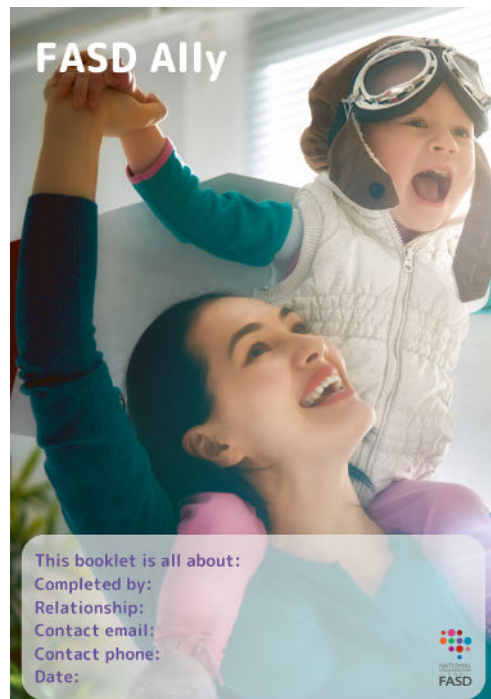




Instructions for Filling in The FASD Ally's Booklet

- Blue writing messages to you
- Red writing Instructions for you
- Black writing suggested ideas to use when talking to people



Write your young person's name and the date on the front page.

Thank you for using this resource supplied to you by the National Organisation for FASD.

We hope that you will find it useful in speaking to the other important people in their lives. This can be education, medical, social care or the leaders of clubs that the young person attends or anyone else who supports them.

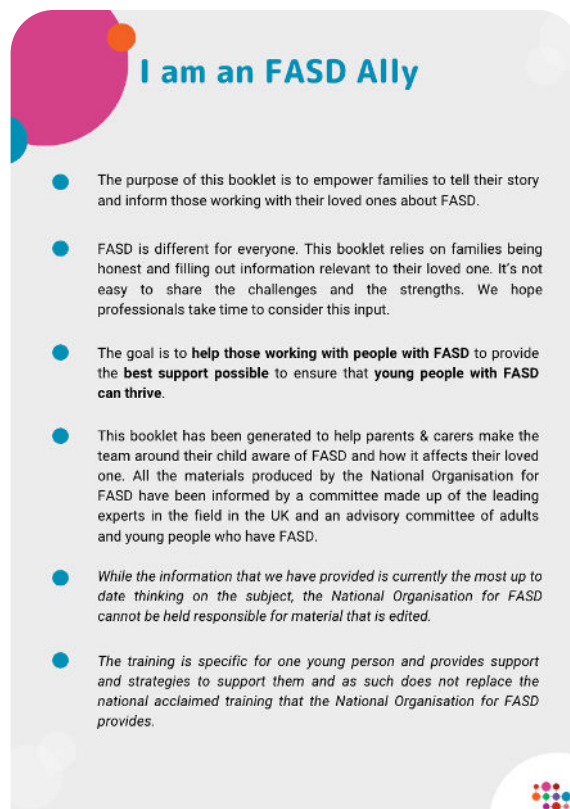
We believe that you are likely to know your young person best. This booklet has been created to allow you to present the needs of your young person in the context of the most up to date national research and advice.

We believe that with better information, people working with young people with FASD will be able to give them, and you much better-informed support.

This does not replace FASD Awareness training for the people that you are speaking to and we do not expect you to be an expert in every field. This is about helping you to explain what **your** child needs and what people can do to help them.

It might be that the young person that you are speaking about might also contribute to some or all this booklet.

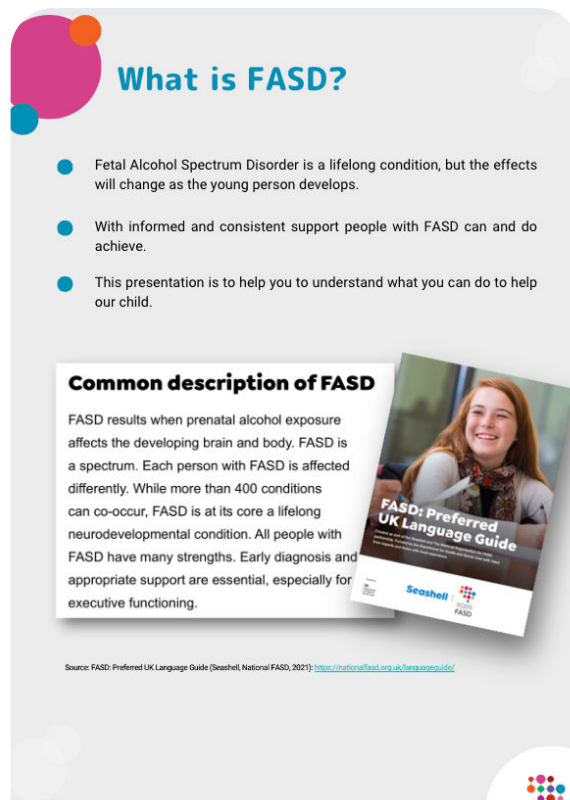
If anyone is interested in more detailed FASD Awareness training, then please signpost them to our training page www.nationalfasd.org.uk/training.



This page is to help you make sure that the people that you are talking to understand what you are trying to communicate throughout this booklet.

Points to make.

- This booklet is to help the people that you are speaking to better understand how FASD (or possible FASD) affects your young person.
- By understanding their needs, we hope that you can work with them to help the young person enjoy what they do more and do much better.
- This doesn't replace full FASD Awareness training that can be found by getting in touch with the National Organisation for FASD.
- This booklet incorporates the most up to date information about FASD in the UK and how it impacts your young person.
- However, how FASD presents changes over time as the young person grows up and often daily as they are affected by changes in their surroundings and the levels of stresses change.
- The national information uses sources from the most recent publications. Members of the National Organisation for FASD have been involved in developing many of the items quoted. All of the pages and resources that use have been guided by people with FASD and fact checked by the national FASD experts committee, some of the people who lead the national developments in the field.





What is FASD?

- Fetal Alcohol Spectrum Disorder is a lifelong condition, but the effects will change as the young person develops.
- With informed and consistent support people with FASD can and do achieve.
- This presentation is to help you to understand what you can do to help our child.

Common description of FASD

FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than 400 conditions can co-occur, FASD is at its core a lifelong neurodevelopmental condition. All people with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning.

Source: FASD: Preferred UK Language Guide (Seashell, National FASD, 2021) <https://nationalfasd.org.uk/languageguide/>

The next 7 pages allow you to ensure that everyone understands what FASD is and effectively raises awareness of the condition.

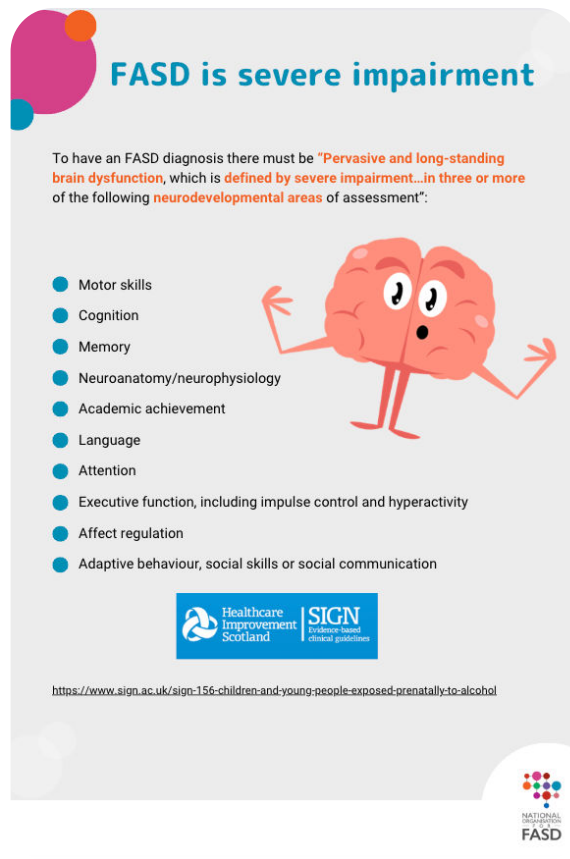
Points to make

- FASD stands for Fetal Alcohol Spectrum Disorder which is a lifelong condition that will change throughout the life course.
- People with FASD can succeed and achieve amazing things with the correct support and guidance which is the purpose of this talk.
- Too often, the focus of FASD Awareness is the challenges that people with FASD face, but there are literally hundreds of people with FASD who lead typical lives with informed support.

You might be able to speak here about the hopes and dreams of your young person.

- This is the description we use of FASD.
- This description was developed by talking to over 70 people with lived experience of FASD.
- It is a neurodevelopmental disorder, the brain of everyone with FASD is affected.
- Everyone is affected differently that is why it is so complex.
- People with FASD will show different aspects of some of the over 400 identified associated conditions.
- FASD can also get identified as different conditions, like Autism and ADHD depending on the characteristics that each individual displays.

You might like to explain how your young person's self-esteem is affected by negative language.



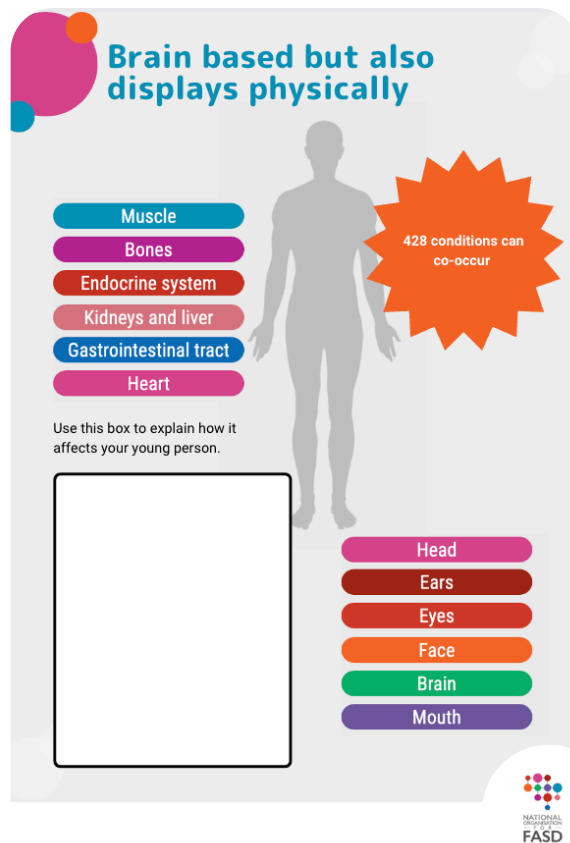
Points to make

- FASD is now defined as longstanding brain dysfunction.
- In order to receive an FASD diagnosis, there must be severe impairment in three or more of the areas on the page.

Highlight the areas that challenge your young person the most.

This page might come as a shock to you especially if your young person was assessed as having FASD some time ago.

This is the criteria now used to assess for FASD as the core for making a diagnosis. If your young person is yet to be diagnosed but there is a history or prenatal alcohol exposure, this is what the medics should be looking for.



Points to make

- Everyone with FASD has organic brain damage, caused when the brain was forming in the womb.
- The brain has been affected before they were born but those effects will last a lifetime.
- With some people there are also physical signs. Some can be seen; some are internal and can be health issues.
- It can affect anything that is happening in the womb so the whole body could have effects. Different things develop at different times in the womb so when prenatal alcohol exposure happens can affect how the body is affected.
- Up to 428 conditions have been identified that are linked to FASD. Everyone will have a different combination of them and therefore everyone with FASD is different. No one will have all of them.

Write in the box the areas where your young person is most affected.



Points to make

- This is a quote from the Department of Health and Social Care FASD Needs Assessment for England (2021).
- They are making the point that everyone with FASD is suffering from a severe impairment. Therefore everyone with FASD should be entitled to appropriate support to address the impairments.
- With the right support people with FASD can and do achieve.
- It's the support that very often accounts for the differences in outcomes.
- Increasingly, governments throughout the UK are recognising the impact that FASD has on our communities.
- The policy is changing. However, it is still early in the process.
- Professionals are advised that they should now consider whether anyone with a neurological disorder has been affected by prenatal alcohol exposure unless there is concrete proof that no alcohol was consumed during pregnancy.
- Over 40% of women have told researchers that they drank some alcohol in pregnancy (2017). There are lots of reasons why this may have happened including poor communication about the risks and as late as 2016 there were no clear guidelines advising women not to drink at all during pregnancy when they were trying to get pregnant. This is now the official advice throughout the UK.
- The Nice Quality Standards now suggests that everyone with FASD should have a multiagency plan to help them succeed throughout their life course.
- We are still very early in the plans for change and different areas of the country will be at a different point in the development of their assessment pathways and support plans.

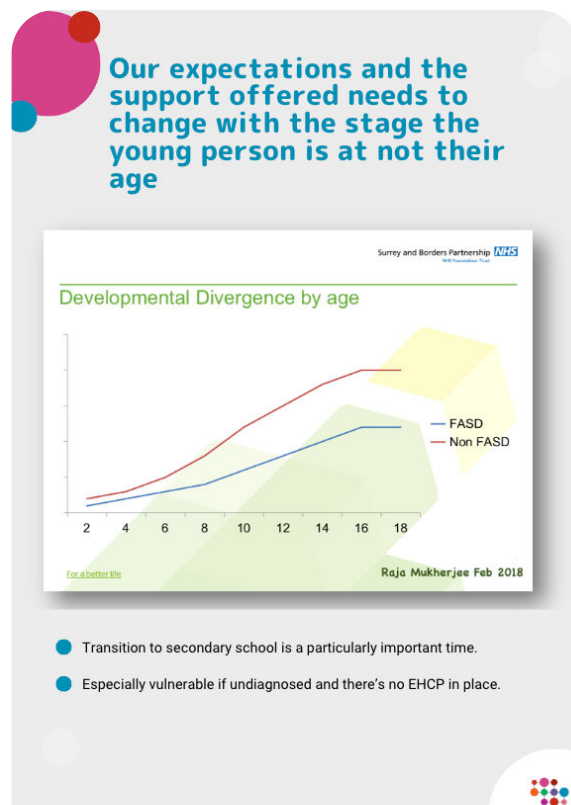
The NICE quality standards were published in 2022. Every Integrated Care Board ICB (who run Health Services in a local area) have 5 aims that they should be addressing that cover information for women about the risks associated with alcohol in pregnancy, recording information, making quality assessments for FASD and supporting people with FASD. However, each ICB started in a different place and the progress that they have made is therefore different. Hopefully, with time they will all be at the same point.



Points to make

- Invite people to think about how many people they work with might be affected if the figures from the Salford University study found that at least 2% of the general population have FASD.
- It is likely that the young person that you are speaking about will not be the only person with FASD that the audience has worked with.
- If your young person has care experience, research quoted in the DHSC FASD Needs Assessment shows that around 27% of children in care may have FASD and 75% of children adopted suffered from prenatal alcohol exposure (many of these children and young people are yet to be assessed for FASD).

You might wish to speak about when your young person was assessed or how you have been trying to get an assessment.



Points to make

- As a very rough guide assume that the speed of development of someone with FASD is roughly half that of a neurotypical brain.
- That means that the gap between someone with FASD and their peers widens as they get older.
- At first, differences may not be as noticeable as when they are older.
- Often the differences are seen as a young person transitions from one phase of school to another and the new staff get to know them. Often staff with a longer relationship know the person with FASD and make adjustments for them without even realising it. It is only when someone new comes into the picture that they see the gaps.
- That is why it is important that we support children in primary school to get the correct support as transition to secondary school can be extremely hard if the correct support is not issued.
- Too many children with FASD begin to struggle with secondary education.

How people with FASD want to be treated

#UKFASD MANIFESTO

<https://nationalfasd.org.uk/the-uk-fasd-manifesto/%20and%20https://fasd.me/uk-fasd-manifesto/>



The poster is titled 'UK FASD MANIFESTO' and 'HOW WE WANT YOU TO TREAT US'. It features a central blue circle with 'FASD' inside. Surrounding it are various icons and text boxes: 'Stop it, catch it', 'DON'T DO IT', 'DO IT', 'NEVER GIVE UP ON US', and 'FASD'. It also includes a list of 'DO' and 'DON'T' items.

This is how _____ wants to be treated:

-
-
-
-

**NATIONALS
NATIONALS
FASD**

Points to make

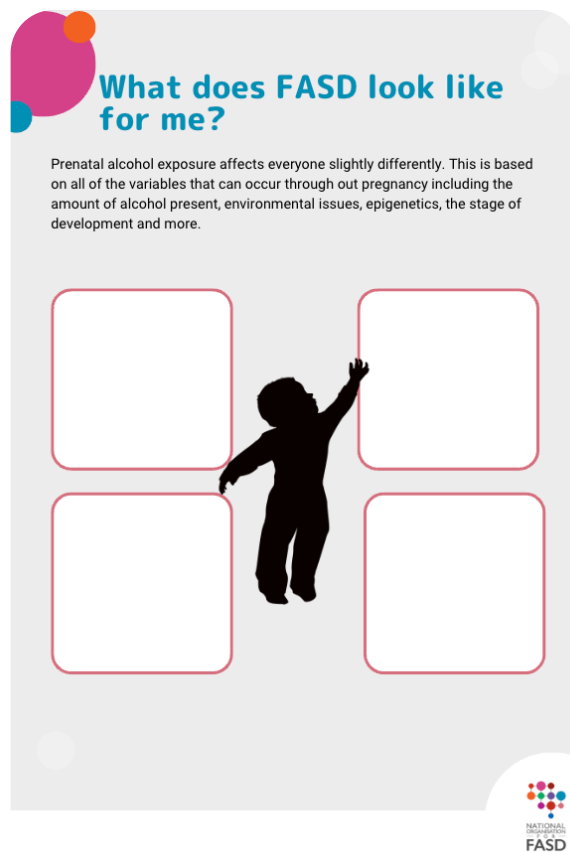
- Often people with FASD know what they need to achieve and have developed strategies to help them get by.
- The UK FASD Manifesto was developed by listening to the voices of over 60 young people living with FASD. In this groundbreaking document, they tell us how they want to be treated and it is important that everyone honours their requests.

There is space on this page for your to record the key things about how your young person wishes to be treated. You can use the UK FASD Manifesto or create your own.

It may well be that in different situations the needs will be different.

Make sure that you can explain why the things that you list help your young person.

You might want to play the 4 minutes of the Manifesto video if you have time which can be found on the link.



What does FASD look like for me?

Prenatal alcohol exposure affects everyone slightly differently. This is based on all of the variables that can occur through out pregnancy including the amount of alcohol present, environmental issues, epigenetics, the stage of development and more.

Four empty boxes for notes are arranged in a 2x2 grid, with a silhouette of a child pointing towards them.

NATIONAL
INSTITUTES
OF
HEALTH
&
MEDICINE
FASD

Points to make

- Once again we are making the point that everyone is effected in a different way.
- "If you have met one person with FASDYou have met one person with FASD."

Write the main ways that FASD affects your young person. You can include more than one comment in each box if you need to.

Explain that you will talk about strategies later.

**What FASD is and is not...
Traditional approaches
may not work**

MYTHS

- The naughty step, detentions and consequences will work to modify behaviour.
- FASD means you have a low IQ.

FACTS

- Behaviour is affected by cognitive processing, emotional regulation and impulse control which are common difficulties for someone living with FASD. Coping and self-regulation strategies are needed.
- Whilst some people with FASD have a low IQ, many will have an IQ within the normal range. However, it is typical to have need of support with executive functioning skills.

**The key is for the trusted adults
to REFRAME EXPECTATIONS**

Acting like a child	↔	Is a child
Won't	↔	Can't
Lazy and does not try	↔	Exhausted with trying
Does not care	↔	Does not understand feelings
Refuses to sit still	↔	Over stimulated /needs contact
Forgets everything	↔	Can't remember
Fussy, demanding	↔	Hypersensitive
Steals	↔	Does not understand ownership
Does not get the obvious	↔	Does not learn from experience
Calculating and sly	↔	Does not understand social norms

NATIONAL
SCHOOL
FASD

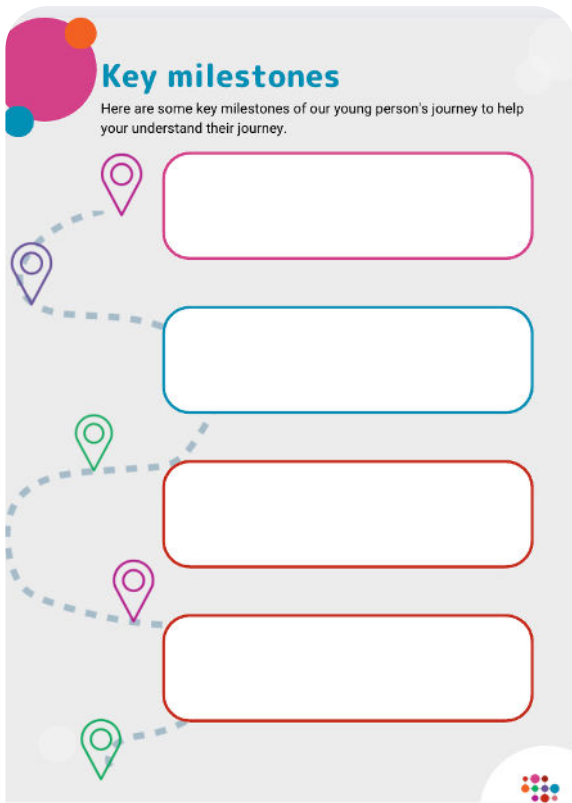
Points to make

- Research has shown that FASD is different to any other condition.
- There are lots of myths surrounding FASD. These are two very important ones.

You will probably have heard many things about FASD that actually aren't true at all or certainly aren't true for your child. You might want to talk about this.

You might be able to use one example here of something that you were advised to do that didn't work and explain why.

- Trusted adults need to understand that the behaviours that they see is usually not wilful but is sometimes the only way that they can communicate about how they feel.
- Because people with FASD have a neurodevelopmental disorder, the way that they behave often reflects what is happening in their brain.
- Often they struggle to control what is happening.
- If the adults working with them have informed expectations that match their ability and build from there, then people with FASD will achieve.
- The way that adults understand what is happening also has an influence on how they react to someone with FASD.
- Many people view a child with FASD as the statements on the lefthand side of the diagram and sadly they are quick to punish. However, the fact is their organic brain damage means the statements on the right are correct and understanding this will lead to positive empathetic behaviour support.



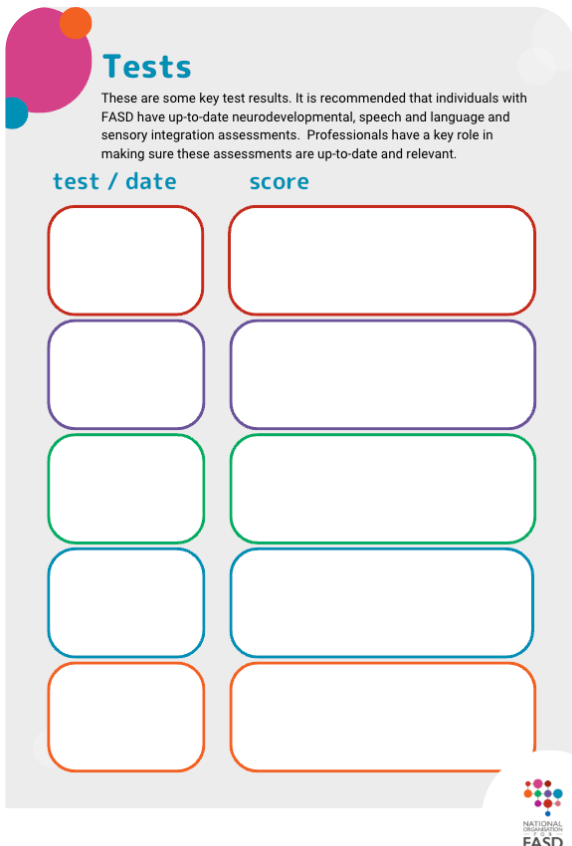
Key milestones

Here are some key milestones of our young person's journey to help you understand their journey.

The worksheet features a vertical dashed line with five colored location pin icons (pink, blue, green, pink, green) on the left side. To the right of this line are five empty rectangular boxes for notes, each corresponding to a pin. The boxes are colored pink, blue, red, red, and red from top to bottom.

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This is another opportunity for you to explain what the journey has been for you and your young person. Everyone's journey is different. You might include here aspects of their life story. It might be why there was prenatal alcohol exposure, why you think that your young person has or might have FASD. You can put more than one statement in each box if needed.



Tests

These are some key test results. It is recommended that individuals with FASD have up-to-date neurodevelopmental, speech and language and sensory integration assessments. Professionals have a key role in making sure these assessments are up-to-date and relevant.

test / date	score

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Tests refers to medical tests not school exam / test results.

Not everyone with FASD will have a range of assessment scores, but if they do this is where you can record them. If you do not have the scores, then you may be able to use this to add pressure for assessment. In the same way, if the assessments are older then you could ask for a more recent assessment of needs. So, you might include assessment scores and what they mean. It could be an explanation of the assessment report. If you have a report, you might like to share it or parts of it. If the young person is old enough, then make sure that they are happy with what you are sharing. What you write in here depends on what you and the young person feel that comfortable to share. You can put more than one statement in each box if needed.



Points to make


- It is always better to use the strengths that a young person has as a building block for any work that happens.

Use these stars to write in the strengths that your young person has. If you need to have more than one in each star that is okay.

Challenges

- Although alcohol can affect the development of all cells and organs, how the brain forms and functions is particularly vulnerable to the effects of prenatal alcohol exposure.
- As a result, children and adults with FASD often experience difficulties in processing information.
- This can be needing to take longer than their peers to appearing to miss chunks of information.
- In order to process information, the brain often has to work harder meaning that people with FASD might also be more tired.

This is what _____ finds most difficult.



Points to make

- Of course, each young person with FASD will face challenges.
- The key is that due to organic brain damage, people with FASD have difficulties processing information.
- This can take much longer than their neurotypical peers.
- They might be making decisions based on an incomplete understanding of what has been said.
- They might not remember what has been said.
- They will repeatedly make mistakes. The brain will fill in gaps where they haven't understood or remembered something. This is called confabulation, but it appears like they are lying because what they say doesn't reflect what has happened.
- The brain is often working harder to keep up this can tire them out.

In this section, you can personalise the booklet to show what your young person struggles with.


There is a separate page about dysregulation. So, use this simply to record the things that they regularly find hard e.g. impulse control, maths etc.

Add the specific things that your young person currently finds difficult.
Add as many as needed in each box.

This is what _____ finds helpful.

Dysregulation

- People with FASD can become dysregulated.
- Dysregulation is the inefficient functioning of the brain networks that control behaviour and/or emotions and is caused by brain damage.
- This can lead to impulsive behaviours and emotional reactions – it is not intentional.
- When dysregulated, their brains are not able to process information efficiently. The more stress the worse this becomes.
- When dysregulated, people with FASD must first and foremost have help to self-regulate and calm.


 NATIONAL ORGANIZATION FASD

Of course, it's not all about struggling. You can add here what helps them with the challenges that you have recorded so the audience can understand how they might help.

Add the specific things that you have found helps your young person.
As many as needed in each box


Points to make

- People with FASD can often experience dysregulation.
- Increased stress leads to greater dysregulation.
- Dysregulation can lead to impulsive behaviours and emotional reactions which they are not able to control and sometimes can't even recall or remember correctly.
- This is not intentional, and, in this state, individuals cannot process information.
- Increased stress can cause this to worsen.
- To come back in control, people with FASD need trusted adults to help them by co-regulating.
- Because processing can be slow often people with FASD act first, impulsively and then when the brain catches up, they can feel considerable guilt & remorse. This can magnify the impact of FASD.




Recognising dysregulation


Because of the brain damage, dysregulation is common. They may not be able to tell you this, but this is what it may look like...



Add the specific things that indicate that your young person is dysregulating.
Add as many as needed in each box.



What helps to decrease dysregulation



Add the specific things that help when your young person is dysregulating.
Add as many as needed in each box.

Resources that can help...

www.fasd.me

- An expert-reviewed website just for young people with FASD and those who support them.
- Contains coping resources that are printable and usable in wide range of contexts.

Coping resources

- Please have a look at the growing bank of resources on www.fasd.me.
- In collaboration with young people living with FASD, the National Organisation for FASD have created a range of materials which help young people to understand and navigate their diagnosis.



 **FASD.me**

 NATIONAL ORGANISATION FOR FASD

The following pages give you some ideas about resources that have been developed alongside young people with FASD to help them.

Not all will be appropriate for your young person so make sure that the people who you are talking to know which would be best.

It may be that you haven't tried some before so please feel free to try them.

There is a whole range of coping sheets on www.fasd.me that may be helpful in a range of situations.

Points to make

- The Me & My FASD is an expert reviewed website for young people living with FASD.
- Everything has been guided and reviewed by young people and adults who have FASD.
- It is interactive and informs young people about FASD, what might help them and showcases awesome people all who have FASD.
- The resources are printable and usable in a wide range of contexts.
- There are also links where the organisation you are speaking to can order a Me & My FASD Tool kit or resources individually.

Invite the audience to have a look at the coping resources sheets that may help.



Break It Down Board

ME & MY FASD

The Break it Down Board has been a life changer. Mum to 7 & 8 year olds

Where was I? Home

What happened? I shouted and swore

What was the cause? What I heard

How did it affect me? Angry

What helps? Being left alone

My strengths I can use coping strategies

Some things that happen can be confusing. This board can help you to break them down so you understand better what can help.

Interactive comic

This explains what FASD is, how it affects people and things that people with FASD have done to make their lives easier.

Too much to look at.

You may not know where to go.

You get tired.

Subjects like maths are confusing.

What? 100+4=?

The teacher gets mad at you.

You get confused by the rules.

It's too noisy.

Go Back

Continue

NATIONAL ORGANIZATION FASD

Points to make

- The FASD break it down board is an excellent way to unpick situations which may have caused dysregulation.
- It helps a young person unpick and reflect on a situation in a non-punitive way.


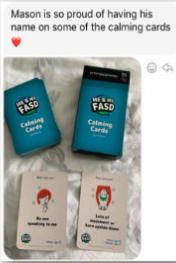
[This can be accessed on the FASD.me website.](https://www.fasd.me)

- The interactive comic is part of the Me & My FASD website and explains what FASD is, how it affects people and things that people with FASD have done to make their lives easier.
- It can be accessed time and time again and strategies can be printed to help others understand what helps someone with FASD.
- This can also be found on the FASD.me website and is available as a hard copy.

[You might like to work through this with your young person before presenting the booklet and allow them to complete some of the lists of strategies that help them to give to the people that you are speaking to.](#)


Calming Cards

A set of cards with suggestions from more than 70 young people with FASD about what helps them to stay calm. Use these cards to plan strategies that will help you too.

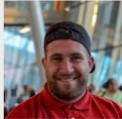



Mason is so proud of having his name on some of the calming cards

The Misunderstood





The game was suggested by Andy Jackson a young adult with FASD and its name came from our Adults and Young Adults with FASD Advisory Committee



We have lots more planned for the characters.

Now and Next Board

A set of cards with suggestions from more than 70 young people with FASD about what helps them to stay calm. Use these cards to plan strategies that will help you too.

Points to make

- The calming cards are a resource which can be used to calm down our young person.
- They are all tried and tested techniques suggested by people with FASD.
- They can also be used to offer choices about activities that they would like to try.
- They can also be downloaded on the FASD.me website to make your own or packs can be brought.
- In certain situations, there are suggestions that will not be appropriate so care needs to be taken when using them.

You might want to suggest what works with your young person.

Points to make

- Andy, a young adult with FASD, suggested a board game for young people helps our young people learn more about living with FASD.
- It allows young people with FASD or their friends to learn about FASD and the strategies that might help them.
- We have also developed a whiteboard with a Now / Next side and a side that allows people with FASD to visualise where they are in the moment. The purpose of the board is to initiate discussions with the young person with FASD.
- This can also be found on the FASD.me website.

Get further training

- This is a very short snapshot. What works for one child or young person may not work for another. It is not intended to replace informed and up to date FASD training. Make your workplace FASD-friendly by undertaking more training.
- National FASD has been at the forefront of providing FASD training throughout its existence.
- We are pleased to remain at the cutting edge, with new offerings.
- Informed by lived experience and fact checked by a committee made up by the leading national FASD experts in the UK.
- Scan the QR code to find out any further information.



Thanks

Any questions?

You can find more information about FASD at www.nationalfasd.org.uk



Point to make

- Whilst this overview focused on your child's FASD, FASD presents differently and it is important to make your workplace FASD friendly.
- Please scan the QR code or visit Nationalfasd.org.uk to find more information on their training.

Key Official Quotes

- "If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum." Chief Medical Officers guidance (2016)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/545937/UK_CMOs_report.pdf
- "Drinking any alcohol can cause difficulties in pregnancy and can result in Fetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy." Public Health England, "Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy" (2020)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_area_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf
- Confirmation of PAE requires documentation that the biological mother consumed alcohol during the index pregnancy based on: reliable clinical observation; self report or reports by a reliable source; medical records documenting positive blood alcohol concentrations; or alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy. <https://www.sign.ac.uk/docs/guidelines/children-and-young-people/exposed-prenatally-to-alcohol/>
- "There is no 'mild' FASD." "FASD Health Needs Assessment for England" (2021)
<https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- NICE Quality Standard 204 on FASD (2022) has five statements: 1) "Pregnant women are given advice throughout pregnancy not to drink alcohol"; 2) "Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded"; 3) "Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment"; 4) "Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns"; 5) "Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs." <https://www.nice.org.uk/guidance/qs204>
- "NHS England has a legal duty to take (NICE Quality Standards) into account in the discharge of its quality improvement duties. NHS organisations locally should take them fully into account in designing services that meet the needs of their local populations." Neil O'Brien MP, Parliamentary Under Secretary of State for Primary Care and Public Health, letter to National FASD, 8 Dec 2022.
- "There is no known safe level of alcohol consumption during pregnancy. NICE, Fetal Alcohol Spectrum Disorder Quality Standard 204 (2022).
<https://www.nice.org.uk/guidance/qs204>
- "There is no known safe level of alcohol consumption in pregnancy. Even low to moderate levels of PAE (prenatal alcohol exposure) can negatively impact a fetus and these adverse consequences can persist into adulthood." SIGN 156, "Children and Young People Prenatally Exposed to Alcohol" (2019) <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol>
- "The government recognises the importance of FASD." Department of Health and Social Care, "FASD Health Needs Assessment for England" (2021)
<https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- "Health assessments should...pay particular attention to health conditions that may be more prevalent in looked-after children (such as fetal alcohol syndrome or attachment difficulties) and which may otherwise have been misdiagnosed." Promoting the health and wellbeing of looked after children, statutory guidance, p. 18-19. [Note it uses the older diagnostic term but according to current diagnostic guidelines would read "FASD"]
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100188/Promoting_the_health_and_well-being_of_looked-after_children_August_2022_update.pdf
- The needs identified for this population group focus on: a) robust prevalence estimates in England; the importance of sector working to support individuals through the life course; better training and awareness for health professionals; better organisation of services to improve accessibility; a need to develop innovative approaches to support those living with condition." "FASD Health Needs Assessment for England"
<https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>
- Definition of learning disability: The Health and Care Act (2022) refers to the Mental Health Act which states, "learning disability" means a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning." (There no mention of IQ.)
<https://www.legislation.gov.uk/ukpga/2022/31/section/1/enacted>
<https://www.legislation.gov.uk/ukpga/1983/21/section/1>
<https://www.legislation.gov.uk/ukpga/2007/12/section/2>

- Some of these quotes have been used throughout the booklet and can be used to direct professionals if questioned when presenting then.
- All quotes are from relevant policy documents which can be helpful as back up if any individuals questions FASD or what you are saying.



Points to Make

- These are a range of websites which can be used to support a wide range of individuals in learning about FASD.