

Why do I have FASD?

What does that mean for me?

It's normal to have lots of different feelings about FASD and why you have FASD.

This leaflet will help you think through those feelings.

It's okay to talk about this with trusted adults if you want to.

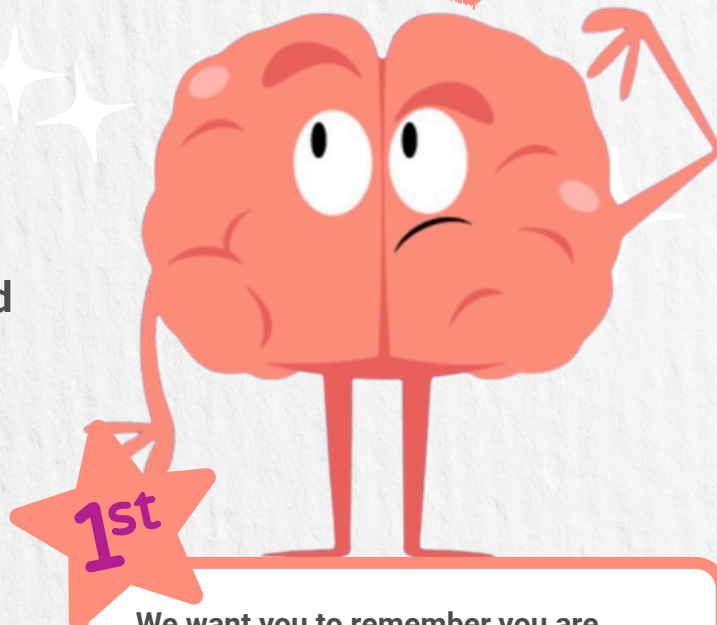
What is FASD?

FASD stands for **Fetal Alcohol Spectrum Disorder**.

It happens when a baby's brain and body were affected before they were born by a chemical called ethanol that is in alcoholic drinks. FASD lasts a lifetime but there are strategies that help.

If a woman drinks alcohol when she is pregnant, the alcohol goes into the baby.

A birth mum may not have known about the dangers of drinking alcohol in pregnancy, they might not have known they were pregnant, or maybe they had problems or a disease that made them dependent on alcohol, which might have made stopping alcohol hard.



We want you to remember you are loved and you are not alone. You did nothing to cause FASD. You deserve care and support. You have strengths and talents as well as challenges. These will help you as you grow.

People with FASD might:

- Struggle with learning, thinking and remembering things;
- Need to be very active and fidget a lot;
- React differently to smells and sounds and the way things feel;
- Have difficulty managing their behaviour and emotions;
- Find it hard to keep friends and to know how to act around people;
- Need help to do daily things to look after themselves and their room.
- Try harder than others every day in so many ways.
- Remember always - people with FASD also have many strengths and are awesome!

For trusted adults reading along: Please stay calm and non-judgemental, listen more than you talk, validate the young person's feelings rather than rush to reassure or explain. Understand this conversation may take years.



For some people thinking about your birth mum or birth dad may feel upsetting. It's okay to stop reading and talk with a trusted adult.



Why do we say “birth mum”?

Most children with FASD are living with their birth families. But that is not true for everyone.

Families come in many shapes.

Single parents, foster carers, adopters, nans and grandads, aunties, uncles, cousins and older siblings (sometimes called kinship carers) and social workers also might be part of the conversation. To understand the cause of FASD we talk about biological parents, especially the person who carried the baby in pregnancy. That is the “birth mum”.

What about birth dad's drinking?



Some new studies show that if a father drinks alcohol in the months prior to the pregnancy the sperm may be affected and impact the developing baby in ways researchers are still exploring. But that on its own is not FASD.

Experts say it's safest to avoid alcohol in pregnancy or if you are trying to have a baby.

FACT

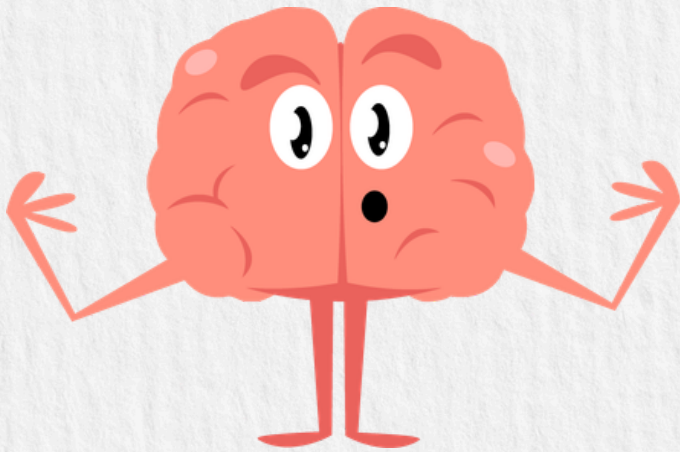
Pregnant women don't drink alcohol to hurt their babies.

Often, they don't know they are pregnant or they don't understand alcohol can affect the baby. Sometimes they need help to quit.



Why does alcohol affect a developing baby?

Alcohol is a very strong substance. It's called a 'teratogen' - that means it can change the way the baby develops while still in the birth mum's tummy.

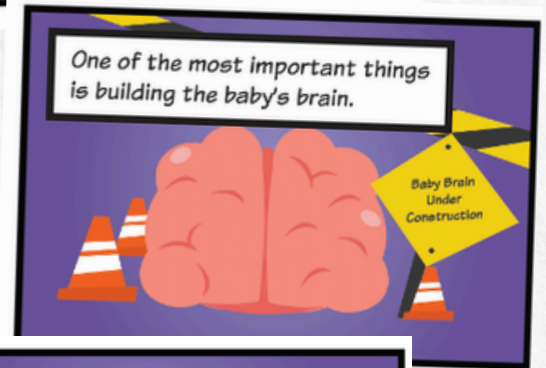


The developing baby's body isn't able to filter out the alcohol that gets into the birth mum's blood.

Everyone with FASD is different because how the alcohol affects the developing baby depends on a whole lot of things. These include when in the pregnancy it was, the birth mum's health and genes, the environment and stress at the time, and all kinds of other things that we are still learning about. Some people have a disease called alcohol addiction and need lots of help to stop drinking alcohol.

Not every pregnancy that was exposed to alcohol will lead to FASD, but no one can yet say which one will.

Experts have learned a lot and now say it's safest to avoid alcohol in pregnancy or if you are trying to have a baby.



Why is FASD different than other conditions?

FASD only happens when a developing baby is exposed to alcohol while it is still growing inside the birth mum's tummy.

We say FASD is "preventable" but it's not 100% preventable because not every pregnancy is planned and not everyone will be able to stop drinking in pregnancy without help.

FASD is very complex. When someone has FASD, it means their brain and body developed differently because they were exposed to alcohol before they were born. This can mean that some parts of the brain – and, for some people, parts of the body – work differently.

This isn't something done on purpose to hurt you.



Frequently asked questions

Did I cause my FASD?



No. Nothing you did caused your FASD.

Why did my birth mum drink alcohol?



Many birth mums did not know they were pregnant or did not know alcohol could harm the baby. Many didn't get the information or help they needed. Sometimes they may have had a disease that made them dependent on alcohol and needed extra help to quit.

Will I always have FASD?



Yes. But you can have a great life. You will learn ways to help make things easier.

Everyone with FASD is different

Alcohol can affect the developing brain and body throughout the pregnancy. This shows a few of the ways that can happen, but there are more than 400 conditions that can go along with FASD. It's all very complicated. You will learn over time how FASD affects you.

9 months of pregnancy



Different parts of the body and brain develop at different times in the pregnancy as the baby grows. That's why there is no safe time in a pregnancy for alcohol.

	What's developing at different points in the pregnancy and what the alcohol can affect	
Week 3	Heart	The central nervous system and brain develops through the whole pregnancy
Weeks 4-5	Heart, eyes, limbs	
Weeks 6-8	Ears, mouth, teeth, genitals	
Rest of pregnancy		

Moving beyond shame and blame

FASD is a medical condition - no-one is to blame. You are unique and you will learn tools and strategies that will help you. Remember to tell those around you what you need.

Some of this can happen before a birth mum knows she's pregnant

Sometimes pregnancies are not planned. It can take a few months before a mum knows she's pregnant. Even if she stopped drinking alcohol after she knows, the baby might already have been affected. Your birth mum did not know what impact this would have on you.

FACT

Everyone with FASD is different.

Everyone with FASD has a unique brain.



Hear what some with FASD have to say

Everyone is different

“

“It’s hard, and there are a lot of life lessons to be learned. But on the other side of the coin, I get to experience life in ways other people don’t get to. I live with my birth mum and we talk about these things all the time and also try to help others understand FASD. She’s my biggest supporter and I love her.”

Rossi, 24

“

We can’t change anything. We can only make it good. I’ve never had the conversation with my mum as I know it won’t help either of us. So I believe I can only help myself understand what I really need help with, like what’s my real struggles and what I do well. There’s so much out there about FASD and yet still people don’t know a lot.

I look at it as it wasn’t on purpose but unfortunate that it did. It’s not easy but we can all achieve amazing things in life. It doesn’t matter if it takes longer to get there or understand why or who or what. What we can do is try.

Nyrene, 53

“

“It sucks.”

Michael, 16

From birth mums:

“

“We need to re-think opinions around birth mums. No-one drinks to harm their child. Birth mums have to live with the fact that their child may need extra support for all of their lives.”

Sue



“

“Finding out that alcohol had chemicals that caused my son’s difficulties was really upsetting and I wish someone had told me about the risks of alcohol when I was pregnant even the doctors didn’t know what it could do.

But, my son is a fully qualified make up artist because we supported him by helping him concentrate on what he was good at, not the things he had difficulties with.

It is so important for young people to learn about the unexpected pregnancy what alcohol can do in school lessons.”

Jan

Remember! FASD is just one part of who you are. It doesn’t decide everything about your future.

Exploring your feelings

This is a lot of information. It's ok to have different feelings about the cause of FASD.

Sometimes your feelings will change over time. It helps people with FASD to know they are not alone. Experts think there are more than a million people with FASD in the UK. But most do not know they have it. Understanding that having FASD is the reason why you may have challenges and struggles is the first step in helping you get the right support.

it's okay to feel your feelings

How does thinking about the cause of FASD make you feel?



sad



confused



surprised



determined



angry



okay



don't want to think about it



understand



frustrated



Add your own feeling here

- You might feel sad, angry and understanding all at the same time. That's okay.
- If you feel angry, that's a signal that you may need strategies to help you calm.
- If you feel 'don't want to think about it', your brain might be trying to keep you safe for now.
- Lots of young people with FASD have these feelings too – you are not the only one

It's individual

Everybody with FASD is different and unique

As you learn about your FASD and your challenges, it's SO important you also learn your strengths.

Live your best life

Remember!

People with FASD have lots of strengths



**Celebrate your strengths!
Every person has them.**

**These are your building
blocks for a positive future.**

**Work with people who
want to support you.**

**Learn to understand your
condition.**

**Tell others what you need.
You are the expert on you!**

**Be patient. Adults with FASD
say while you'll always need
support, things get easier
as you get older.**

My story

(only if I want to)

You do not have to know or remember everything about why you have FASD. You are allowed to keep some parts private.

It is okay if you don't know the answers.

It is okay if adults keep some details private to keep you safe.

What I know about why I have FASD (if I want to write it)



Things I am not ready to talk about yet



My feelings about having FASD

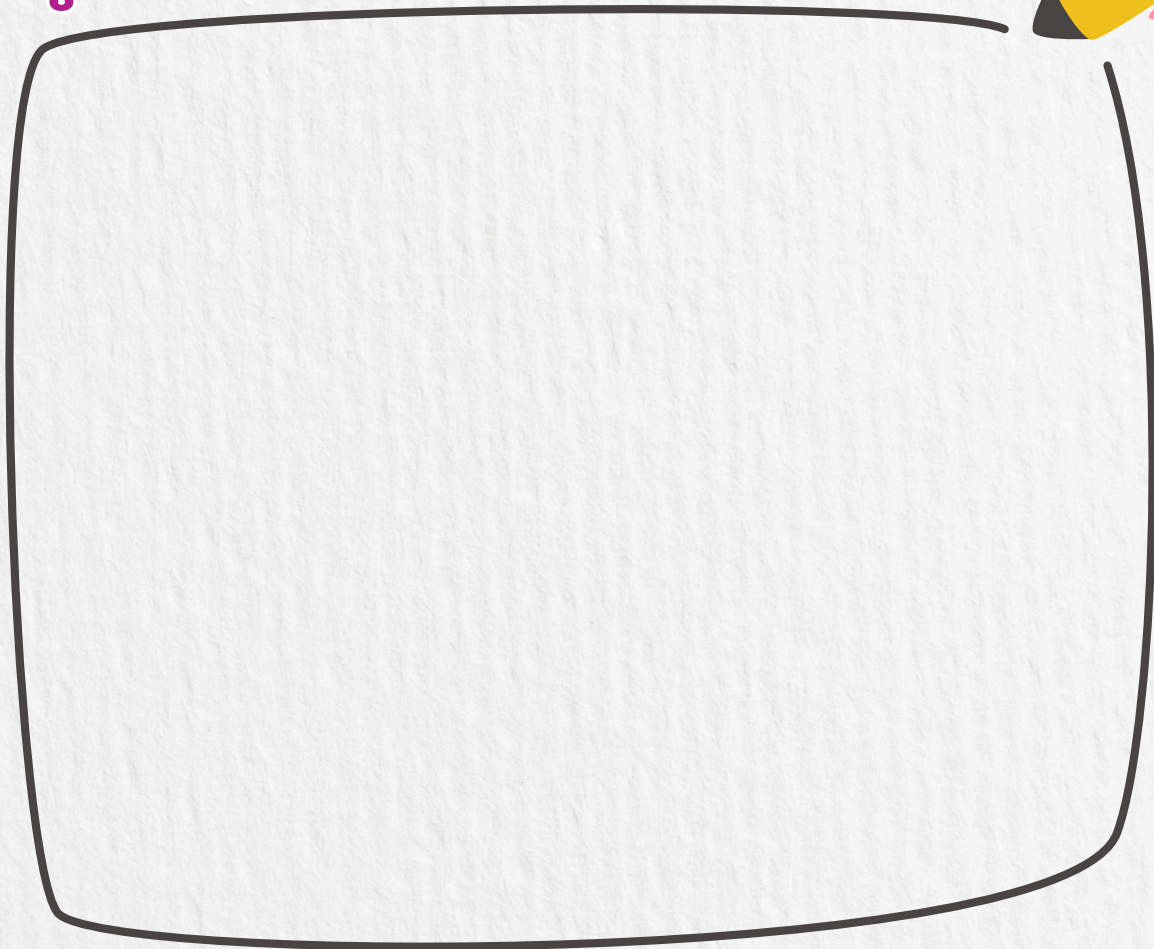
(you can feel more than one feeling at a time)

When I think about having FASD, I feel:

- | | |
|-----------------------------------|---|
| ☐ sad | ☐ proud |
| ☐ okay | ☐ hopeful |
| ☐ confused | ☐ I don't want to think about it |
| ☐ angry | ☐ another feeling: _____ |
| ☐ worried | |



Here is a picture or some words about my feelings today



Many other young people with FASD
have big feelings too.
You are not the only one.
Your feelings make sense.

Things that help me when I feel upset, angry or worried:

- ☐ taking 3 slow deep breaths
- ☐ squeezing a pillow or stress ball
- ☐ wrapping up in a blanket
- ☐ having a drink of water or a snack
- ☐ listening to music I like
- ☐ going somewhere quieter
- ☐ talking to someone I trust
- ☐ other ideas that are good for me: _____

**If your feelings feel
too big or scary, tell
a trusted adult.
You do not have to
manage them on
your own.**

My strengths and good things about me

Having FASD is one part of who you are.
You also have many strengths and talents.
These are important.

You deserve kindness,
understanding and support.

You are allowed to ask for help.

Three things I am good at:

1

2

3

Three words that describe me in a good way

(for example: kind, funny, brave):

1

2

3

People who can help you with your story

You do not have to figure this out on your own.
It can help to choose people you trust.

I can talk with:

- ☐ my carer / parent
- ☐ another family member
- ☐ my social worker
- ☐ my teacher or someone at school
- ☐ my doctor
- ☐ someone else I trust: _____



What else you can do

Learn as much as you can about FASD and how it affects you.

Remember everyone with FASD is different.

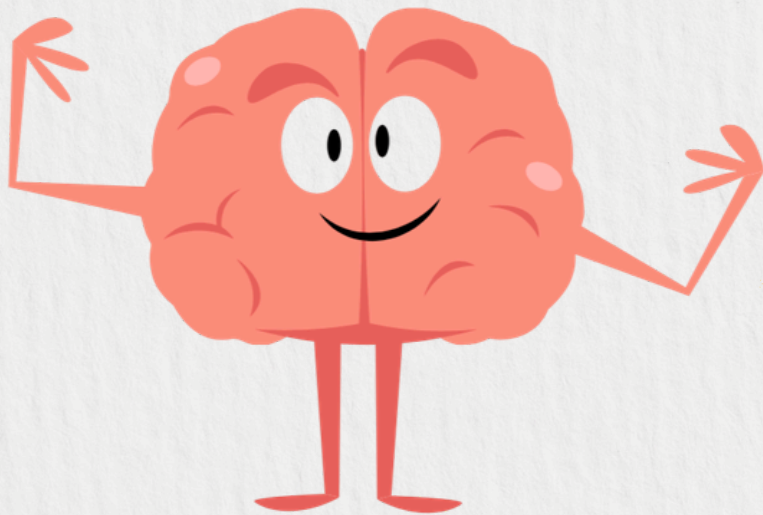
You know you best.

It's okay to have help

You have rights.

Know your rights.

Accept benefits and support that you deserve.



FASD UK
ALLIANCE



You and your family can contact a local FASD support group for help if there is one near you. You can find one via the FASD UK Alliance.

<https://fasd-uk.net>



Check out Living FASD for positive stories about people with FASD



Check out fasd.me



<https://gmfasdnetwork.info>



<https://nationalfasd.org.uk>

