



Healthcare
Improvement
Scotland

SIGN
Evidence-based
clinical guidelines

Fetal Alcohol Spectrum Disorder (FASD)

A booklet for parents, carers and families of children and young people exposed to alcohol during pregnancy

Living
skills
age 11

Reading
ability
age 16

Physical
age 18

Communication
and social
maturity
age 6

Social
skills
age 7

Expressive
language
age 20

Money
and time
concepts
age 8

PLAIN
LANGUAGE
COMMISSION
CLEAR
ENGLISH
STANDARD

Acknowledgements

We would like to thank all the parents, kinship carers and young people who helped develop this booklet by sharing their experiences.

Thanks also to the voluntary organisations who contributed to this booklet.



Cover image illustrates the developmental stages of an 18-year-old with FASD. This is an example profile and every child is different.

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Who is this booklet for?

This booklet is for parents, carers and families of children and young people up to the age of 18 who:

- are affected by alcohol in pregnancy
- may be going through assessment
- may be described as having fetal alcohol spectrum disorder (FASD).

Anyone in touch with your child may find it helpful too. It can help them to understand and support your child.

Throughout the booklet, 'parent' refers to people who live with the child and are the main carers. This includes foster parents and legal guardians.

'Child' refers to children and young people up to age 18.

Details of support organisations and other places where you can find out more are on pages 38-46.



What is this booklet about?

This booklet explains the recommendations in a clinical guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about:

- identifying children who are at risk of FASD
- assessing children and young people who have been exposed to alcohol before they were born, and
- supporting and following up children and young people who may have FASD.



This is the first UK guideline for this condition. For many years, it has been known that drinking alcohol in pregnancy can harm the unborn baby, but the condition remains poorly understood for several reasons:

- Not knowing how children may be referred for professional help and which service to refer them to.
- Difficulty accessing the recommended standardised assessment process.
- Lack of training on FASD for professionals.

The professionals in Scotland involved with your child should now be following this guideline.

The clinical guideline was published in 2019. It is based on what we know from current research. Some parts of the clinical guideline were adapted from the Canadian guideline for diagnosing FASD. The Canadian guideline also gives advice based on the opinion of professionals who have experience of identifying and assessing children and young people who have been exposed to alcohol during pregnancy.

The full SIGN guideline is available on our website www.sign.ac.uk/assets/SIGN156.pdf

On page 47 you can find out more about us at SIGN and how we produce guidelines.

There are two types of recommendations in this booklet:



Recommendation

based on the research
evidence



Recommendation

based on clinical
experience

What is FASD?

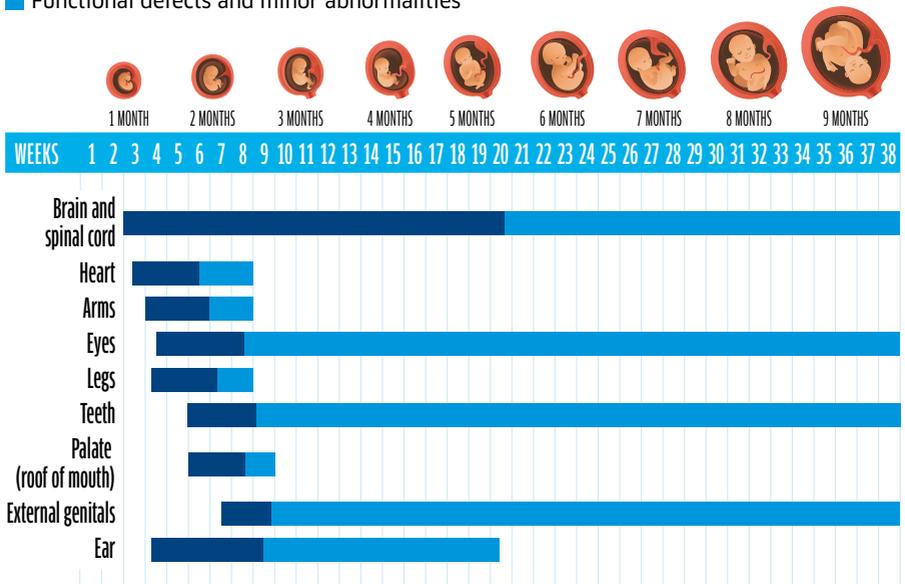
Fetal alcohol spectrum disorder (FASD) refers to the lifelong effects caused when an unborn baby is exposed to alcohol.

When a pregnant woman drinks alcohol, the alcohol in her blood passes through the placenta into the developing baby. The baby can't process alcohol as well as the mother can, which means it can limit the growth of brain cells and damage the baby's central nervous system (or CNS) and other organs.

How alcohol in pregnancy can affect the developing baby

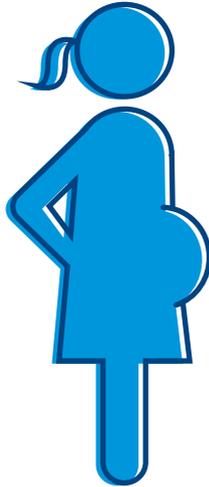
Stages of fetal development

- Major abnormalities
- Functional defects and minor abnormalities



This illustration has been adapted from www.slideshare.net/SDRTL/fetal-development-10766134

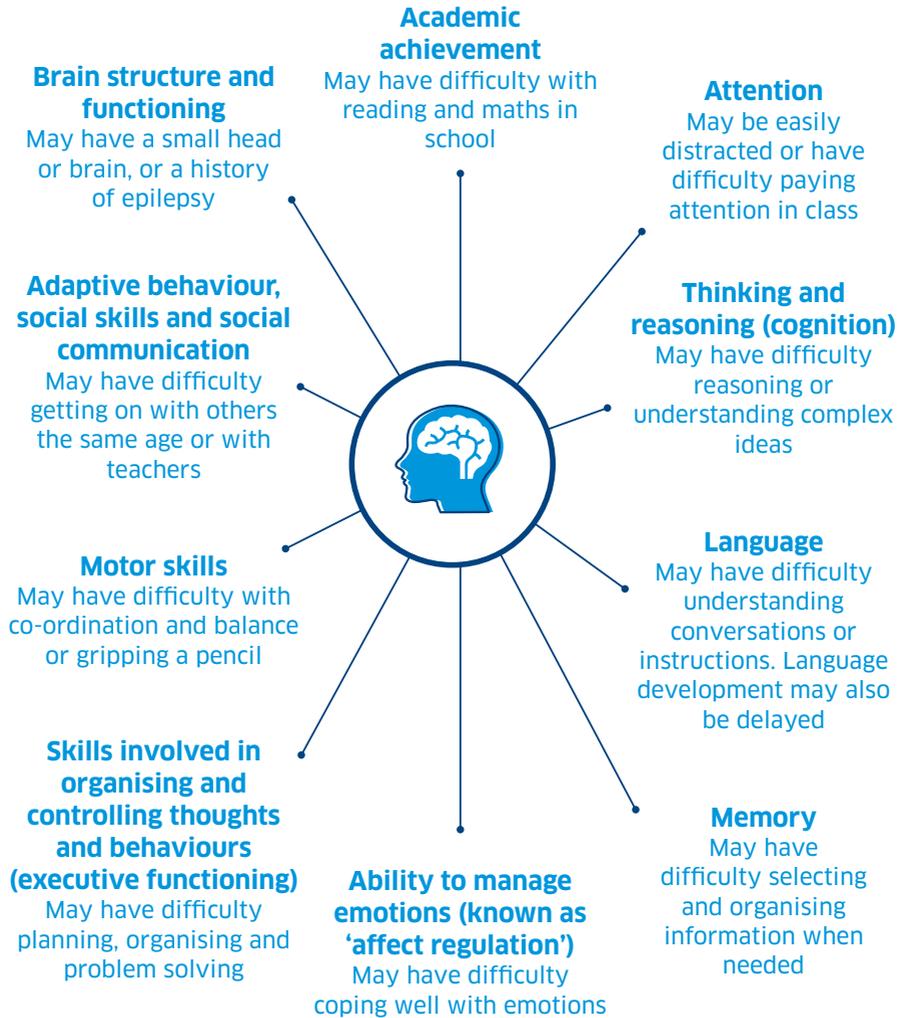
There is no way of being certain how alcohol might affect an individual unborn baby. The only sure way of avoiding harm is to follow the Chief Medical Officer's recommendation, which is No Alcohol, No Risk.



FASD is a hidden lifelong condition that can affect physical health, social skills, communication skills, memory and behaviour. However, with the right support, people living with FASD can achieve things in life.

Differences in the brain and central nervous system may be the underlying reason for difficult behaviours in children and teenagers. To understand the difficulties your child is having, their skills and abilities shown on page 7 will be considered during the assessment process for FASD. You can find out more about the assessment process on page 18.

There are ten areas of assessment



This illustration has been adapted from a diagram in “Every Day is an Adventure: What Parents and Caregivers Need to Know About FASD”, Healthy Child Manitoba.

How common is FASD?

It is estimated that at least 3 in every 100 babies born in the UK are affected by FASD.

Some professionals are still learning about the condition. They need to be aware of it and good at identifying and assessing it.



Recommendation based on clinical experience

FASD is more likely to be present in some groups of people, such as:

- children and young people in the care of their local authority
- children and young people with learning difficulties
- those with mental health problems
- those who are known to the police or courts.

It is important that organisations and professionals working with them are aware of FASD.

If you want more copies of this booklet for family members or professionals who support your child, please feel free to ask us (see page 48 for contact details).

What are the signs of possible FASD?

Some children may have a mixture of physical, behavioural and thinking difficulties.

What behavioural and thinking difficulties may you notice?

- Disturbed sleep
- Speech and language delay
- Mood, behaviour and attention difficulties
- Being easily led, which may increase their risk of criminal behaviour and substance misuse
- Poor short-term memory
- Difficulties in school, which become more noticeable as the child gets older
- Difficulties with social communication, particularly with their emotions
- Difficulties with daily living (for example dressing, or travelling independently)
- Difficulties making and keeping friends
- Poor judgement skills
- Depression
- Sensory difficulties (for example dislike of the sound, smell, feel or touch of certain things)

What physical difficulties may exist?

- Premature birth
- Sucking difficulties in babies
- Not growing as expected for their age
- Small head size
- Small eyes
- Poor fine motor skills (for example, this may make good handwriting difficult)
- Vision or hearing impairments
- Movement, balance and co-ordination difficulties
- Thin upper lip
- Smooth philtrum (the ridge that is usually seen between the nose and upper lip)

People affected by FASD can have particular strengths also.

What kind of strengths do families recognise? A child may be:

- creative
- musical
- active
- eager to please
- good at remembering visual information.

FASD can exist along with other developmental conditions. These include **autism** and **attention deficit hyperactivity disorder (ADHD)**. Some behaviours are common in all these conditions. Assessment should consider an overall profile of strengths and difficulties.

Autism is a lifelong developmental condition affecting social skills, communication skills, and behaviour.

ADHD is a condition where a person has consistently high and inappropriate levels of activity, acts impulsively and is unable to pay attention for long periods of time.

Other neurodevelopmental disorders and mood disorders (mental health conditions that affect mood).

Developmental co-ordination disorder (a condition affecting physical co-ordination).



Worried your child may have FASD?

As a parent or carer, you may be able to see for yourself that your child has difficulties with their development. Sometimes your child's difficulties may only become clear as they get older.

“When X first came to us, he was perfect. He would eat every meal at 5 years old and would say thank you but he would sit with his fists clenched so that his knuckles were white. It was clear to me that something was wrong. It was very hard to try and get the professionals to listen to my concerns. No-one wanted to help.”

“Sleeping was an issue, he didn't sleep and constantly sucked his thumb. The mood swings are unreal and he doesn't have many friends.”

“They (grandchildren) were slow to pick things up. X didn't ride a bike until he was in primary 4, he's always found gym a challenge, couldn't jump like the rest and always had poor pencil grip. The older they get, the harder it is for them so it's important to get the help they need.”

“When she took temper tantrums, her face would glaze over and you couldn't reason with her at all. We could only understand what was happening when we realised it was down to FASD.”

What should I do if I'm concerned?

You should speak to your GP about your concerns. If your child is under 5, you could also speak to your health visitor. Be specific about your concerns. You may wish to write down a list of behaviours and difficulties you have noticed. Keep reports from nursery, school, social work and healthcare professionals that refer to your child. Photos of your child when they were younger may also be useful. These things can help professionals to understand your concerns.

You can raise your concerns with the key people involved with your child and who work in partnership with you as part of the Scottish Government's Getting it Right for Every Child (GIRFEC) policy. This may be your child's health visitor, head teacher or guidance teacher if they are at secondary school. They can help you get the support your child needs. Support services will not be specific to FASD.

GIRFEC is a national approach in Scotland to improve outcomes and support the wellbeing of children and young people by offering the right help at the right time from the right people. It supports them and their parent(s) to work in partnership with the services that can help them.

What information should I share with my GP or health visitor?

The amount and timing of the baby's exposure to alcohol are important things.

It's good to have as much information as possible about the intake of any alcohol during pregnancy. This includes the amount and stage of pregnancy when it happened and if it was binge drinking or social drinking. If you have this information, please share it with your GP or health visitor as diagnosing FASD is difficult without it. They will not make this information available to other services without your consent.



Recommendation based on the research evidence

If your child's difficulties might be caused by exposure to alcohol during pregnancy, your GP or health visitor will make a referral for assessment.

The referral pathway

1 Referral

- A referral usually comes after concerns have been raised, for example by a parent or caregiver to a GP, social worker, teacher or by a health visitor to the relevant child service. Professionals may also raise concerns and ask for consent from families to make a referral. Referrals are made to one of the following departments where appropriate:
 - Community paediatrics.
 - Child and Adolescent Mental Health Services (CAMHS).

2 Initial assessment

- Some child health departments, for example Child and Adolescent Mental Health Service (CAMHS), may offer an initial assessment. This is normally a broad assessment by one or two professionals. It includes questions about early development, family history and current difficulties.
- As part of this, information may be requested from school and social care.
- To find out more, screening questionnaires may also be given to caregivers or school staff.
- At this point, more assessment may be needed, or plans for support may be made.

3 Neurodevelopmental assessment and feedback

- If there are any concerns about a child's development, a more in-depth clinical assessment may be made. It looks at various areas of their ability and is common in children's services.
- Team members from different professional backgrounds may be asked to assess the child's skills, for example language. This is often called a 'multidisciplinary team'.
- The team may provide several appointments to work out strengths and difficulties. They then give feedback to caregivers. This could include diagnosis and ongoing support as needed. Sometimes this is called the Child's Plan.

How will I be prepared for the assessment?

Before the assessment your healthcare professional should do the following:

- Explain why an FASD assessment will be useful.
- Explain what will happen.
- Offer you the opportunity to bring someone with you, for example a friend or relative.
- Explain that the assessment may involve taking a photo of your child's face and taking measurements.
- Ask for your consent.

What information will the assessment team need?

You may not have all the information but you should take the following to the assessment if you have it.

- Birth records that give information about your child's date of birth, and the baby's weight and length.
- Parent-held child health records (PHCHR or Red Book). This gives information about your child's history of growth, weight and height.
- Your child's medical history such as illnesses, any surgery, vision or hearing problems.
- School reports and any concerns raised by teachers or the school.
- Photos of your child showing their face at different ages.

How are children and young people assessed?

Ideally your child should have an assessment as early as possible. This means the right support can be put in place to help your child cope with difficulties.

This can help them achieve things in life and minimise future problems. These may include not doing well at school, exclusion from school, mental health issues, homelessness and substance misuse. These can sometimes lead to getting into trouble with the police.

“It took a few weeks to assess our son, he was a toddler who had been exposed to alcohol, he wasn’t meeting milestones he had sentinel facial features so it was easy to diagnose him. With our daughter it was very different. When she was 18 months old we had concerns. We knew about the alcohol history but we didn’t pursue getting a diagnosis because they kept saying she just had development delay so we got fed up asking. We just loved her and got on with it but we treated her differently because we knew she was different. We went on a FASD course for parents of children who have FASD and afterwards we recognised our teenage daughter was living with it but it hadn’t been diagnosed. Round about the same time, our daughter started to realise she was different from her friends and she thought she might also have FASD. We contacted our social worker who advised against getting a diagnosis. We were told not to mention it and not to discuss it in front of our daughter. It was like it was a secret and it shouldn’t have been. It was easier for our daughter to understand FASD because her brother was also living with it. After a year, doctors confirmed that her brain had been affected by alcohol in pregnancy. Support was arranged for her and knowing that she has FASD has helped her to live with it.”

“I had concerns about FASD, but ruled it out due to no facial features. It was only after understanding the condition better that I was able to feel confident to ask for an FASD assessment.”

Gathering information about your child

The assessment team will need to gather information about your child. You may be asked to fill out a form before you go to the appointment. The team will usually do the following:

- Look at the documents you brought with you.
- Ask about the birth mother's pregnancy and the baby's birth.
- Examine your child including:
 - testing their hearing and eyesight
 - measuring their weight and height.
- Test your child's ability to communicate and move.
- May take a photo of your child's face or look at their face and take measurements of it.



Recommendation based on the research evidence

The assessment may take some time and will involve seeing different professionals. It should be tailored to your child's needs. It should bear in mind their ability to cope with a busy place, or that they may be too tired to attend appointments late in the day.

Who does the assessment?



Recommendation based on the research evidence

The signs of FASD are complex and vary from person to person, so several professionals who are skilled in different assessments will be involved (known as a multidisciplinary team).

A multidisciplinary team can include different kinds of professionals, for example:

- paediatrician
- speech and language therapist
- occupational therapist
- physiotherapist
- psychiatrist
- psychologist.

See pages 45–46 for what each of them does.

What will happen at the assessment?

The professionals will want to get to know your child and hear about your and their experiences. This is important because family members can be the first people to notice that the child has some difficulties.



It may be easier for you to make a list of these difficulties before any appointments so you can give it to the professionals you meet.



Recommendation based on the research evidence

The multidisciplinary team will also want to gather information about how your child gets on in their day-to-day life. They will do this with your permission by contacting other people who can provide relevant information (for example your child's teacher or learning support teacher, educational psychologist or social worker).



Recommendation based on the research evidence

The assessment should involve:

- a physical examination
- finding out about the child's earlier development, the family situation and any problems the young person is having
- measuring the eyes, lips and philtrum (the space between the nose and upper lip) to look for facial characteristics.

The assessment team will assess the following areas. These are explained on page 7.

Areas of assessment

Brain structure and functioning

Academic achievement

Attention

Thinking and reasoning (cognition)

Language

Memory

Ability to manage emotions known as 'affect regulation'

Skills involved in organising and controlling thoughts and behaviours (executive functioning)

Motor skills (movement)

Adaptive behaviour, social skills and social communication

For younger children, parts of the assessment may need to be put off until they are older.

What will happen after the assessment?

The assessment team will talk with you about the results as soon as they can. You should also receive a written report summarising what the assessment found and the team's decision about your child's condition, which may be FASD or another diagnosis.



Recommendation based on the research evidence

Your child may receive a diagnosis of **FASD with sentinel facial features** if they have all three facial characteristics described as being specific to FASD. These are small eyes, thin upper lip and smooth philtrum. The facial features must be accompanied with confirmed or unknown alcohol use by your child's birth mother when she was pregnant and severe difficulties in at least three of the areas of assessment.



Recommendation based on the research evidence

If your child does not have all three typical facial characteristics but has confirmed exposure to alcohol before birth and severe difficulties in at least three areas of assessment, they may be described as having **FASD without sentinel facial features**.

The professionals will consider other possible genetic causes, as well as measuring growth. They will also consider other birth or health issues.



Recommendation based on the research evidence

Healthcare professionals may use the term **at risk for neurodevelopmental disorder and FASD** if there is confirmed alcohol exposure before birth and your child has some developmental difficulties that are assessed as not severe.



Recommendation based on the research evidence

Children and young people who are 'at risk for FASD' and have the sentinel facial features but do not have microcephaly (small head) may be referred to a clinical geneticist.

The clinical geneticist is trained to recognise the physical and facial features seen in FASD. They will consider other possible genetic causes.

Getting the assessment results

The team should do the following.

- Explain the assessment results and the implications of having FASD or another diagnosis.
- Develop a 'next steps' plan with you and your child and ensure it is appropriate, whatever the diagnosis. This will help identify goals and priorities. The plan will consider the difficulties you and your child are having. You should receive a copy of this.
- Discuss the importance of sharing assessment reports with your child's school and ask for your and your child's consent to do this.
- Make you aware of any need for referrals and further review and of the expected waiting times for services.
- Listen to any concerns you have and answer any questions.
- Give you a contact number of a team member who can answer questions you think of after the assessment.
- Encourage you to seek professional support where needed or contact support organisations that provide information, advocacy and support for people and their families. Details of support organisations are listed on pages 38-40.

“Every plan needs to be individualised for each child.”

Talking about the assessment results with the team will enable you and your child to raise any concerns.

The team should talk to you about the following:

- Difficulties of daily life, for example caregiver fatigue, the need for routine and repetition.
- Emotional or behavioural problems for many individuals with FASD, including aggression.
- Your family's need to use multiple health services who might not know what each other is doing (and the need to ensure that support is co-ordinated).
- Where to access information to support others to understand FASD as a cause of disability, and to find out next steps for getting more help with education or money.
- Information to help you recognise associated mental, developmental or physical health conditions.

What can help?

Understanding FASD

No two people with FASD will have it in the same way. It's important to know they will have different needs as well as different strengths.

It's crucial that you and everyone working with your child learns about how FASD affects them and the difficulties and strengths they have. Better understanding of the condition can help you and your child cope better.

Everybody working with your child needs to understand that FASD is a lifelong disability that can't be cured and requires ongoing support. They should promote and develop your child's skills. It is helpful to know the ten brain functions that FASD affects (see pages 7 and 22). To support your child, everyone around your child needs to be ready to learn about FASD. They also need to adapt the surroundings your child regularly encounters (see pages 32-33). You and your child will become experts in FASD. You will also have a good understanding of their strengths and when to seek support.

"X is very caring and sympathetic, he does care about other people."

“Knowing what the triggers are is very important and schools should have a strategy for that. Make an appointment with your child’s teacher to make them aware of them.”

“There needs to be an educational plan in place and subjects for FASD children need to be vocational. Speak to school about your child so the education is tailored for them.”

Strategies that can help

There is no set way of working with individuals with FASD. The following strategies, known as the 8 magic keys, on pages 29–31 can be used by people involved with your child to help them cope.

Remember that every child is unique and has different difficulties. Some strategies may not be suitable for them. You can try all the strategies to find out what works best. You may wish to make a note of these on page 34.

8 magic keys

1 Concrete terms

Children living with FASD do well when parents/carers and teachers talk in concrete terms. Don't use words with double meanings, etc. The social emotional understanding of children living with FASD is often below their age in years, so it helps to 'think younger' when helping, giving instructions etc. It's also important not to make assumptions.

"They would take the phrase, 'get on your bike' literally."

2 Consistency

Children with FASD have difficulty taking what they have learned from one situation to another so they do best in an environment with few changes. This includes consistent language and routines. Teachers and parents/carers should co-ordinate with each other to use the same words and gestures for key phrases. Communication books are effective ways of sharing what's happening and agreeing on language and behaviour in the classroom and at home.

"Need to work with the school so there is consistency - meet class teachers."

3 Repetition

Children with FASD have chronic short-term memory problems. They forget things they want to remember, as well as information they need to learn and retain for a period of time. For them to commit something to long-term memory, it often needs to be taught many times.

"Teachers would have taught something one week but the child forgets the next week. The teacher expects the child to remember it but it needs to be repeated."

4 Routine

Stable routines and seeing the same things around them from day to day make it easier for children with FASD to know what to expect next, and decrease their anxiety, enabling them to learn.

“Routine is so important. They find school holidays really difficult and it can be very challenging.”

“Important to have a structured routine on holiday.”

5 Simplicity

Remember to keep instructions short. Children with FASD are easily overstimulated, leading to ‘shutdown’, at which point they can’t take more information. Break down every task into small steps and always communicate the task in a positive way.

“Say ‘in school, we walk’, instead of ‘don’t run’.”

6 Specific language

Say exactly what you mean. When given an instruction, children with FASD have difficulty with abstract ideas, vague statements and ‘filling in the blanks’. Tell them step-by-step what to do. This will help them develop habit-forming patterns. Keep instructions concise. Break them into achievable chunks.

“I have to keep giving instructions over and over. ‘Brush your teeth’, ‘put your jacket on’. He forgets them so I have to give one at a time.”

7 Structure

Structure is the 'glue' that enables a child with FASD to make sense of the world. If this glue is taken away, things fall apart. A child with FASD achieves and succeeds because their world gives suitable structure as a permanent foundation for learning.

"If you're going on holiday tell them where they're going and what it will be like. It's good to show them pictures so they know what to expect."

8 Supervision

Children with FASD can be naive about daily life. They need constant supervision, as with much younger children, to develop habit patterns of suitable behaviour and ensure safety and well-being at all times.

"Social media can be very dangerous for children with FASD. They are at a high risk of being groomed due to their trusting nature."

Adapted from Deb Evensen and Jan Lutke (1997) who developed it for the Fasalaska Project (see page 42).

Make simple changes to adapt things for your child

Here are some examples:

- Have a structured timetable where possible. For example, bedtime and meal times should be the same.
- Try to avoid over-stimulating activities before bedtime, so have quiet time.
- A white board or calendar in their bedroom reminds them of daily activities.
- If your child has a phone, you could encourage them to set the alarm as reminders to do things.
- Keep in mind that your child gets tired and restless.
- Model or teach coping strategies such as taking a warm bath and time to ‘chill’.
- Avoid shopping or travelling on public transport at busy times.



“Teachers need to be able to recognise that children with FASD start to get fidgety so they can give them a break by giving them a wee job to do in the classroom.”

Simple changes that can help your child at school

Here are some examples:

- Organisation box to store things in, for example jotters, bag and coat
- Visual timetable
- Friendship support
- Preparation/pre-warning if things are going to change
- Eye contact/say their name when asking a child to do something
- Time-out zones in classrooms for when things get too much for them
- Slanting boards



“It is important to respect their physical age but be aware that mentally they are much younger.”

What doesn't work

- Punishments and rewards to condition behaviour
- Time out as a punishment
- Trying to keep up with peers in education
- Expectations set by age

You may need to advocate for your child (speak on their behalf) to make sure they are understood and get the support they need.

You can use this space to make a note of what works for your child.

Will I be put in touch with services that can help?

Some professionals are still learning about FASD and some services are still being developed. Providing a care plan for children and those that support them is important to improve how they get on day-to-day and what they can achieve in future.



Recommendation based on the research evidence

You and your child should be put in touch with services that can help. Where services are limited, your child should still have a care plan of appropriate support. This will help them achieve their goals and minimise future problems.

Having a good network of social support can also help you cope. Professionals will ask you about this and will consider helping you get some extra support if you need it.

You may find it useful to contact voluntary groups who can offer you advice and enable you to meet other people going through a similar experience. We have listed some of them on pages 38-40.

“This support group has been a great help to me. It’s a safe place, you can say what you want, it stays in the room and you’re not judged. We’re all in the same boat.”

What happens as my child gets older?



Recommendation based on clinical experience

FASD will change as your child gets older. At times of change, like starting or changing schools, or starting higher or further education, reassessment and revision of care plans are important. This should be linked to the GIRFEC process (see page 43).

What happens when my teenager moves into adulthood?

When your teenager is moving into adulthood it is essential they receive support from family members, friends, teachers, social workers and others who understand their difficulties. Transition planning is important to help them adjust to the next stage of their life.



Recommendation based on the research evidence

Young adults who move to a living environment where there is appropriate help and support may need other assessments to identify changes and have adjustments made to their management plan.

“Dealing with the changes to your body when growing up is difficult and there needs to be an understanding that it’s not just school that’s important but the changes that are happening to you too.”

Where can I find out more?

If you haven't found what you're looking for, here are some further sources of information. The organisations we have listed may be able to answer your questions and offer support.

SIGN accepts no responsibility for the information they give.

National organisations

FASD Scotland

www.fasdscotland.com

Email: info@FASDscotland.com

FASD Scotland offers information and awareness about the lifelong risks of pre-birth exposure to alcohol as well as support and advocacy to families caring for a child with FASD. It provides strategies for managing FASD and training for professionals involved with FASD. Through partnership with other agencies it aims to prevent FASD and reduce future problems.

National organisations (continued)

FASD Hub Scotland – part of Adoption UK Scotland

Helpline: 0131 322 8500 Open Monday to Friday 10am to 2.30pm – FASD-specific enquiries 10am to 2pm Tuesdays, Wednesdays and Thursdays

Phone (office): 0131 322 8501

Email: fasdhub.scotland@adoptionuk.org.uk

FASD Hub Scotland Facebook group: This is a closed group for parents/carers and can be accessed by visiting [@AdoptionUKScotland](#) Facebook page and searching within 'Groups'.

FASD Hub Scotland is a support service for parents/carers who are living with people who have been exposed to alcohol before birth. Support can be given before, during or after a formal FASD diagnosis. FASD Hub Scotland operates as part of Adoption UK Scotland, providing a Helpline service. Its FASD advisors can signpost, offer advice and support callers. Additionally, FASD Hub Scotland provides peer support and community for adoptive parents, foster carers and kinship carers across Scotland through its dedicated Facebook group. FASD Hub Scotland can offer the families it works with direct support including advocacy in school, access to training and, for those who are eligible, therapeutic support services. FASD Hub Scotland also offers training to those who support/work with families such as social work teams, teaching staff, and health visitors.

National organisations (continued)

Children's Health Scotland

www.childrenshealthscotland.org/contact-us

Phone: 0131 553 6553

Email: enquiries@childrenshealthscotland.org

Children's Health Scotland promotes the needs of all children and young people in the health system. They work to enable children and young people to exercise their health rights and have their needs met in partnership with families, carers and professionals; this is done by working to improve standards and quality of care, representing families' views and ensuring their voices influence health policy and provision as well as providing information and support to families.

They give free workshop sessions to kinship carers on various health-related topics to help them care for their children. Carers can also contact Children's Health Scotland directly for information and advice on individual issues. Their film *Health matters for children and young people in Kinship Care* explores health issues for the children in their care and discusses sources of support and help.

National Organisation for Foetal Alcohol Syndrome - UK (NOFAS UK)

www.nofas-uk.org

Helpline: 020 8458 5951

Email: help@nofas-uk.org

The NOFAS-UK Helpline responds to enquiries from parents, family members, carers and others needing advice or referrals for children with FASD disabilities. NOFAS-UK organises events about well-being for families and carers of children with FASD and provides resources that help support those with FASD at home and in school.

Websites

Enquire

www.enquire.org.uk

Offers a flexible outreach and training service aimed at parents, carers and people who are involved in educating children and young people who need extra support for learning.

Scottish Transitions Forum

www.scottishtransitions.org.uk

Aims to improve the experience of people with additional support needs, as they go through life transitions, particularly the transition of young people from school or college to adult life.

Skill Scotland

www.skillsotland.co.uk

An information and advice service for young people over 16 and adults with any kind of disability in education, training and employment.

Sleep Scotland

www.sleepscotland.org

A charity providing support to families of children and young people with extra support needs and severe sleep problems.

Useful publications

Autism: a booklet for parents, carers and families of children and young people with autism.

www.sign.ac.uk/assets/pat145_parents_and_carers.pdf

Eight Magic Keys: Developing Successful Interventions with Students with FAS

www.come-over.to/FAS/brochures/EightMagicKeysBroch.pdf

Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Pathway - To improve the identification and diagnosis of affected children

www.knowledge.scot.nhs.uk/eomscormplayer/fasdpathway/j459160/fasd-02.html

Highlights the pathway that all statutory and voluntary agencies should use to diagnose and support children or young adults who have or may have FASD.

Useful publications (continued)

Getting it Right for Every Child (GIRFEC)

www.gov.scot/policies/girfec/

Provides information on the GIRFEC policy.

Health and social care support publications

www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/health-and-social-care/

The Scottish Government produces materials to support young people with disabilities.

The experiences of caregivers looking after individuals with fetal alcohol spectrum disorder: A rapid synthesis of qualitative studies

www.sign.ac.uk/assets/a_rapid_synthesis_of_qualitative_studies.pdf

Describes the impact of FASD on caregiving, based on experiences from a range of caregiver and family contexts. Also shows how this helps to improve the quality of care and services.

Books for parents, children and young people

You can buy any of the following books from bookshops. You may also be able to borrow them from your local library for free.

Foetal alcohol spectrum disorders: Parenting a child with an invisible disability

J Brown, M Mathers, CreateSpace Independent Publishing Platform (2014)

The way I am is different: A children's book about Fetal Alcohol Spectrum Disorder

H Simpson, Independently published (2018)

Advocate!: Strawberry and Cracker, Twins with Fetal Alcohol Spectrum Disorder

B Studham, Barbara Studham (2018)

Fidget!: Strawberry and Cracker, Twins with Fetal Alcohol Spectrum Disorder

B Studham, Barbara Studham (2018)

The School Day: Strawberry and Cracker, Twins with Fetal Alcohol Spectrum Disorder

B Studham, Barbara Studham (2018)

The best I can be: Living with Fetal Alcohol Syndrome or Effects

L Kulp, J Kulp, CreateSpace Independent Publishing Platform (2013)

List of useful terms

Attention deficit hyperactivity disorder (ADHD)

A condition where a person has consistently high and inappropriate levels of activity, acts impulsively and is unable to pay attention for long periods of time.

Autism

A lifelong developmental disability affecting social skills, communication skills, and behaviour.

Central nervous system (CNS)

The brain and spinal cord make up the CNS. The brain controls all body functions by sending and receiving messages through nerves.

Educational psychologist

A professional who helps children and young people with conditions that make it difficult for them to understand and be understood, and to join in with school and other activities. These problems can include a range of emotional and social problems or learning difficulties.

Microcephaly

A condition where a baby is born with a small head or the head stops growing after birth.

Neurodevelopmental

Relates to the development of the nervous system.

Occupational therapist

A professional who helps you to be confident in everyday tasks.

Paediatrician

A doctor who specialises in the health care of children and young people.

Philtrum

The space between your nose and your upper lip.

Physiotherapist

A professional who helps to keep your body moving.

Psychiatrist

A medical doctor who helps you keep well and stay calm. A psychiatrist can assess suitability for medication to treat mental health problems.

Psychologist

A professional who helps change how you think, feel and behave. They may ask you to complete puzzles and tasks to find out strengths and difficulties.

Sentinel features

Distinctive facial features specific to FASD. These are small eyes, thin upper lip and smooth space between the nose and upper lip.

Slanting board

Typically consists of a flat surface positioned at an angle with clips or anchors to hold materials (such as paper and books) in place.

Speech and language therapist

A professional who works with people who have difficulties with speech sounds or spoken communication and social interaction.

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



1

Gather lived experience



2

Identify the questions



3

Search for the evidence



4

Look at the evidence



5

Make judgements and recommendations



6

Ask people for feedback



7

Publish



8

Let everybody know about our guidelines

You can read more about us by visiting www.sign.ac.uk or you can phone **0131 623 4720** and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available. We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

We are happy to consider requests for other languages or formats. Please phone **0131 623 4720** or email sign@sign.ac.uk



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