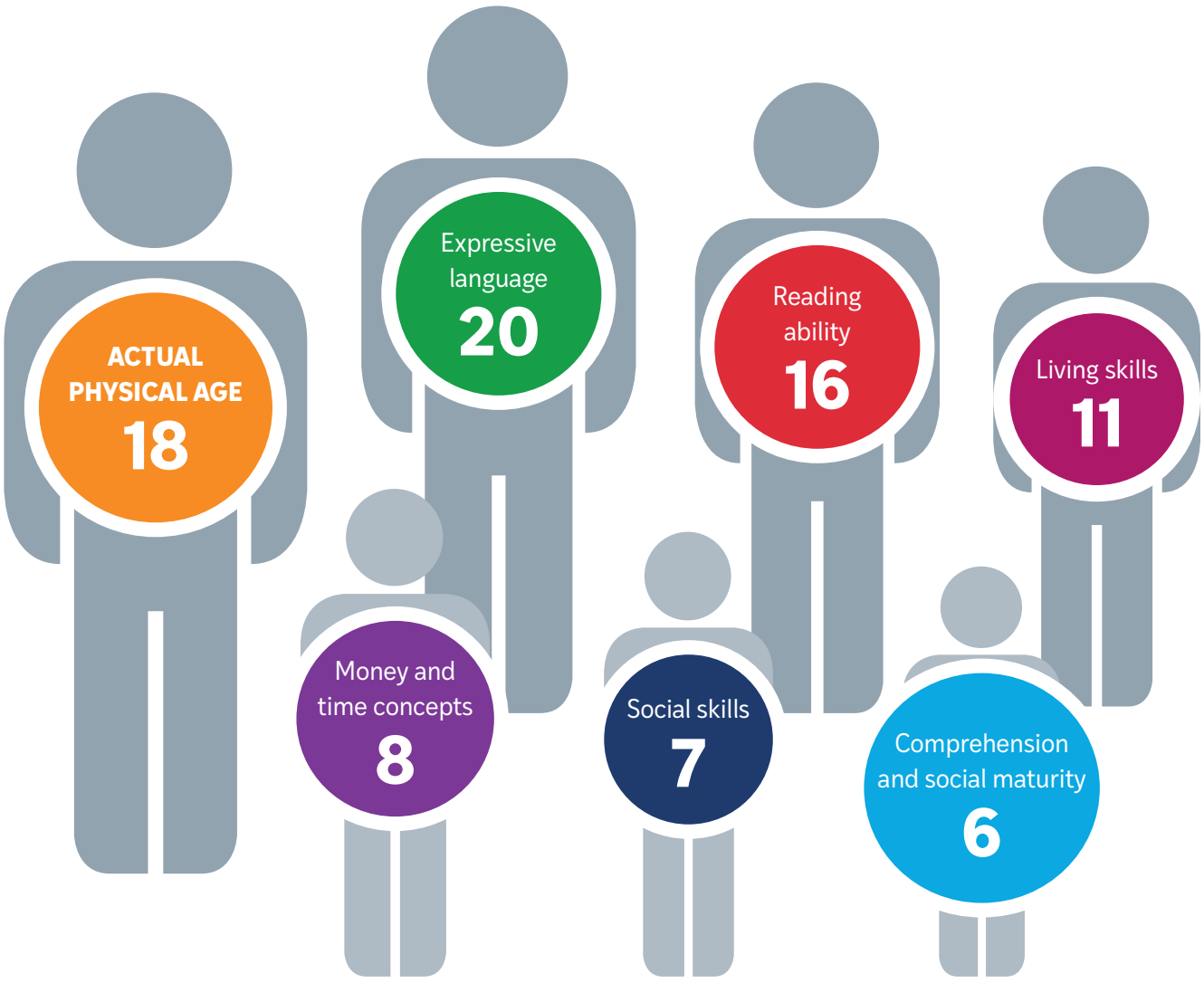
(FASD: Parenting a child with an invisible disability. Brown & Mather, 2014)

Developmental age and FASD

As parents, we have expectations for our children based on their age, for example 'Katie should be able to walk to school by herself because she is old enough'.

This thinking assumes that the child is meeting their developmental milestones. Research has shown that children and teenagers with FASD are usually developmentally younger than their peers. However, we must remember that every child is unique.

The diagram below shows common stages of development for a teenager with FASD. In some ways the young person may be developmentally average or indeed, ahead of their peers, yet, in other areas they may be well behind. Imagine how problems could be avoided if expectations were adjusted to match a child's ability.



Example of developmental stages of 18 year old child with FASD

When you look at this pattern of development, it may be easier to see how a person with FASD can become frustrated and discouraged when, over time, the expectations placed on them exceed their ability. This is described as a 'poor fit' between developmental ability and expectation. This can lead to other problems or disabilities, for example, depression and isolation.

Diane Malbin, researcher and author in the field of FASD, suggests that we should adjust our expectations and 'think younger' when we support people with FASD.

An example of this would be to consider a five year old with FASD. Normally 5 year olds are ready to start school, can play with friends and follow instructions.

Adjusting your expectations and support does not mean that your child should not be held accountable. It just means that your expectations should match their developmental age.

It is common for children and teenagers to have 'off-days'. These 'off-days' may be more frequent and noticeable for children and teenagers with FASD. Due to damage from alcohol exposure, the brain seems to misfire more often than normal. When the child is able to follow instructions one day, and is unable to follow the same instruction the next day, it may be misinterpreted as stubborn behaviour.

"We need to keep reminding ourselves, and others, that our son is developmentally about half his actual age. This helps the adults caring for him understand that we deal with his behaviour differently."

A 5 year old with FASD may be more like a 2 year old – they may not be ready for school, can't sit still, always want their own way and are unable to play with other children of the same age. If you are able to understand that your 5 year old is developmentally closer to 2, then you can adjust your parenting to suit a 2 year old.

"Thinking younger" reduces the frustration both child and parent feels when expectations are not being met. This does not mean that your child will not grow and develop. They will, but perhaps, at a slower pace and not always in 'line' with other children their age.

It would be helpful to think of this behaviour as 'FASD days' or times that the brain is misfiring because of their disability. It is important to be as flexible as possible in your parenting as these 'FASD days' are out with your control and more importantly, out with your child's control.

2

Strategies for Parents of Children and Teenagers with FASD

Building on strengths

Every child with FASD has their own set of unique strengths. Unfortunately, many children with FASD are defined by their problem behaviour or their disability.

While it is important to understand and accept the disability and focus on solving problems related to behaviours, this approach falls short of appreciating your child as a whole person. Focusing on problems limits possibilities and can sometimes overshadow your child's amazing strengths.

Focusing on strengths can help your child be more successful in school, will help you appreciate your child as a whole person, not just a child with a disability. This focus will help you build a strong relationship with them, enhance their self esteem and decrease their stress levels as well as yours.

Identifying strengths and talents in children with FASD is a very helpful strategy. Understanding your child's strengths allows you to change your environment to build on these strengths.



"...he loves sports and never gets fed up playing ice-hockey, football or swimming"

The following list of strengths is not unique to children with FASD, but it does show areas where your child may excel:

Affectionate • Trusting • Wonderful story tellers • Strong visual memory • Friendly • Loyal • Loving • Eager to please • Creative • Musical • Artistic • Good with animals • Determined • Active • Learns best by 'doing' ...and lots more!

How do you build on strengths?

- Start by identifying your child's strengths, talents and interests. Consider the things that help them get active and use their body because most children with FASD need a lot of physical activity to help them manage their day. For example swimming, cycling, playing at the park.
- Include your child's strengths, talents and interests in everyday activities. For example, if your child likes to be active and wants to help out at home, they could help in the garden or help with the cooking. If they are not so keen on physical activity then perhaps an allocated time on the computer can be built into the daily routine.
- Build on these strengths by developing plans to prevent or resolve problems. Example: If your teenager is getting into trouble because they have too much unstructured time available after school (for example, hanging about the streets with friends) but they also like horses, perhaps they could get involved in riding lessons or help out at a local farm.
- Try to use behaviour problems in a positive way. This might be easier said than done, so it will require will power as a parent and consistency to put it into practice.

  Example: If your child has trouble getting ready in the morning and is annoying everyone in the household, they may need more specific direction from you, or by using visual cues to help them get ready. If they are very active, your child may need to use some of their energy in the morning, before going to school, to help them focus. You may need to get them involved in some morning chores or perhaps structure in a morning exercise routine. This also gives your child the opportunity to be praised and feel part of the family.
- Ask your child/teenager with FASD to help with this process. Ask them what will work. This will help them discover their abilities and have some input into their surroundings. You may be surprised to hear that your child has a creative solution to a behaviour problem.
- Anticipate problems based on past experience and intentionally change the situation to avoid challenges whenever possible. Example: If you know that your child is easily over stimulated, gets wound up and runs off when they are in the supermarket, make plans to do the shopping when they are at school or when you have a sitter/carer. If you have to go shopping with your child then think of things that will help reduce the challenges – take someone with you or give your child a 'responsible job' like pushing the trolley.



"My son gets overstimulated during car journeys. When we go out as a family, he always sits in the front so that he doesn't annoy the others. This prevents him getting wound up before we arrive."



"My daughter is really kind and caring and loves to entertain people"

Celebrating achievements

"We have a magic box that he can select a special treat from. The treats range from putting makeup on mum, choosing a song which all the family have to dance to, leading a salsa around the house, being swung by mum and dad in a blanket in the garden, or getting a hand massage – lots of fun, no cost, family things that he loves"

Structure, routine and consistency

All children do better with structure in their lives. This is especially important for children with FASD. They need structure to help them with daily activities because their brains have trouble figuring out the steps needed for each activity. We don't realise how much planning our brain is doing every minute of every day, just to do simple things like brushing our teeth, getting ready for work or making it to an appointment.

Change can be confusing for children with FASD because their brains have trouble adjusting to change and making transitions. Even the most minor changes, such as putting something in a different cupboard, can create major confusion for a child with FASD.

To help your child or teenager to succeed with everyday activities, make sure you have a consistent daily routine at home. Provide them with a structured schedule whenever possible.

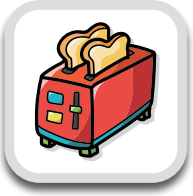
Strategy suggestions:

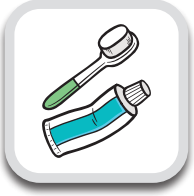
- Meal times should be at the same time everyday whenever possible.
- Structure routine into after school activities.
- Set routine for bedtime.
- Use picture or visual cues as well as calendars, white-boards and visual apps at home. Children and teenagers with FASD are best at visual learning, so it is easier for them to figure out their day with visual help. Depending on their age and reading skills, they may also find lists very helpful. Another idea is to take photos of your child doing each step – these can be used to make visual schedules. This is, perhaps, more useful with older children when cartoon pictures may seem 'childish'.
- Break down everyday tasks into simple, easy-to-follow steps. Easy steps can be made into visual cards and posted in appropriate areas, for example kitchen, bathroom, bedroom.

Visual Schedule

Morning


Get dressed


Breakfast


Clean teeth


Schoolbag



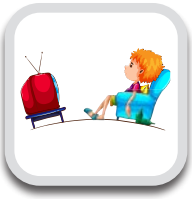
School

After school


Snack


Gymnastics


Homework


TV


Bed time

"The more predictable a day is, the smoother things will be. Weekends are more challenging. We settle on a fully structured Saturday and a more flexible Sunday. This meets the needs of the rest of the family. Holidays are the hardest for us.... going to the same place each time helps."

- While structure and routine help children and teenagers who have FASD, remember to be flexible, as sometimes strategies lose their effectiveness over time and new ones need to be tried.
- Be ready to change things about depending on what kind of day your child is having. Even the best ideas don't work for everyone all the time.

"We have found that using visual schedules with our young Apprentice has taken a great deal of stress out of working in a flexible work environment. Working together, we designed the best format for him: using different colours, simple text fonts and details allowed easier identification of start/finish times along with venues and details of sessions. After a few attempts we hit on a simple, colourful timetable that goes home on a weekly basis"



Sensory processing and everyday activities

What is Sensory Processing?

Every moment of every day we are taking in information through our senses; sight, hearing, touch, smell and taste. Nerves throughout our body take in the information and our brain processes the information and tells us what to do with it, for example respond to it or ignore it.

FASD and Sensory Processing.

Children and teenagers with sensory processing difficulties have trouble managing information from their senses. Their brains either do not understand the information or the information is mixed up. This is because sensory processing in the brain has been affected by alcohol exposure. Some people with FASD feel bombarded by sensory information and they tend to shut down or ignore the information. Others may need more information and they are busy seeking more sensory input. Many children and teenagers struggle to keep their sensory systems balanced. It is difficult for them to adjust and adapt to different environmental expectations Example: Working up to football training, calming down after a party or adjusting to bedtime routine after watching TV.

"Colour and noises upset him."

"Smells annoy her, she has to investigate where they are coming from"

Here are some examples of sensory processing difficulties:

Sight/visual

- Gets easily upset in a busy place, such as the supermarket or shopping centre.
- Frequently can't find belongings.
- Frequently distracted.

Hearing/Auditory

- Easily upset by noise from appliances at home, such as hoover or a hairdryer.
- Cover their ears; overreact with anger or bolting when they hear loud noises, such as school fire alarm.
- May create noise to drown out other upsetting noises.
- May misinterpret a normal speaking voice with yelling.

Touch/Tactile

- Tags/labels on clothes annoying.
- Overreact when touched, especially if it is unexpected, for example may respond by hitting or lashing out.
- May not feel hot or cold, for example goes outside in winter without coat or hat and want to wear coat in summer.
- Constantly exploring the environment, for example touching buttons, switches, touching other people's belongings.

Taste

- Fussy eater.
- Chew on clothing.
- Put everything in their mouth.
- Overfill mouth with food.

Smell

- Strong dislike of smells that are often undetected by others.
- Tell others they smell bad.
- Refuse certain food because they 'smell bad'.
- Over sensitive to perfumes and detergents.

Joint Sense and Movement

- Easily become travel sick.
- Fear of their feet leaving the ground.
- Struggle with co-ordination, may seem clumsy.
- Have poor danger awareness.
- Have trouble with pressure and movement, may be too rough during play.
- Have poor body awareness, for example, stands too close to others, tend to be 'in your face' and constantly touching others.

Children and teenagers who are struggling with sensory processing difficulties often communicate these challenges through their behaviours as they often do not have the language to tell you how they feel.

Remember: Children can have a mix of sensory behaviours. They can be sensitive to auditory input but seek out movement. They also may be ok managing sensory input one day but are distressed the next. For example, a child can manage the conversation at the dinner table one night, but be upset and be unable to eat with the family the next.

Helping children and teenagers with sensory processing difficulties

Your child's behaviour is trying to tell you something. It is up to the adult to try and determine what they are trying to tell you. Example: a child hiding under a table may be telling you that they need a safe place to calm them down.

At first, as a parent, you act as an 'external brain', recognising the needs of your child or teenager. By working together, and with time and lots of practice, your child or teen will be able to participate in daily activities and some self-regulation will develop.

Practical sensory solutions and strategies for everyday activities.

When trying any new strategy keep in mind your child's unique strengths and challenges. You may need to try a new strategy for a while before knowing whether it works for your child.

What is self-regulation?

- Help your child develop a way to express emotions when feeling upset or overwhelmed.
- Help your child identify and talk about an emotion. Sometimes, using simple pictures showing 4 or 5 feelings is a good tool. This can be displayed, for example, on the fridge door. Websites, such as do2learn.com, have lots of free artwork for visual schedules and feelings charts. Photos of real people are sometimes more effective than picture symbols.

Below is an example of an emotions chart

Be creative! Print a picture of a tree and some faces with different emotions (these can be real photos of your child). Your child can stick them on the tree to let you know what emotions they are feeling at that time.

As you adapt different environments and begin using various self-regulation strategies, point out to your child how they are using 'brain-tools' to help stay calm, settled and focused.

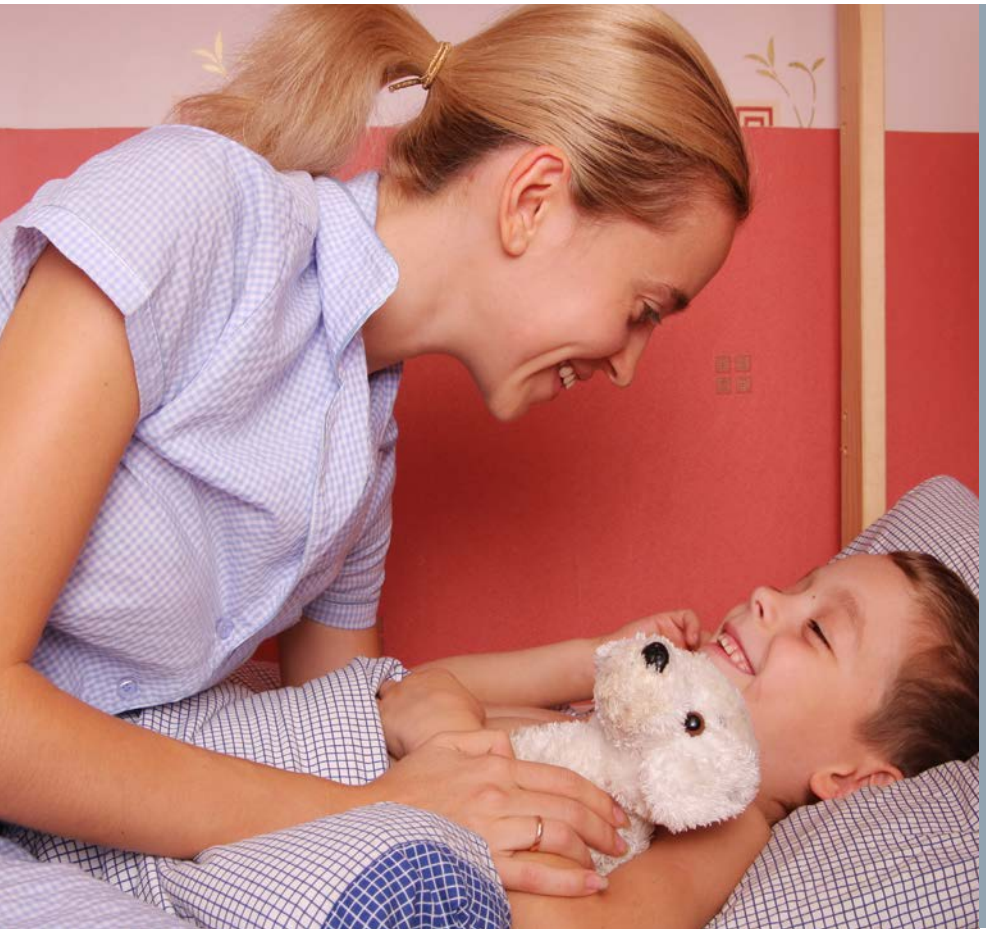


"My son sometimes can't control his emotions and gets frustrated if someone doesn't understand him... we need to rub his feet and put him on my knee, hold him tight and rock him."

Bedtime

Strategy suggestions:

- To help a child transition from an alert wakeful state to a calm and restful state, try some calming strategies, such as a back rub or some gentle squeezing of the feet, legs, hands and arms.
- An auditory-sensitive child may need total quiet to fall asleep. If this is not possible, try some alternative calming sounds. Example: quiet, relaxation music, humming noise from a fish tank pump.
- Give older children a light snack before going to bed. Find out what snacks have a calming effect as some tastes/textures can be stimulating, for example, spicy, cold or chewy.
- For the child who needs time to settle or wakes up during the night, have a basket or list of acceptable things they can do in their bedroom.
- If your child has difficulty sleeping, think of activities between dinner and bedtime as a time for your child to wind down. Try to avoid activities that are exciting and stimulating, such as rough-and-tumble play.
- Remember that deep pressure touch is calming. Have blankets and pillows on your couch available for them to tightly wrap up in and snuggle. This type of calming touch could be used while a bedtime story is read or when talking about the day.
- Avoid caffeine, video games and computers before bedtime – the light from the screens affects the ability to fall asleep.
- Use a visual schedule to help your child learn a bedtime routine.



"We read bedtime stories about his behaviour throughout the day...we do this using animals or superheroes."

"We have a bedtime routine and we keep to it...always"

Mornings

Strategy suggestions:

- Make mornings predictable by following a routine.
- With children that have a hard time getting up, make sure they are sitting up in bed, with their feet on the floor, before you leave the bedroom.
- Avoid TV in the mornings.
- Alert their senses with music or a drink of juice and open the curtains immediately to let in the light.
- Help your child with organisation in the mornings. Set out clothes and shoes the night before. Always help your child get ready for school in the same place. This is helpful when there is a busy household and everyone is getting ready to leave at the same time.

"My daughter struggled to get up in the morning... we now gently waken her and remind her after 5 more minutes. She needs prompting with her morning routine; getting dressed, washing and brushing her teeth. She's 15. Providing a structure in the morning has helped her stay focused."

"Mornings can be very difficult without any sense of time. We try motivating with reward systems and with visual charts. Also timers can help. Nothing works for any great length of time and we have to keep changing strategies to keep him motivated"



Mealtimes

If your child:

- **Has trouble with personal space at the dinner table** - use place mats to designate their space.
- **Has difficulty sensing fullness** - be aware of portion sizes to avoid your child overeating.
- **Has trouble sitting still** - let them stand or try a home-made 'wiggle cushion', for example a partially inflated beach ball. Use a visual timer to let them know how long they should sit at the table.
- **Is easily overwhelmed by noises** - let them wear headphones to reduce auditory input. Turn off TVs or music at mealtimes.
- **Becomes overwhelmed by the smell of food** - let them eat in a different room or use a fan to eliminate food smells.
- **Is a fussy eater** - experiment with new foods to find out what works best for your child. Some children respond better to spicy, hot foods while others do better with bland food.
- **Is easily distracted by conversation** - you may find it better if your child eats before the rest of the family. This will allow them to finish their dinner and still join in mealtime conversation.

"We have set places to sit and a set menu. A set routine helps although we have to reinforce rules every mealtime, 3 years on..."

"She needs me to help out with her clothes as she can't pick out things that match"

"He has a constant resistance to dressing independently. We just have to keep reinforcing and rewarding good behaviour."

Clothing

Children with FASD who are oversensitive will, at times, find their clothing distracting or upsetting.

Strategy suggestions:

- Turn your child's socks inside out to avoid the seam rubbing against the skin.
- Help them express their discomfort by giving them appropriate words for example 'I don't like how my shirt feels'. Picture/feelings cards may help with this.
- Soft clothing might be more appropriate. Avoid clothing with scratchy nylon threads and remove tags from clothing.
- Tight or loose clothing? Some children prefer very loose clothing, while others like the deep pressure that comes with the feel of tight clothing.
- If your child is chewing through material, try providing them with something more suitable for chewing, for example edible jewellery or chewing gum.

Shopping

Shopping centres are visual wonderlands, with many people moving about, bright lights, noises and the opportunity for unexpected bumps and touches. Shopping can be a very stimulating and overwhelming environment for many children with FASD.

Strategy suggestions:

- Shop during off-peak hours when the shops are less crowded.
- Let your child push the trolley. Pushing the trolley is heavy work activity and can provide calming sensory input.
- Your child may want to wear a baseball cap or hoodie as this will help reduce some of the visual information. Some children find the pressure from a hat calming.
- Have your child find the items in the shop that you need. Have a list or picture of the items you want to buy. Having 'a job' helps keep the child regulated.

"I always have little note pads or activity books in my bag to distract her when we are shopping or in restaurants"



Homework

A number of challenges can make sitting down to do homework very difficult for a child with FASD. As a general rule, children with FASD are only able to handle 10-20 minutes of homework per evening.

Strategy suggestions:

- Set up a homework routine – same place, same time.
- Create a homework station that is visually quiet, for example clean table away from TV, family or pets.
- Have hand fidgets like stress balls, stretchy elastics. Remember if fidgets look too much like a toy, it may be distracting.
- Use visual support, for example a visual timer or visual schedule to keep your child on track.
- Turn off all TVs and ensure no mobile phones. A quiet environment will help children with sound sensitivities to concentrate – even noise from another room might be distracting.
- Let your child wear headphones or ear-protectors to decrease environmental sounds.
- Have a glass of water with a straw or chewy snack nearby to help extend focus. Chewing gum if appropriate for the age of your child.
- Some days just might not work for homework. Accept this and let school staff know.



Bathing and Hygiene

Strategy suggestions:

- If your child doesn't like slimy soap or shampoo, try foamy soap. Foamy soap is also good for tactile play.
- If children avoid bathing because they don't like the feeling of being rinsed with water, try other strategies for example, use a large container to rinse instead of the shower head. Some children might be more comfortable if they are in control of the water. In this case then the shower head or watering can may be beneficial.
- To promote independence, use visuals, such as a reminder list or pictures of what has to be washed in the shower. This works particularly well with teenagers.
- With girls, teach them proper period hygiene. You may need to repeat this every month.

"It took until he was 7, but now I can wash his hair with water running down his face...he loves bath time."

"My daughter struggles with bath or showers. She doesn't understand she needs to wash every day."

"I use visual schedules to remind my daughter to wash and clean her teeth before school every morning".



"I need to remind her every month how to use sanitary towels."



Restaurants

Strategy suggestions:

- To help with waiting times, have some fidgets available for example pencil and paper for doodling.
- If the environment is too noisy, have your child use ear protectors.
- Take movement breaks, for example trips to the toilet for hand washing.

"We use the same restaurant as the staff know that he likes to eat the same food although it's not always on the menu"

'Out and About'

Strategy suggestions:

- Have fidgets for your child to hold and touch.
- If possible, get your child to take pictures at events to keep eyes and hands busy and focused.
- Take convenient, calming snacks with you like crunchy food, drinks with straws or chewing gum.
- Be aware of triggers that may affect your child, such as the size of crowds, smells, touches and noise. Have a plan B in case an activity becomes too much. If the excitement of a birthday party becomes too much for your child then plan to take them for a break in another room.
- Have your child wear a backpack with items in it. Carrying extra weight can be calming.
- Try aromatherapy. Scents that might be calming are lavender, chamomile, orange and rose. Alertness and attentions aromas could be: peppermint, basil, lemon, cinnamon and rosemary.

"He rocks himself back and forth to sooth himself as he doesn't like being strapped in the seat. We have plenty of things for him to do – earphones and music usually so that he can sing along."

"Keeping calm when he was out of control was important. This helped him calm down. We sit quietly until he feels ready to talk about something."

Car Journeys

Strategy suggestions:

- Use a visual planner to help your child understand the car routine, for example seatbelt on, keep hands to yourself. A planner could show a stop for petrol, a visit to the supermarket before going to the park.
- Have some car activities available to help with restlessness.
- Allow your child to use headphones and music.
- Try to offer enough seating space to help reduce the chance of unexpected touch or a sensory-seeking child touching and bothering other passengers.
- Sometimes extra child-proof buckles, available in shops, may be needed to help a child stay safely in their seat.

General Calming

Strategy suggestions:

- Avoid or limit time in situations where your child will become over-stimulated.
- Have a quiet or calming place for your child to go, not as a punishment, but as a place to be calm. Make this area quiet, with pillows and blankets available, and soft lighting. In your house this could be a bedroom, a corner of a room, a special chair/ beanbag, a play tent or even under a table.
- Deep pressure like bear hugs, being tightly wrapped in a blanket or large beanbags, can be calming. Some children like head massages. Always ask the child if it's ok to be touched.
- If you are not at home and your child or teenager needs time to calm down, then look for a quiet place, for example sit on a bench or go for a walk.
- For younger children, calming can also be accomplished with some distraction. Try changing the focus to a different activity.
- Always point out to your children when they are calm, so that they can recognise how their body feels. Be specific by pointing out how their breathing is slower and their voices are at a good volume.
- When your child is upset, limit how much you talk – less is more. Children and teens with FASD often have difficulty understanding language.
- Be calm and regulate your own breathing. Children will often feed off the energy of the people around them. If a parent's energy is agitated, children will have a harder time calming. If a parent is calm, children can better organise themselves.

Praise

It can be easy sometimes to place focus and attention on the child's sensory processing difficulties, rather than focus on what the child has done well. When you see that your child or teenager has been able to successfully self-regulate, make sure to provide them with praise. This type of positive reinforcement is very effective. It helps them to recognise that they used a self-regulation strategy, it helps build their self esteem, and it helps build the parent-child relationship.

"Let me know how proud you are of me... remind me that I'm a great kid even if I did something wrong."



Transitions

Children and teens with FASD often have a hard time with transitions or shifting from one activity to another. They may also have difficulty stopping an activity or starting a new one, moving to a different place or shifting their thinking from one thing to another. Transitions are a large part of the day. When the day is structured with a great deal of consistent routine, transitioning becomes easier.

Think of all the transitions that happen in a day. For example, the first transition is the shift between sleeping and waking. Many children and teens with FASD need more time in the morning to wake up. It helps if there is a consistent wake-up time and morning routine.

Some children like to wake up to the sound of a person's voice, while others may prefer music or a certain alarm sound. After the first wake-up call, it usually helps to wait a few minutes before doing another one. Sometimes, pulling the blankets back and laying out a dressing gown or school clothes may be a cue to the next step in the routine.

Most children with transition challenges will need a reminder about what comes next in the routine. 'Now and next' boards can be useful if the child has difficulties processing what they hear.

Many children with FASD miss the subtle cues that a transition is about to happen. They may not notice everyone has finished eating or that the other kids at the park are going home for dinner. A child's interest level in an activity may also affect their ability to shift, for example they may be really interested in the current activity and don't want to do what's coming next.



"...we gently shake him and tell him he has 5 more minutes."

Strategy suggestions:

- Tell your child that the activity is about to change. Some kids need the verbal cue well ahead of time and some are ok with an instructions right before the activity is changing. Example: "It's time to put your toys away." "It's time to leave for school." "In 10 minutes, it will be time to put your coat on."
- Trying using the 'first and then' approach: "First we will go to the toilet, then we will get dressed." "When the big hand gets to 10 and the little hand gets to 9, you will leave for school."
- Because time is an abstract concept, using a visual timer sometimes helps because they can see how much time they have left before transition to the next activity. A visual timer shows the passage of time.
- Counting down a transition is a good strategy when the timing of the transition needs to be flexible, for example, "I'm going to count down from 5, then it will be time for bed."
- Use pictures to show where your child is going next. Give your child an object that represents the next activity like a book when it's time for a bedtime story, a snack at snack time
- Visual schedules can help children see what happens next. For teens, a visual schedule on a computer device like a tablet, can be helpful.

The **Visual Schedule Planner** is a customised visual schedule iPad application, designed to give an audio or visual representation of the events of the day.

Events that require more support can be linked to an activity plan or video clip to help define the task even further.

Not every approach is going to work perfectly the first time. Often, you must change a strategy to meet your child's needs.





The FASD brain has to work harder than other brains, so it may take your child or teenager longer to complete assigned tasks.

Learning

Because FASD is a brain-based disability, your child is living with unique challenges. Children and teenagers with FASD often have trouble with:

- Learning from consequences, for example connecting cause and effect.
- Applying learning from one situation to another.
- Remembering things, for example short term memory.
- Setting goals and following them through.
- Organising themselves.
- Keeping up with their work at school.
- Figuring out how to get started.
- Following a detailed list of instructions.

Children with FASD have a wide range of IQ scores, with some in the disability range and others above average. Also, there does not seem to be a pattern of deficits within this range. For example, you may have a child who has above average use of language, but gets lost going from one classroom to another. Other children may be talented artists, but may be unable to explain their paintings.

People with FASD tend to be visual learners and even better hands-on learners. They usually don't do as well with auditory learning.

The FASD brain has to work harder than other brains, so it may take your child or teenager longer to complete assigned tasks. They may just run out of steam earlier than everyone else. That is normal for them, so try again the next day or try a different strategy.

Strategy suggestions:

- Use step-by-step instructions and visual cues. A picture is worth a thousand words. Use simple language, not a big elaborate explanation. Children will switch off if the explanation is not clear.
- Tell the child what 'to do' rather than what 'not to do' - 'sit on the chair' rather than 'do not stand on the chair'.
- Use repetition and re-teaching because they may need more practice to master a skill.
- Use calendars, written schedules and lists to remind your child about what is happening that day, or what they need to remember to take to school.
- Focus on practical functional maths and science. Children may also benefit from using technology to help them learn.
- It may also help to rehearse a new skill in advance, for example how to greet people or how to play well with other children.

"Invest time in developing relationships with the school – this always pays off."

"Our daughter has extra support at school but struggles at home. She is very tired when she comes home as she has had to work twice as hard as the other kids at school."



- Get creative to help your child learn. Instead of using numbers on paper, teach maths skills using objects that the child can relate to, such as building blocks or pasta shapes.
- Praise and encouragement along the way will help your child build bridges to success.
- Work closely with your child's teacher to make sure that you know your child's learning goals. Ask teachers to modify expectations, based on the child's abilities and break down assignments into smaller tasks.
- Focus on your child's strengths.
- Slow down the pace to allow your child time to process.

Impulsivity

Many children and teenagers with FASD have trouble controlling their impulses. This often looks like typical Attention Deficit Hyperactivity Disorder (ADHD) type behaviour, for example fidgeting, can't sit still, acts before thinking and is one of the brain 'functions' that can be affected by FASD. Some children and teenagers may benefit from medication for these ADHD-types of behaviour. You can also help your child manage their impulses in many different ways.

Managing physical activity

- Allow a good balance of rest times and activity. Some children need more activity than others to manage their behaviour or more rest than others to keep them from becoming overwhelmed. This all depends on your child's particular challenges. As noted earlier, all children with FASD are unique. If you know that your child is better able to control their impulses after physical activity, such as swimming or jumping on a trampoline, then this can be used to help your child manage their behaviour – something you will need to programme into your daily schedule.

- Other sensory activities, such as chewing gum or playing with a bean bag or hand fidget can keep your child focused and stay calm (see sensory section).
- Children and teenagers with FASD tend to need more down time than others, because their brains have to work extra hard to understand and respond to day-to-day activities. Becoming overwhelmed may lead to meltdowns if the child doesn't have any other options. It is still important to keep their down time structured. For example, after school can be scheduled time for playing outside, helping around the house or watching TV. But, remember to monitor what they watch as they may model the behaviour they see on TV and misread the social information they are absorbing.

"Impulsiveness can cause many safety issues such as running out onto the road and poor decision making. Supervision is the key here... and lots of it!"

Teaching and rehearsing with your child

- Teaching positive strategies can help your children prepare for situations where they might struggle. For example, when they feel hurt or judged by friends, they might lash out physically. Over time, strategies like counting to 10 when they are upset or simple pressure point exercises in stressful situations might help your child learn to control their impulses.
- For social situations, try role playing with your child to help them practise using words to express themselves, rather than responding to impulses.
- Social stories help your child understand social cues and responses. There are some great social story cards that you can buy to help your child practice positive social interaction. Carol Gray first developed social stories for children with Autism. However, they are also very useful for children with FASD who need support with social skills.
  You can also create your own social story using the link **www.thegraycentre.org/socialstories**

Controlling your child's environment

- When your child's impulsive behaviours lead to hurting others or placing themselves in danger, look at what is triggering these behaviours. For example, if your child is lashing out at their siblings while out shopping, it may be that your child is too stimulated by the lights or the noise. Understanding this can help you decide whether or not to take your child shopping.
- When you see your child or teenager start to escalate because of their frustration or lack of understanding, try to redirect them to another activity or to a calming strategy before the outburst occurs. This will save you both from dealing with the outburst and over time it will help teach your child or teenager how to recognise when they need to take a break.





FASD and Sleep

Sleep issues are common among children with FASD. There are many causes for this. FASD can cause permanent damage to the structures of the brain that can affect sleep. Sleep is also affected by other health problems, emotional issues, social issues, sensory processing difficulties and impaired abilities to sense time and self-organise. Sleep disturbances make behavioural, emotional and cognitive difficulties worse. Poor sleep for a child can also mean poor sleep pattern for the parent, which can also lead to stress and frustration for the whole family.

Common sleep issues for children and teenagers with FASD include:

- Difficulties falling asleep, for example taking more than 20 minutes to fall asleep.
- Frequently waking during the night for minutes or even hours.
- Waking early in the morning.
- Trouble getting out of bed in the morning
- Tired, hyperactive or irritable during the day.
- Restless sleep, for example tossing and turning.

"We have to make many changes including reducing the number of visitors to the house, no sleepovers accompanied to birthday parties, very carefully picked clubs with leaders who understand, very limited freedom and a huge degree of supervision."

Strategy suggestions:

Sleep environment:

As many children and teens with FASD have trouble processing sensory information, it is important to create a calming environment to promote sleep:

- If possible, a bedroom should be totally dark. Use of black-out curtains or blinds can help. If a child needs some light, use a night light and make sure it is not shining towards the child's eyes.
- Be aware of sensitivities to touch. Cut tags off pyjamas and use bedding that feels soft. Know your child's material preference, for example flannel or cotton, loose-fitting or snug.
- A quiet environment is best for sleep. Some people benefit from ear-plugs. Carpets can also absorb sound.
- Some children and teenagers find alternative bedding that provides deep pressure helps with sleep, so try using oversized quilts, heavy blankets or a sleeping bag.
- Make the child's bedroom for sleeping only. Avoid TV and all electronic games, computers and phones in the bedroom. For younger children, toys should be cleared and put away at bedtime.
- Keep the bedroom layout consistent and uncluttered.

"We have a calm bedroom environment – not too much going on except some pictures on the back of the door of things we want him to remember."

"My daughter doesn't sleep well. She falls asleep late and wakens frequently throughout the night. She gets up around 5am and that's her up for the rest of the day"

Sleep Routine:

Many children and youths with FASD have poor organisational skills and an impaired sense of time. Parents find that rules, structuring, routines and consistency are helpful:

- Maintain a consistent bedtime and wake-up time.
- Establish bedtime routines. Some children also benefit from the use of a visual schedule to help reinforce the structure, routine and expectations, for example pictures of having a bath, brushing teeth, story time.
- Include a scheduled wind-down time for about 30-60 minutes before bedtime. This can help reduce the time needed to fall asleep. Calming activities can include a warm bath, stories, massage/quiet adult-child snuggle/together time or a snack. Listening to soft music can also be calming.

Sleep Promoting Activities:

- Many children and teenagers with FASD are very sensitive to their environments, so they are easily over-stimulated.
- Avoid screen time, for example no TV, computer or video games for an hour or two before bedtime. Studies have found screen time can make it harder to fall asleep.

- Limit activities that increase stress or excitement, for example limit time on homework and keep in mind that some busy households can cause over-stimulation.
- Avoid food and drinks containing caffeine.

Medication:

- Some children and teenagers can also benefit from medication. Some over-the-counter medication may help to establish a sleep schedule. Talk to your doctor or pharmacist to see if this is a suitable option and that it won't be contra-indicated with any other prescribed medication.

Your environment

One of the best ways to think about strategies for children with FASD is to think about changing the child's environment, rather than changing the child's behaviour. The term 'environment' refers to many things, including where the child lives or goes to school.

Environment includes:

- physical environment.
- family, friends and the community.
- expectations and rules.
- schedules and routines.
- language and communication.

"In parenting children with FASD, it seems the harder we try to change behaviours, the worse they become. The shift in the definition of the source of the problem provides a different focus for interventions: from trying to change the child to changing elements in the environment"

Diane Malbin in her book 'Trying differently rather than harder' (2002)

"It can take on average over an hour to fall asleep. Waking up during the night can be problematic too. Music with headphones is always available.. music is preferred but audio stories also work."

"She sleepwalks every night. We have to make sure the house is safe so that she doesn't harm herself. We use stair gates and have locks on cupboards and doors"

Following are some tips about adapting your environment to meet the needs of your child or teenager:

Physical environment

- Children with FASD often struggle with loud, bright, over-stimulating and cluttered environments. This is because their brain has trouble filtering out outside stimuli. Think about a busy, bright supermarket, a loud birthday party or a crowded theatre. If your child often has tantrums or meltdowns in these kinds of settings, they might need help to manage this. Consider taking ear plugs for your child when it's too noisy, sunglasses or only staying a short time at the busy birthday party. In some cases, these kinds of environments may need to be avoided.
- Other ideas include using calming paint colours, such as pastels or keeping the volume down at home and in the car. Remember that every child is unique – sometimes, the only way to study is when the music is turned up loud. In this situation they want to try using headphones.
- Give your child a place to calm down when needed.
- Changing the environment may not bother most people, but moving the furniture at home, a new person coming to stay over or having a substitute teacher at school may overwhelm your child to the point where they are unable to tolerate the change. The challenge is to identify strategies to help your child cope.
- This may be as simple as preparing the child in advance that you plan to move the furniture or plan to keep your child at home on the days when there is a substitute teacher at school.
- Making space 'visually concrete' helps the child to better understand their environment, for example labelling boxes for toys. Try to use labels for clothes and other belongings. Use visual cues as needed in the bathroom, kitchen and other rooms to help the child clean up or take care of themselves.

Family, friends and the community

People around your child with FASD are very important assets, often providing the supervision and structure that they need to function on a daily basis. Support people can guide your child on outings, at family events or at school.

"Instead of turning the T-shirt round when my daughter is having difficulty getting dressed, I hold the T-shirt and she turns around so that she is the same way as the top. It has really sorted out the problem....daft, but it is fun and it worked!"

Whenever possible, think about ways to expand and nurture the supports surrounding your child, including grandparents, relatives, neighbours, family friends and support workers. This circle of support can make a huge difference in your life and in the life of your child. It may be hard to ask for help, but most people are willing to help when they know they are needed.

"We have a good circle of support within the family, at school and even when out playing with friends."

"We have to keep reminding family and friends she has FASD. Sometimes they forget or don't understand." Support is so important"

Expectations and rules

It is very important that your expectations for your child are realistic and in line with their feelings and abilities. This will help your child's feelings of success and will prevent problems down the road. It can often be helpful to 'think younger' when you are frustrated that your child is not living up to your expectations. Perhaps your 12 year old with FASD is acting more like an 8 year old. How can you change your response to fit your child's developmental age, rather than their actual age?

- Rules in your family or household should be clear, concrete and as consistent as possible. Maintain firm limits that are consistently applied. Do not do the 'just this once' routine as your child may be unable to see this change as a one-time thing. Don't debate, negotiate or try to over-explain rules. Just do it.
- Use calendars, sticky notes and visual cues as well as social stories to help your children understand what to expect each day and what is expected of them. Visual cues can include photos of step-by-step instructions, picture books of places and people, charts or lists with tasks identified or appointment books.
- In any shared parenting or care giving situation it is important that everyone is using the same strategies and routines with your child.



"Expectations... In reality these must be lowered but also stretched gently. Learning happens at a painfully slow pace."

Schedules and routines

Routine and schedules help your child predict what comes next. Create an activity routine throughout the day or the week. Some children need a lot of detail. Having an organised, predictable routine can also help ease the child from one activity to another.

- Try to be as consistent as possible with the schedule (do the same thing every day of the week, for example laundry on a Friday or swimming on a Saturday morning). Provide gentle reminders, including the use of visual or auditory cues.



- Monitor your child or teenager's free time as much as possible. This helps prevent them from having the opportunity to make poor choices.
- Transitioning can be hard for children with FASD. You can help by using timers (for example a sand or egg timer) or provide reminders and preparation when your child is moving from one activity to another. The more visual, the better.

"We take every opportunity to speak about friendships – use examples from TV programmes to spark discussions about who is a good friend and why and who is not really being a friend."

Language and communication

- Make sure your child understands you. Remember that children with FASD struggle with auditory learning so, while you are busy talking, they may not be able to interpret what you are saying in a meaningful way.
- Keep your instructions short, clear and concrete. If your child doesn't understand, use fewer words for the same instruction every time.
- Use visual reminders whenever possible. For example, thumbs up or thumbs down signs can help the child know, right away, what is good or bad behaviour. Ensuring you have eye contact with your child can help them better understand your words.
- Keep your tone as calm as possible.
- Slow the pace down to allow your child more time for processing.
- Always state what you want your child to do rather than what not to do. For example, if you want your child to stop running, ask them to 'walk' instead of saying 'don't run'.

"I hear and I listen, I see and I learn, I do and I understand."

(Anonymous)

Ownership

Children and teenagers with FASD often have trouble understanding ownership for many reasons. Most likely, the child does not have the ability to understand an abstract concept like ownership, especially when the object is not attached to a person. For example, if a child with FASD sees a bike on the pavement that no one is using, the child may think it doesn't belong to anyone. The idea that somebody not in sight owns the bike is abstract in nature, so the child may not be able to make the connection.

You may also notice that your child is very generous and shares easily with others. This is a strength that you want to encourage. This tendency towards generosity contradicts the idea that your child is stealing. It is more likely that they just don't understand ownership.

A child or teenager with FASD may have memory problems and forgot who owns a particular object. They may have thought it was theirs or that someone had given it to them.

They may also have trouble understanding when something is loaned to them. In their minds, it may seem that the person gave them the item. They may not be able to understand that the item must be returned at some point.

It can be hard for parents to know what to do in these situations. Your child may be accused of stealing from others. This can create consequences that are confusing for the child and are rarely effective. There are also times when children and teenagers with FASD do steal intentionally, which makes this even harder to figure out. Use your best judgement to interpret their behaviour and how best to deal with it.

Strategy suggestions:

Here are some tips for responding to your child's 'taking' behaviour:

- When you have discovered something that doesn't belong to your child, simply and calmly say that it needs to be returned to its owner. Watch for items that appear in your home that may not belong there.
- If your child has taken something that doesn't belong to them, make sure they return it with an apology. Avoid lecturing on the topic of stealing. The action of returning the item with an apology will be more effective than any explanation you may have about the idea of stealing.
- You can teach ownership in creative ways. Label your child's items in your home. If something doesn't have a label on it, then it is easier to explain to your children that it doesn't belong to them.
- Keep your environment de-cluttered so that other people's belongings are not lying around and available to be taken.
- Supervision and redirection of your child are the best ways to prevent opportunities for taking things that don't belong to them.



Storytelling/filling in the blanks

Many children and teenagers with FASD have problems with memory. Because of this, they may find it difficult to remember events in the correct order in which they happened or that they may not remember what someone has asked them. Their memory problems may also cause them to confuse what really happened with things they imagined, heard in a story, or seen on TV. This can cause children and teenagers with FASD to tell stories (or 'confabulate') to fill in the blanks in their memory.

Children and teens may also tell stories if they struggle with communication skills. In this case, they may not have the ability to properly explain what has happened.

This storytelling often causes people to assume that children and teenagers with FASD are lying to them, when, in fact, the child or teen is not able to recall what has happened. It is important for parents to learn the difference between lying and storytelling. The difference between lying and storytelling for a child or teen with FASD is that when they are storytelling, they are not trying to be dishonest.

"Storytelling was a huge issue when we didn't understand. It can make children and young people very vulnerable as there is a tendency to not believe a word they say"

Some children and teens with FASD may struggle with lying if they have trouble controlling their impulses. They may tell a lie when they think it is what the person wants to hear, when they do not want to disappoint someone or if they are trying to get someone's attention. With impulsive behaviour, it might seem like a good idea to tell a lie at that moment, but they have not thought ahead to the consequence of telling the lie.

"Lots of times I forget as soon as you say what I'm supposed to do. I look at others, not because I want to cheat, but because I want to work out what I'm supposed to do."



Strategy suggestions:

Here are some strategies to help your child or teen with storytelling and lying:

1 **Help your child figure out the difference between storytelling and the truth.**

- Give your child positive opportunities to tell stories and then, help them practice learning the difference between reality and fantasy/fiction.
- If you suspect your child might be telling a story, ask 'truth or story?' This will cue your child to stop and think before continuing to tell you what happened.

2 **Try not to punish your child for storytelling.**

- By providing a consequence for storytelling, the child is being punished for having short-term memory problems. Instead, praise them for having a good imagination, while also teaching them when it is appropriate or inappropriate to tell stories. Try using real-life examples to help them understand.

3 **If your child or teen is impulsive, reduce the number of opportunities for them to lie.**

- Instead of asking them if they did something, ask them to show you instead. For example, ask your child to show you that they cleaned their room instead of asking 'Did you clean your room?'
- Try to avoid unnecessary questions, such as 'Are you sure that happened?' These types of questions may cause the child to tell you what they think you want to hear.

4 **Try to avoid punishing an impulsive child with FASD for lying.**

- Instead, try using strategies to help your child manage their impulsive behaviour. (see section on Impulsivity).

Getting along with others

The gap between chronological age (how old they are) and developmental age (the age of their developmental level) is important to note for all people with FASD. This gap is particularly important to consider for the social relationship challenges that children and teenagers with FASD often experience.

For example, imagine supervising a 7 year old with FASD in a playground full of other children the same age. You may have similar expectations for all of these children because they are the same age. When the child with FASD begins playing and behaving similar to a 3 year old, the other children may stop playing with the child or start teasing the child. The child with FASD may become impulsive and/or invade the other children's personal boundaries, or be easily influenced by other children. These situations make it easy to understand how social gaps/delays may be one of the biggest frustrations for both children with FASD and their parents.

"My daughter is very shy and doesn't make friends easily. I have to help her with making friends."

Strategy suggestions:

Here are some strategies and tips to help your child get along with others:

Before arranging a play date or visit, begin to practice important social skills with your child:

- Practice how to communicate what your child wants and the appropriate answers, for example 'please', 'excuse me', 'no', 'no thank you'.
- Practice how to handle frustration, disappointment and hurt feelings, for example time out, count to ten.
- Practice how to manage someone bothering your child, for example walk away, speak to an adult.
- Practice appropriate body contact and personal space.
- Practice taking turns and sharing activities.
- Also practice appropriate behaviour with your child through role play, for example 'Sophie, can I play with you?'
- Practice the behaviour with guidance, for example 'What will you say when your friend doesn't want to share the colouring pens?'
- Reinforce your child's success in getting along with others as often as possible.
- Consider developmental age, rather than chronological age when organising and planning activities. Your child may be younger in their social skill development than their actual age. Note this trait for teaching skills.
- Try to understand what is happening for your child in social situations and where your child may be feeling vulnerable and unsafe. Create a safety plan with your child, for example develop a plan which can be followed when your child is feeling overwhelmed by other children, sound, light, movement and the environment.
- Many children with FASD like to be active. Sports and recreational activities may be a good place to channel energy and engage in social relationships.
- Maintain ongoing communication with your child's teacher, supports, neighbours, coaches and other caregivers. Discussing your child's social considerations will help your child to be included. It will also promote inclusion and appropriate behaviours in relationships and activities. Working with your supports, you can structure social environments and activities so that they are successful for all the children and parents involved.



Communication

It is common for children and teenagers with FASD to develop language skills at a slower rate than other children, which can affect their ability to communicate. The ability to communicate involves several different parts of the brain working together at the same time. This can be a difficult task for children and teens with FASD.

Sometimes there is difficulty with expressive language and receptive language development. This means that children and teens with FASD may find it difficult to understand what someone is saying to them or they may have trouble telling someone what they want, feel, or need.

Expressive language is a person's ability to put thoughts into words in a way that makes sense, using proper grammar. Children and teens with FASD who struggle with expressive language may use the wrong word to describe someone or something, for example using 'he' instead of 'she' or describing the kettle as 'the silver thing in the kitchen'. Often, they know the word but, because of how their brain works, they are not able to retrieve it from memory.

Receptive language is the person's ability to understand language that they have heard or read. Children and teens with FASD may have problems understanding language because they have difficulty processing information, for example hearing someone speak, trying to figure out what they mean, remembering it correctly, and then, acting on that information. Because of these difficulties, your child usually needs more time to process information.

Your child may lead you to believe they understand when they really don't. They may be able to repeat instructions word for word but still not understand or have the ability to follow through.

"School assignments are difficult especially when she has to read a few chapters of a book over the weekend and report on it on a Monday. She can't remember what she has read."

"Our daughter has trouble telling people what is wrong with her, what she needs or if she is struggling with anything... she just smiles and keeps it to herself. If she hears a conversation and you ask her what was said, she usually can't tell you... she makes it up!"

Children and teens with FASD may understand language in a literal way and may not understand abstract ideas. They may have trouble responding to an abstract request because they do not know what is being asked of them. What may appear to be disobedience may actually be their inability to put instructions into action. They tend to experience more success when they are provided with simple, concrete instructions.

Some children with FASD struggle to pronounce words properly, which can make it difficult for them to be understood. This is usually identified before a child starts school. In some cases, the child may need speech and language therapy to help them at home and in school.

Strategy suggestions:

Strategies to help your child with communication skills:

- When you start to speak, always use the child's name and make eye contact to help ensure that they are listening.
- Use simple, concrete language when giving instructions.
- Give instructions one step at a time and repeat instructions as needed.
- Use the same key words or phrases for tasks. This helps to place instructions in the child's long-term memory.
- To help ensure the child has understood verbal instructions, ask the child to show you what needs to be done, instead of asking them to repeat the instruction.
- Use visual cues to help your child understand verbal instructions.
- Record stories so children can listen and read along. There are audio books available to buy or download.
- If your child or teen is unable to put their thoughts in the right order, ask some more questions to help figure out what the child is trying to say.
- When you and your child attend meetings with several service providers, make sure that everyone allows time for your child to process what is being said.
- Keep meetings with service providers to a reasonable length. When meetings are too long, children with FASD can get tired or overwhelmed when trying to keep up with the conversation.



"Be careful with common expressions – a careless 'do that and I'll shoot the boots off you', can lead to distress. Don't use sarcasm to get a point across - it is usually taken literally'

3

What doesn't work and why?

Well known parenting methods are usually based on learning theory and include strategies such as:

- time-outs
- grounding
- using consequences
- discipline involving added work/chores
- contracts and/or positive reward systems, for example sticker charts
- verbal consequences, for example lectures, threats, shaming

Parents often turn to these strategies because they are so popular. We are all familiar with the use of consequences and cause-and-effect reasoning to manage behaviour.



Unfortunately, these parenting methods do not recognise the brain differences of people living with FASD. They fail to consider that some brains have difficulty storing and retrieving information, forming associations, generalising, thinking abstractly and predicting. Strategies, such as time outs and the use of consequences, require brain power that may not apply to people with FASD. For example, people with FASD struggle with cause-and-effect, so they have trouble connecting an action to a result. They make the same mistakes over and over. They may be unable to process and understand information or remember what happened the last time.

When using strategies to deal with behaviour, it is very important for parents to note:

- Typical strategies and learning-based parenting are not wrong, but they may not match how your child with FASD understands the world.
- Look for patterns of behaviour, anticipate problems and change the situation. This will help prevent the need for punishment and consequences.
- Pay attention to your child's most effective learning style and build on their strengths associated with this style.



"We had tried everything with her but she'd scream and have a tantrum unless we gave in to her. Now we have changed our approach and different strategies have made a difference to us as a family. Instead of grounding her for being late home, we send her a reminder on her phone. Just a small change has made a huge difference."

4

Finding Support

Within your family

Family members and close friends can be a huge source of support. You can help them understand your child by doing the following:

- Give them basic information on FASD. Don't bombard them with information. Instead, give a quick summary, say you can talk more about the diagnosis or offer some reading material if they want. You can also say you are trying to learn more about FASD at this time. It might sound something like this:
- "..... has been diagnosed with FASD. It is a brain-based disorder that sometimes makes it hard for her/him to think and act in expected ways. It is caused by exposure to alcohol during pregnancy and lasts a lifetime. I'm learning more about it as I go along."
- Be prepared to share your fears and concerns as well as theirs. They care for you and your child!
- Give them time to absorb the information.
- Tell them what your child needs. You are the best guide for the kind of support you and your child need.
- Teach them how to guide your child in the best way and explain that guidance is needed. Lead them by reframing actions, for example say your child 'can't' instead of 'won't' in terms of brain function.

Most importantly, focus on strengths and celebrate their success!

Within the community

Being out in the community is not always easy when there are others who do not understand your child's challenges and struggles. There may be people in school, organisations, the local shop or even your street who have unkind words and thoughts about your child. Remember that these thoughts belong to someone who doesn't understand that your child has a different way of thinking and feeling. If you want, you can help them see things differently. However, be sensitive to whether this is appropriate to say when your child is present. Try saying things like:

- "My child has FASD"
- "He/she has developmental delays"
- "He/she has special needs"
- "His/her brain is wired differently than yours"

You may want to give them more information in the form of a leaflet, booklet or direct them to a website.

Advocating for your child

You may need to advocate for your child or teenager. There will be times when they may be misunderstood and they will not have the right words. When you are educating others and speaking up on your child's behalf, you are acting as your child's advocate. You are taking on the role of 'interpreter' so everyone has the same information.

Instead of saying
"I need..... for my child",
say
"my child needs....."

Strategy suggestions:

Below are a few ideas about how to become the best advocate for your child or teenager:

1 Know the facts

- Teach yourself, and adults around you, that FASD is a brain-based physical condition with behavioural symptoms. Invisible physical changes in the brain can effect behaviour. This may mean trying different approaches to managing behaviour.
- Understanding FASD can help you explain your child's challenges. In many situations, you are going to be the expert on your child. Don't assume everyone knows as much as you.
- Understanding how your child is affected, their learning style and strengths, as well as your rights and responsibilities under the law.
- Keep a file with all the information you have collected over the years including assessment reports, personal notes and journals. This information is part of the big picture for your child and can help demonstrate your case.

2 Be specific about your concerns.

- What are you worried about? Having enough supervision? Having enough support? Or are you worried that others aren't seeing your child's talents along with his/her challenges?

3 Avoid being antagonistic when meeting with others.

- Think solutions and team-work. Remind them the goal is to help your child reach his/her full potential and each person has an important part to play.
- It's ok to get angry, but vent your emotions with a trusted friend or family member instead of professionals you are meeting with.
- Go into meetings armed with facts.
- Be ready to propose possible solutions.

Give examples about what has worked in the past, or what you think might make a difference. It may be a good start to finding a great solution!

- Finding the right system or agency to help is part of the challenge so don't be discouraged if it takes a few tries to find the right people to help. Keep trying!
- Make requests in writing to make it easier to remember and respond.

4 Share information...

- Remember FASD is a hidden disability and some people may take some time to understand your child. Keep lines of communication open. Listen and be visible.
- Use various ways to share information about FASD. Talk about it, provide leaflets, booklets or direct them to a website.
- An FASD information sheet that explains your child's disability can be very helpful. A sample sheet is on the next page. You may want to add information such as:
  - '.....learns best when you use.....'
  - '.....does not react well to.....'
  - 'when he/she is uncomfortable, he/she can.....'
  - 'when he/she is uncomfortable, you can try to.....'
- Success is more likely when all adults around your child are aware of your goals and strategies.

5 Join support groups.

- Not only are other parents a source of strength, but together, you can find solutions, promote learning and increase awareness. Many disabilities have common challenges, so you don't have to stick to just FASD support groups. If your child has other disorders, for example ADHD, feel free to join those groups too.

You can access national FASD support groups:

- **FASD Scotland**
  www.fasdscotland.com
- **FASD Trust**
  www.fasdtrust.co.uk
- **Adoption UK**
  www.adoptionuk.org

6 Find additional secondary advocates, if you can.

- A good role model at school, child care provider or family friend can be helpful.

7 Teach your child to advocate on their own behalf

- Help your child understand what is in the information sheets and practice how your child might explain FASD to others.

8 Give yourself credit for doing all you can

- Advocacy may be outside your comfort zone, but it will be worth it when you get the support you need.

What you need to know about me...

Adolescents and adults (13 and over)

I have Fetal Alcohol Spectrum Disorder (FASD). FASD is a brain disorder that affects the central nervous system and involves permanent damage to the cells and the connections between the cells in the brain. This is caused by exposure to alcohol during pregnancy. The effects last a lifetime. However, that doesn't mean that I cannot be successful in life. Here are some of the things you need to know about the way my brain works and how to understand me.

- Repetition of directions, instructions and concepts is very important because it allows information to be stored in the habit area of my brain where it will be remembered more easily.
- Routine and consistency help me to make better sense of the world. Establishing a routine and sticking to it helps me to function more effectively.
- I can be impulsive at times and this can affect my relationships. Role modelling and visual cues can help assist my interactions with others.
- You may need to adjust some of your expectations to my developmental age, which may be different to my actual age.
- My receptive and expressive language may not be the same. Often, I may not fully understand it. It is very important to follow through with me and ensure that understanding is reached.
- I often have sensory issues that lead to sensory overload. I may also become overwhelmed if too much stimulus or information is entering my brain at once. This may show itself through intense frustration, anger or other emotional outbursts. I need a safe place of my choice to calm down when I am feeling overloaded or overwhelmed.
- I have a unique level of sensitivity to criticism. I can become very upset with a sigh or angry glance. It helps to be aware of my sensitivity and to act accordingly.
- Learning and retention of information is achieved in small steps or stages. I may need you to guide me through a task in simple steps, one step at a time.
- I can have difficulties with time and money concepts, so I may arrive late or miss appointments and forget to pay bills. It helps to have things like reminder phone calls before appointments and help with budgeting and due dates for paying household bills.
- I may request that a parent or support person comes with me during appointments, meetings and job interviews so that they can help to interpret information.
- I have many strengths and things that I am good at. Take time to find out what I can do and emphasise the positive!

Notes.....

What you need to know about me...

For children (12 and under)

I have Fetal Alcohol Spectrum Disorder (FASD). FASD is a brain disorder that affects the central nervous system and involves permanent damage to the cells and the connections between the cells in the brain. This is caused by exposure to alcohol during pregnancy. The effects last a lifetime. However, that doesn't mean that I cannot be successful in life. Here are some of the things you need to know about the way my brain works and how to understand me.

- Repetition of directions, instructions and concepts is very important because it allows information to be stored in the habit area of the brain where it will be remembered more easily.
- Routine and consistency help me to make better sense of the world. Establishing a routine and sticking to it helps me to function more effectively
- Children with FASD can be impulsive at times and this can affect my relationships. Role modelling and visual cues can help enhance my interactions with others.
- You may need to adjust some of your expectations to my developmental age, which may be different to my actual age.
- My receptive and expressive language may not be the same. Often, I may not fully understand it. It is very important to follow through with me and ensure that understanding is reached.
- I often have sensory issues that lead to sensory overload. I may also become overwhelmed if too much stimulus or information is entering my brain at once. This may show itself through intense frustration, anger or other emotional outbursts.
- I have a unique level of sensitivity to criticism. I can become very upset with a sigh or angry glance. It helps to be aware of my sensitivity and to act accordingly.
- Learning and retention of information is achieved in small steps or stages. I may need you to guide me through a task in simple steps, one step at a time.
- I have many strengths and things that I am good at. Take time to find out what I can do and emphasise the positive!

Notes.....

.....

.....

.....

.....

Parent notes for Teacher

To my child's teacher.....

My child.....has been diagnosed with Fetal Alcohol Spectrum Disorder (FASD). This is a medical diagnosis and is an invisible neurological disability which impacts on the brain, causing the child to think and learn differently. Due to this, my child may act or react in ways that may surprise or dumbfound you.

My child can easily become over-stimulated. His/her nervous system overreacts to stimuli that other people hardly notice. You and I can filter out irrelevant sounds, colours or activities and still focus on a task to be done. 'Filtering' requires an ongoing, conscious effort on my child's part. .....is distracted by everything around him/her and has a hard time 'switching' from all classroom stimuli to focusing on what's important or required in class.

In addition, the 'different brain wiring' in my child's nervous system makes it extremely difficult for him/her to follow directions when they are given verbally or all at once. My child works best when you give only the first step of the instructions, let him/her do that step, then proceed to the next step. Modelling, demonstrating or giving visual cues can reinforce what needs to be done. That can range from simply pointing to something you've written on the board to an actual checklist for my child to follow. This checklist can be in print form or in visual form. Instructions need to be articulated in very simple, concrete and literal terms. Usually his/her behaviour is a way of communicating to you that something is not working for them. It is not wilful, deliberate or intentional.

I realise that this can sound somewhat intimidating. Children with FASD don't respond like other children to traditional teaching methods or behavioural modification methods. I want to give you as much information as you need to feel comfortable with my child. Your comfort level helps immensely in creating an environment in which my child will want to learn.

Please consider the following so that all professionals involved in.....'s learning can be aware of the interventions that will help him/her to attain.

What can over-stimulate my child	Warning Signs	What helps make my child feel safe

School is a highly unpredictable environment for a child with FASD. It can be a very frustrating experience regardless of how hard he/she tries. If my child wants to call me during the day, please allow this. It's a good way for him/her to touch base, and will help him/her to stay grounded in a 'just right' state.

Regular communication between home and school can help ensure that my child is working to his/her potential. With your permission, I would like to propose the following:

.....

.....

.....

.....

.....

.....

Let's try this for .....weeks/months; then we can discuss this to see how effective this was for us all.

My child has some amazing strengths. Building on these can help as well:

.....

.....

.....

.....

.....

.....

FASD can make it hard for my child to trust a teacher or to make friends – not from the lack of wanting to or trying, but from not being able to understand the variations of communication (like interpreting body language, reading facial expressions and tone of voice). My child's social skills are usually at a lower developmental level than their peers. Structure, repetition and patience are key elements of creating an environment in which my child can learn. Let's work together to come up with the 'best fit' possible for my child.

Thank you for taking an interest in my child.

.....

Parent/Carer

Adapted from FASD: Parent Notes for Teachers, Everyday is an Adventure: What parents and caregivers need to know about FASD, Manitoba.

5

Helping your Teenager with FASD

The transition from childhood to teenager can present some unique challenges for both caregiver and teenager. All teenagers want independence and freedom to make decisions. As a parent/caregiver of a teenager with FASD, you may need to find ways to safely respect these desires in tune with the teen's strengths and challenges. In this section, we will discuss some of the challenges you may have and some strategies to help you through these years.

"He can't cope well with relationships but with a little help we try and manage them"

Understanding and minimising secondary impacts

Secondary impacts are those problems that arise later in life, often during the teenage years but sometimes earlier. Secondary impacts are sometimes due to a poor fit between the person's needs, level of functioning and the environment. However, sometimes secondary impacts may be a worry, but the good news is that in many cases they can be minimised.

As a parent, you can do several things to help your child/teenager reduce the risk of negative experiences. Streissguth and Kanter in their book, The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities (2002) describe some common secondary impacts or secondary disabilities for people with FASD as:

- school disruption
- mental health concerns
- addictions
- poor self-esteem
- self-harming
- high risk sexual behaviours
- criminal justice involvement

It is important to note that there may be other reasons your teenager is struggling with these issues. The impact of trauma, poor attachment, genetic factors, and other conditions may need to be considered.



School Disruptions

School can be challenging for any teenager. There are often higher expectations on pupils and less support available to them when entering secondary school. Teens with an FASD diagnosis may not want to ask for extra help because they don't want to appear different from other children. Without help, they may end up feeling frustrated and fall behind in their schoolwork. This, along with other challenges, can lead to school disruption. Following is a list of ideas that can help you with the school system to ensure your teenager gets proper support:

- You may want to share the FASD diagnosis and information with teachers and support staff.
- Discuss your teenager's strengths and challenges with teachers and support staff.
- Ensure that the school is aware of other service providers/supports in your teenager's life.
- Provide additional resources for teachers and support staff.
- Advocate for your teenager as you know them best.
- Do your best to form a relationship with your teenager's teachers and support staff to help ensure their individual learning needs are met and their strengths are developed.
- Recognise that transition times may be especially sensitive and difficult, for example moving from Primary to Secondary school; school holidays to first day of new term; change of teachers or support staff.

Mental Health Concerns

Some teenagers may struggle with mental health issues which need professional help. The following are some of the more common concerns that teenagers may experience and how you can support them.

Addictions:

There are many reasons why your teenager may experiment with drugs or alcohol, such as low self-esteem, peer pressure, a need to fit in or as a way to cope with their feelings. Following is a list of strategies that 'may' help you support your teen.

- Talk to your child/teenager about substance use and your family expectations about using alcohol and other drugs.
- Be curious when asking your teenager about their substance use but do not judge. Staying neutral will encourage them to be honest with you.
- If you suspect your teenager has substance use problems or has developed an addiction, contact your local Addiction Services for support and information about how to talk to your teenager about substance use.
- Provide the counsellor with information about your teenager's FASD diagnosis to ensure the service provided is best suited for your teenager's learning style.
- Get involved to help your teenager at home and in the community with the goals they set during counselling sessions.
- Provide reminders and/or transportations to appointments.

"We have a box with treat coupons - we use this to celebrate achievements. Treats are fun, low cost family things"

Poor self-esteem

Most people, at some point in their life, struggle with low self-esteem. This may be especially true for a teenager with an FASD diagnosis because they may feel different, have trouble socially or struggle in school. As a parent, there are things you can do to try and help your teenager feel good about themselves, such as:

- Create opportunities for your teenager to build on their strengths, talents and interests.
- Celebrate even the smallest of success with your teenager.
- Highlight your teenager's strengths at school, and with other service providers to ensure they use and build on them.
- Get your teenager involved in organised recreational activities that can provide opportunities for building friendships and experiencing success. Remember that they may need reminders about rules, practice and game times, as well as transportation to get to the activity.



Self-harming behaviours

Self-harming behaviours may take many forms, such as cutting, scratching, not eating, vomiting after meals, not allowing wounds to heal, burning or hair pulling. It is important to know that self-harming is most often used as a way of coping. It is best to get professional help to find out if your teenager is using this as a way to cope with feelings. If that is the case, try to react calmly, without judgement or blame and be aware of your body language. Ask professionals for more ways you can help your teenager overcome self-harming behaviours and develop healthy ways of coping.

- Explore healthy coping methods your teenager can use, such as writing their feelings in a journal, listening to music, drawing and other artwork or exercising.
- Use feelings charts to help your teenager normalise all feelings including anger, sadness and joy.
- If you find your teenager 'getting stuck' in a negative emotion, try to steer them towards something positive.

High Risk Sexual Behaviour

Many teenagers with FASD have a strong desire to please others, which can make them vulnerable to social pressure and sometimes places them at risk. Teenagers can be sexually curious and may misinterpret social cues like a smile to mean someone is interested in them romantically.

- Talk to your teenager about boundaries, relationships and personal space.
- Openly discuss sexuality, sexual health, contraception and safe sex.
- Consider the challenges of FASD when thinking about birth control options for females. For example, if your daughter struggles with memory, a contraceptive pill that needs to be taken daily may not be the best option. Discuss the options further with professionals at your local Family Planning Clinic, GP Surgery or School Nurse.

- Help your teenager attend appointments about their sexual health.
- Even though your teenager may have a desire for independence, supervision and support is crucial to help them handle social situations, such as not recognising a potentially dangerous situation or befriending a stranger.
- Be mindful of your teenagers internet usage and speak to them about Internet safety.

"They both believe everything people tell them on the Internet. They don't understand why people would say things that aren't true."

Criminal justice involvement

In some cases, teenagers with FASD can find themselves getting into trouble with the law. If this happens, it is very important to talk to professionals working in the criminal justice system to ensure they can help the parent and the teenager get through this challenging time. Many of the processes and the language can be complicated. Asking questions will help everyone understand the process. Following are some ways to help with communication:

- If your teenager is in police custody, inform police of the FASD diagnosis and areas of challenge for the teenager. Ask that they are not interviewed for a statement until a lawyer or guardian is present. Explain that young people with FASD may behave younger than their chronological age.
- If your teenager is detained in custody, inform the custodial staff or healthcare staff within the prison of the FASD diagnosis. Tell them about your teenager's strengths and challenges to help staff to understand FASD better.
- Tell the lawyer about the FASD diagnosis and if possible, provide a copy of the assessment/ diagnostic report. This information may help the court to understand your child.
- The parent/carer's attendance in court is important to help answer questions and consider community supports.
- If your teenager is assigned to a Criminal Justice Social Worker, parents are encouraged to communicate with that person. If possible, go to appointments to ensure the teenager understands the information. This will help them comply with a Community Payback Order. CPOs can include language that is hard to understand, so ask questions. If your teenager is more visual, ask about visual tools, such as probation icons.

Transition from teenager to adulthood

Transition planning is an important step to help the adjustment to the next phase of your child's life. Your teenager may have a strong desire to live independently because they hear others talk about moving out of their family homes. Parents should consider several things when planning for their teenager's transition into adulthood. Start planning well before they turn 18. Keep in mind that although 18 is often used for a benchmark for adulthood, you as a parent must assess your teenager's developmental age, as they may be developmentally much younger. When it is appropriate, there are steps you can take to prepare them for this transition period:

- Ensure that your teenager has been assessed by an appropriate professional and has all current diagnostic assessments available. The assessment results will determine whether your teenager will qualify for adult support services and/or benefits that will help with their independent living.



- If your teenager has a support system in place at school or through other services, include them in the transition planning. Help your teenager to gain more understanding and acceptance of the type of support they may need in adulthood.
- Consider if your teenager would benefit from living at home as an adult or if they need supported living. If your teenager is able to live independently, remember they may need extra support to be financially independent. Be creative in coming up with ideas to help them with budgeting, so they can be successful in paying rent and fulfilling other basic needs.
- Keep in mind that your teenager may be very generous with their money which leaves them vulnerable to financial victimisation. Do what you can to protect them from this because it can happen more than once due to difficulty with associating one situation to another, as well as understanding cause and effect.
- When your teenager is looking for work, help them build on their strengths and abilities. Remember that a busy, high-paced work environment may not be a good fit . You may want to consider supervised work-placement options. Encourage your teenager to discuss their strengths and challenges with their employer, as well as ways to increase success in the workplace.

"It was important to support him as much as possible when he moved on."

6

Talking with children and teenagers about FASD

It is important that your child or teenager understands that they have FASD. Your child needs to know about themselves, who they are and how their brain works. Without this information, there is no way for a child with FASD to understand why their brain works differently from others. We all have to make sense to ourselves. Understanding how FASD affects your child will help them do that.

As a parent, you may be worried about talking with your child or teenager about FASD. Maybe you are worried about:

- making things worse
- your child being stigmatised
- your child being treated differently by others
- them feeling badly about themselves
- them being angry about how this happened to them

Some of this may happen, but working through these questions and feelings can lead your child to a better understanding of themselves – and even empower them to face the world with more confidence.

Once your child/teenager understands their disability, it can open the door...

How do I talk with my child about FASD?

It depends on the age of your child. Even young children can benefit from information about their diagnosis if it fits with their age and stage. Prepare yourself in advance by getting information about FASD, its diagnosis and the words you will use to explain it. Use concrete, simple terms and try to keep explanations short – at least at first. You may want to use visual cues for example, pictures of the brain, to help your child to understand what is happening for them. Try to normalise what is happening for them as much as possible, such as 'all of our brains are different – we all have different strengths and learning styles'. Talk about your child's unique strengths and reinforce their worth and abilities. FASD is only a part of who they are.

Prepare yourself emotionally. Try to have supports in place, for both you and your child, before having your talk. Choose the time and place for this talk when things are quiet, stable and there is enough time. You should follow-up at another time to see what your child understood from the talk and to answer any questions. Make sure their support system also knows about this talk, so that they can support your child and reinforce your supportive messages.



You may need to help your child or teenager deal with anger about having FASD. No one drinks during pregnancy to harm their child. There are reasons why women drink during pregnancy. Some mothers:

- don't know they are pregnant right away
- don't realise that drinking will harm their baby
- have an addiction to alcohol and need help to stop drinking

Acknowledge your child's feelings of anger, fear or frustration about having FASD. Help them work through these feelings to help them understand and accept them over time.

Once your child/teenager understands their disability, it can open the door so that you can work together to find ways to address their challenges. Many children and teenagers say that they feel relieved when they find out that this is a medical condition, rather than feeling 'stupid' or 'bad'. Over time, your child will develop positive coping strategies because their understanding of FASD and will be better equipped to advocate for themselves in the community.

7

Grief and Loss

Many parents experience feelings of grief, loss and guilt along their journey with the child with FASD. These feelings are normal and natural. The feeling of loss for what 'could have been' for the child can be overwhelming if it is your only focus. Hopes and goals can be adjusted to your child's strengths. Building on the possibilities can help to shift the focus from negative to a more positive, productive path.



The feeling of guilt for the effects of alcohol on the child can also be difficult for parents. No parent sets out to cause harm to their children. People consume alcohol for many different reasons and to various degrees. Because it is unknown how much alcohol produces what effects, no alcohol is the best practice when pregnant. **No Alcohol** = **No Risk**.

Often, mothers are unaware that they are pregnant until several weeks into their pregnancy and have, unknowingly, exposed their unborn baby to alcohol. Some have addiction issues. Whatever the reasons have been for alcohol exposure, intentional harm was not what the mother had set out to do. It is important to recognise these feelings, seek appropriate support and help to understand your own feelings about this. You need to be well, physically and emotionally, so you can be the best parent possible for your child.

8

Taking care of Yourself

Parenting can be hard work. Parenting through FASD behaviours can be extremely hard work. The hard work goes on and on, because it takes a long time to raise a child. Parents also continually deal with intense emotions, such as frustration, disappointment, and sadness, as they try to help their children manage the extra challenges FASD causes. Deliberately making time to take care of yourself will help you avoid the emotional fatigue that can take a toll on you and interfere with loving parenting. Being the best parents you can be, for the children you love so much, requires a focused effort on your own self-care.

Be the strongest version of yourself. Look after your own physical needs – get enough sleep, eat well, exercise. Invest in the relationships that give you emotional support. Remember the interests and passions you had before parenting a child with FASD and spend time enjoying them again for example sports, music, and art.

- Know yourself and your responses. Notice your strengths and resources and lean on these. Notice your limitations and find help in these areas. Be aware of your triggers and how to avoid them.

"We all know how important it is to get 'me time' but just pay it lip service. When looking after a child with FASD it can be even more difficult to ask for help and there are sometimes less opportunities open to you. However, it is vitally important to be able to take time out for yourself as it definitely enables you to reenergise and build up your reserves for the next challenge."



- Stay informed about FASD. Continue learning. Read research, go to workshops, join committees and connect with others who understand.
- Make use of respite and resources for your children. Learn what is possible and accept help from organisations and personal supports.
- Be an active part of your community. Families affected by FASD risk isolation because of behavioural challenges. Embrace your community and enjoy the support it offers.
- Accept the challenges of FASD and adjust your expectations, both for your children and yourself. Don't worry about the little things. Know that there will be rough moments and decide to bounce back from these even stronger. Have a long-term perspective, knowing it will be better tomorrow. Allow for mistakes from yourself and your children – and forgive.

Try using 'the positive game'

'It's all about finding the positive in the FASD moment...for example; when our daughter locks herself in the car in opposition to bedtime...we find the positive that she is sitting in the back seat and not in the driver's seat, the car's not running and the keys are not in the ignition.... at least it's a nice night and we can sit outside. It's a good time and it reminds us that there is always an upside, provides us with a little humour, controls the stress levels, makes our relationship stronger and gives us time to process and figure out an appropriate strategy while at the same time giving her time to process the situation as well.'

One last thought...

Starfish Story

One day an old man was walking along the beach just before dawn. In the distance he could see a boy picking up stranded starfish and throwing them back into the sea. As the old man approached the boy he asked "Why do you spend so much energy doing what seems to be a waste of time?"

The boy explained that the stranded starfish would die if they were left in the morning sun. The old man exclaimed, "But there must be thousands of starfish. How can your efforts make any difference?"
The boy picked up another starfish and as he threw it back into the sea he said to the old man, "It makes a difference to this one!" *Author Unknown*



Though parenting is hard work, it can also provide indescribable joy. Laugh at the many 'FASD moments'. Be grateful for your children. Keep yourself strong enough to recognise the joy.

9

Useful websites

If you have more questions about FASD, you can access further information at:

Fetal Alcohol Advisory Support and Training Team (FAASTT)
www.faast.ed.ac.uk

NOFAS
www.nofas-uk.org

FASD Hub Scotland:
https://www.adoptionuk.org/fasd-hub-scotland

Fetal Alcohol Advisory Support & Training Team

THE UNIVERSITY of EDINBURGH

Copyright ©2023 Fetal Alcohol Advisory Support and Training Team (FAASTT), The University of Edinburgh. This material has been produced by the Fetal Alcohol Advisory Support and Training Team and is the property of The University of Edinburgh. As such, material can only be copied / reproduced / shared with the express permission of the copyright owner. Please contact FAAST@ed.ac.uk for further information.