## NEBRY FASD CUB

Awesome People Amazing Minds SERIES 1.1

# The making of **The FASD Song**

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Help create a no



#### INSIDE

LO Manifest

People with FASD tell you what helps them Music Mindfulness Sport & activity Sunflower lanyards Art & crafts Dance And lots more! + activities for you to try

### Welcome to Series One!

The Me and My FASD Club is for children and young people with FASD. Living FASD Series One will have 5 magazines between January 2023 and March 2024.

FASD is part of what makes you, you. There are lots of other things too. Are you right or left handed or can you use both hands? Are you awesome at sport, music, dancing, acting or something else? Everyone is unique and everyone is special.

Our magazines will help you to find out:

- what you are good at
- what support and help is best for you
- how your brain works
- how you can encourage others to help you in ways that work for you

Then you can work on your skills to be the best you that you can be. Practice takes lots of time because you have to do things again, and again, and again.

We'll also find what you want others to do to help you feel happy and respected.



Thank you to



and the disability charity Contact Check out **www.fasd.me** for more fun

How does a snowman get to work?

On an icicle!

You don't need to do this all at one time. Come back often!

Awesome

Watch for our awesome stars! If you see an orange star, it means that story features someone with FASD

# Tolka

Tolka has FASD. He has always been really good at dancing, singing and now he likes to make electronic music. When Tolka got his last Me and My FASD Club pack, he took it to college and showed it to others. When he came home he wrote 'The FASD Song' music and lyrics to help others with FASD. National FASD thought it was super, and decided to create a music video for September FASD Awareness Month. Others with FASD helped!

> Shout out to Tolka, D, Dominic, Em, Hattie, Riley, Katie, M, Mia, M & P, The Showman, Riley, Ruby, Shania, and Super Dancer! Great job! And thanks to James from Crackerjac for making the video, inspired by Tolka's favourite music - K-Pop.

# The FASD song

Awesome

Lyrics and music by Tolka (TB)

This song goes out to everyone who has FASD. Just remember you guys are not alone. We're all in this together. Hello everybody, this is me TB. I wrote you all this song because of ... FASD! Come along with me by singing this special song and shall we have some fun? YEAH! YEAH! Learning can be hard to cope through at school or even at college when it's maths. UGH! Don't let yourselves down cause it ain't your fault, cause all of our brains are ... DIFFERENT! Don't give up!

When we have FASD we all have some good times and some hard times.

Now I want you guys to repeat after me: When I say 'F-A-S' you say 'D' FASD! FASD!





Tolka says: "Don't give up! When we have FASD we all have some good times and some hard times"

# **Music rocks!**

Music is good for people with FASD.

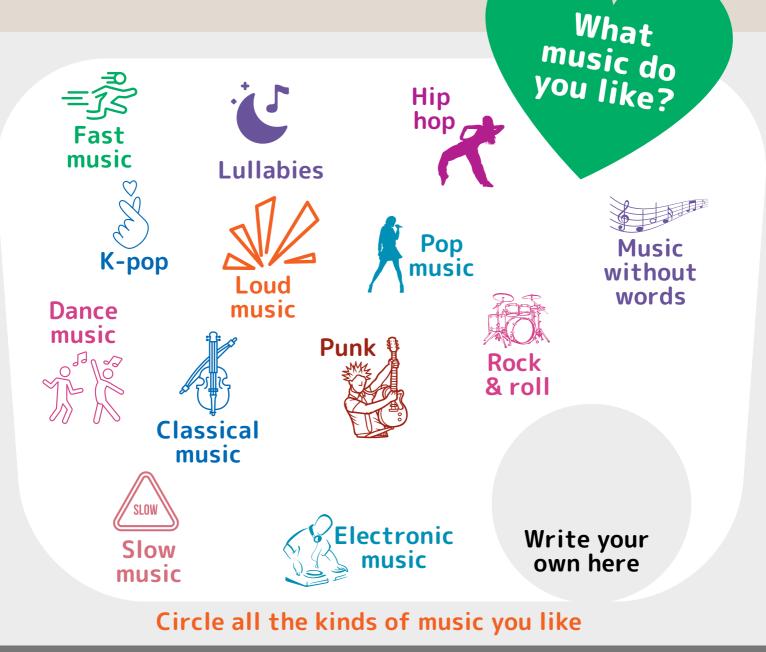
There are lots of people with FASD who are talented. They sing, play musical instruments and write songs. You can see more on your website - Me & My FASD.

But you don't need to have special talents. Lots and lots of people just enjoy listening to music.

In fact, many people with FASD listen to music in earbuds to help them concentrate on things that are happening. Others use it to help them stay calm.







## Being different is cool

Can you spot 10 differences in these pictures?



Playing games like these can help people with FASD train their brains and calm them when starting to escalate.

It's okay if you can't find all the differences. You can colour these pictures too.

#### Living FASD 1.1 Keyword Search

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WINTER	DANCING
CROCHET	COMMUNITY
AWESOME	SUNFLOWER
FASD	MINDFULNESS
DIARY	FOOTBALL
SPORTS	MANIFESTO
SWIMMING	BRAINS
FASD SONG	MUSIC
LANYARD	STREET ART
DOODLE	

#### What do snowmen eat for lunch?

Icebergers!



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#### You can do this anywhere

Just find one thing to focus on for 30 seconds. Perhaps something pretty… or fuzzy…or unusual…or comforting. Find one thing and focus. Count slowly in your head or use a timer. This strategy is called mindfulness.

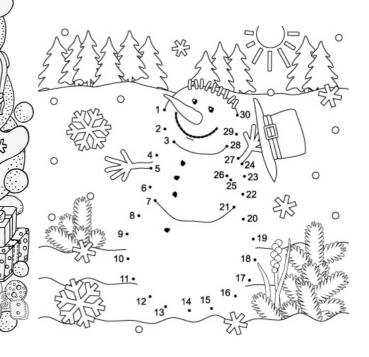
Watch our animation to learn more

### Mindfulness

Colouring and doing artwork are also mindfulness strategies.

They can help you calm your brain and body.

Plus, they are FUN!



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### Have you ever thought about your brain?

Maybe that is a silly question. Many people with FASD think about their brains a lot. They don't always like the way their brains work. When you have FASD, your brain doesn't always work the way people expect it to. That's because of the way alcohol affects developing brains in the womb.

But if you think about what your brain does do....it's pretty amazing. Everything that you can do is because your brain is working hard.

When you do something awesome that is because of your brain. Sometimes people with FASD can be better at certain things than other people. This is because of their unique brains.

People with FASD can be talented sports players, actors, dancers, and artists or have other strengths. Just look in this magazine to see some of them. Every brain can learn. Sometimes your brain just takes a little longer and works a little harder. It might need a little more practice to get things straight. There may be some things that you always struggle with. Every person if they have FASD or not - has some things they can't do alone.

-15

**FACT** The brains of people with FASD work HARDER than other people's brains! True story! It's science.

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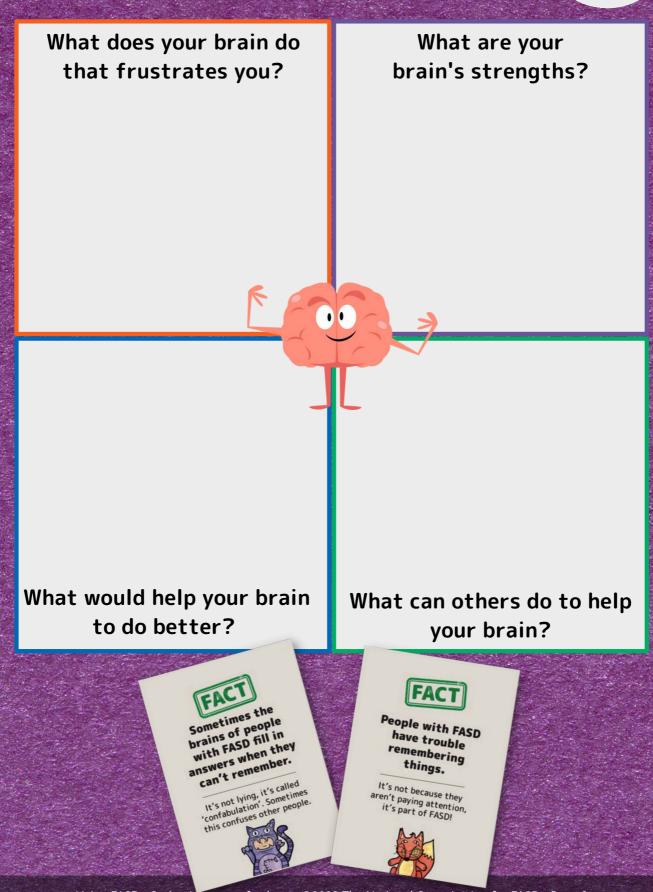
Everyone struggles when they try something for the first time; like tying shoelaces, kicking a football or driving a car. But we all get better at it if we practice and that is all down to your brain.

It's okay to be you. Adults with FASD tell us they are able to find their strengths and to get help for things they find hard.





Ask a trusted adult to help with this



# Grace

Grace has FASD. She loves animals especially horses and her support dog, Pheonix.

Grace's special strength is gymnastics. Grace has been a part of Special Olympics in her area for around 4 years. She has told Living FASD that she trains for 7 hours a week and has won loads of medals. She has recently become British Disability Champion.

Grace has been selected to represent Great Britain in the Special Olympics World Games in June 2023 in Germany. There are only 6 gymnasts representing Great Britain. Grace will perform on Floor, Bars, Beam and Vault. Grace says that she enjoys Beam and Floor the most. She is also a good dancer and can use her moves for gymnastics too.

Between now and the games, there is lots to do - with training camps in Glasgow and Lowestoft. The family also need to fundraise to cover the costs of flights, hotels, and competition kit. So, they are thinking of lots of ways of doing this.

We will let you know how Grace does at the World Games in later editions of Living FASD.

#### **Exciting times ahead!**

We think Grace is awesome.

Go Grace!!



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# Sports & activity

Many people love playing sport on their own or in teams. Lots of people with FASD are really good at sport. Others don't like to compete but just like the freedom that playing sport or taking part in activities gives them.

Sport doesn't have to be a team game, or organised by a club or a coach. Going out to play is a physical activity. Activity and sport are important because they keep you fit and give you a bit of time where you don't have to think about anything else.

Some people with FASD can play as part of a <sup>4</sup> team and they become valued team players.

Other people with FASD take part in individual sports and activities.

Whether you play sport or not, keeping fit is something that is important to everyone. There are lots of things that you can do to keep your body fit.

## What can you do to keep fit?

Have you listened to "I Get Through"? Some of these photos are from the video

#### Remember YOU ARE ALL AWESOME!

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These are all photos of people with FASD having fun while being active

# **Being active diary**

#### Can you do something active or sporty every day?

These are some ideas from others with FASD - what do you like to do?

	Monday			Keep a record here
Singing and dancing	Tuesday			*
Ø ↓ Running bare foot	Wednesday			Boxing, punchbag & working out
on grass	Thursday			H J J J
Playing football	Friday			Cycling
* SY	Saturday			
Swimming	Sunday	L		Lots of movement or turn upside down
the t	to to		*	
Swinging	Power kiting	Pushing a wall	Horse riding	Trampolining

## Sunflower lanyards

Everyone, if they have FASD or not, needs a little bit of help and understanding to make their lives easier. When you have FASD, the people that you live with might know how to help you. What about people who can help when you are out and about, but who don't know you?

Sunflower Lanyards are a signal that you might need little changes to make things easier - for example letting you join a special queue for people with hidden disabilities like FASD.

If you look when you are not at home, you will see other people have them. They can be used in shops, on buses and trains, in the cinema or in lots of places. Some people wear them all the time, but you don't have to. Some people just wear their Sunflower Lanyard when they need a little extra bit of help. Sometimes it is a trusted adult who wears it for the person who needs it. The important thing is that the Sunflower Lanyard lets people know that you might need a little bit of extra help.

Nyrene says, "I like wearing the sunflower lanyard. It's like a safety barrier to others to inform them of my disability and if I need any help. Plus another person may see it and ask me about it, or they may also have FASD, it opens up a lot of discussion." Nyrene wears her National FASD Sunflower Lanyard at work

Iwesome

At Me & My FASD / The National Organisation for FASD we have produced our own FASD Sunflower Lanyards so that people know that you have FASD and might need help when you are out and about.



You can order your National FASD Sunflower Lanyard here

# Callum

Callum wore his Sunflower Lanyard when he was on holiday. It helped!



#### Here's what Callum said about why it helped:

Airports are busy places with lots of people, lots of noise and lots of queues. I don't like any of these things. I used my FASD Sunflower Lanyard so that people understood this, and I got to the front of the queue to get on the plane and to get into Spain.

People saw the lanyard, understood what it meant and came to help me. I didn't wear it all the time, only when I thought things would get difficult.

It made a big difference to my holiday and helped a lot. I don't always like people knowing that I have FASD, but sometimes if they know that I need a little extra help it makes everything easier. My football coaches know I sometimes need things explained to me more than once and that's okay:

But there are people that I have never met who could help. The Sunflower Lanyard is a little signal for them.

"It made a big difference to my holiday and helped a lot."



What is a snowman's favourite time at school?

Snow and tell!

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# Arts & crafts

Taking part in Arts and Crafts helps some people with FASD find space to have some peace and quiet. Art can be drawing and painting, but there are plenty of other things that people with FASD do. Some people make models. (Yes, Lego building is a craft!) Some people knit and crochet, like Rachel. Other people with FASD take photographs or do other projects.

#### Do you like Arts and Crafts?

We would really like to see what you do. You can send us pictures of your arts and crafts work via our portal: https://fasd.me/portal/ We might feature them in the next edition of Living FASD.



# Rachel

Rachel is 20 and she has FASD. She is super creative and artistic. She especially likes to crochet. Here are some photos of her crocheted creations.

Rachel says, "Crocheting makes me happy and helps me to calm down and destress from the day. To know that other people enjoy them makes me happy."

Awesome

#### What do you call an igloo without a toilet?

An ig!

# Josh Avvesome

Josh is a street artist who has FASD.

At Living FASD we love his art. These are just a few of his new works of art. We are sending posters of his street art to members of the Me and My FASD Club.

Josh got hooked on street art after his mum took him on a street art tour in London. Now he paints to relax at an outdoor studio in Peterborough where he lives.

Josh says street art is different for everyone. He finds it fun and he likes to do fun things.

#### Josh says, "Street art gives me time not to think about anything else and I can separate myself from all the annoying things."

Josh's mum told Living FASD that street art "definitely helps to calm Josh down. He can go into a session quite angry and says that he doesn't want to do it or that he only wants to do something easy and simple and by the end of the session he is happy and proud of what he has achieved."

You can find more about Josh here and watch a video.





What do you like to draw or doodle? Have a go on the next page.



# Doodle about

#### Use the space below! You could doodle about:

- Your family life
- Your pet
- Your friend
- Yourself!
- Your favourite place
- A holiday you went on
- Something that helps you feel calm
- Someone who inspires you
- Anything that makes you happy!

#### Positive things about FASD could be:

- How it helps people see things differently to others
- How creative people with FASD are
- How people learn to manage FASD
- And many more!

Send us a photo of your doodle to https://fasd.me/portal/ or



# **Community** activities





People with FASD tell us that they really love being part of clubs and activities that happen in the communities where they live.

In this edition of Living FASD you have met: Josh who makes street art in his community; Grace who is part of a Disability Gymnastics Development Squad and represents England in Special Olympics; Angel who dances in Scotland; and Tolka the musician who created a music video with people with FASD from all over the country.

We know that loads of people take part in sports and activities where they live all of the time. Some of you play football, go to Cubs and Brownies, swim, sing in choirs, or do other activities.

We would love to know what you do. You can get your trusted adult to send us information via our portal https://fasd.me/portal/. We would love to see photos. Who knows, maybe you will see yourself in future editions of Living FASD. Most of all HAVE FUN.

Here is information you could print out for coaches or club/ activity leaders: https://fasd.me/for-sharing/









#### **Our website**

You will probably have found our website: www.fasd.me. It has lots of information and suggestions about what you can do to learn about FASD and how you can help yourself to do your very best. Have a look and keep going back to learn more about FASD. You can sign up for updates from Me & My FASD so that you don't miss out when something new is added. This magazine and the Me and My FASD Club pack are designed by www.crackerjac.com

#### www.fasd.me

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What do you call a snowman in the summer?

A puddle

### Dance

We know that lots of people with FASD love to move, to run and bounce and spin. Are YOU like this?

# Have you ever thought about trying to dance?

# Lots of people with FASD love to dance.

There are many great things about dance. It keeps you fit and helps with skills like balance, flexibility, and co-ordination. Dance teachers tell us that dance is important for developing a special sense called proprioception – how your body knows where you are in your surroundings, whether you are standing straight or at an angle.

Dance is a way of enjoying music with other people. It's a way of communicating your thoughts and feelings without words. It's also a super coping strategy. Did you know that all that bouncing and spinning and crossing the midline can help your brain stay calm?

You might make new friends at a class or maybe you prefer to dance alone.

#### Don't be afraid to try something new – You might be awesome at it – go for it.

Here is Angel dancing see more about Angel on the next page

# Angel

Angel has FASD. She has been dancing since she was two years old. She represented Scotland at the Dance World Cup held in San Sebastián in Spain in 2022.

Her mum says, "Angel has had some journey throughout. At first she didn't like being upside down. She just stood and watched and wouldn't take part but her dance principal kept going and did not give up on her".

In Spain, Angel's team came 10th in the world. Angel played an important part in this success. Angel tells us that she loves to dance and really would like other people with FASD to try it too.

All of Angel's dance teachers know about her FASD. If something doesn't work for her, they try things in a different way. Angel is very quick at picking up dance routines, especially tap dancing and musical beats.

She has taken loads of dance exams in ballet and acrobatic arts. She gained Distinctions and the highest mark in her dance school. She tells us that she doesn't always find concentrating easy, but it never stops her trying her best.

In her latest competition, Angel came 5th for ballet and 8th for modern jazz (which she had only learned the week before the competition). Angel would like to thank her teachers for their encouragement and support.



Congratulations Angel! We think you are awesome.

#### What are YOU proud of?

Every day our lives are full of wonderful accomplishments.











Getting dressed

Riding in the car

Brushing teeth

Writing

Celebrate your successes!



# Help write the UK FASD Manifesto

Have you ever been in school, at a doctor's appointment or with family or friends where you felt like the person talking to you wasn't supporting you in a way that was helping you? Maybe they were even making things worse for you?

How do you want the people supporting you to treat you? If you could remind them of some ground rules, what would they be?

People with FASD are creating a manifesto that explains to people what is important for them to remember when they are supporting you.

We are collecting ideas from people with FASD all across the UK. We want do know what YOU think this manifesto should say.

### What's a manifesto?

It's an important statement by a group of people that shows the world they have some really good ideas about how to create a better society.

#### What's the UK FASD Manifesto?

You will help create this. It is a statement by people with FASD in the UK that will explain what others can do to better support people with FASD. It will be presented at a national conference in March 2023. We will let you know the results!

TELL US WHAT YOU WANT PEOPLE WHO SUPPORT KIDS WITH FASD TO DO



Ask your trusted adult (if you need them to help you) to head over to our survey monkey form and complete the questions.

Or you can fill out the form on the next page and send a photo of that back to us at https://fasd.me/portal/



### For more information about the conference

National FASD is a co-sponsor!





## Dear world:

When you are supporting people with FASD, we feel happy & respected when you:

First name:

Age:



Please take a photo and upload this at https://fasd.me/portal/



"Listen to us"

"Don't assume you know what it's like for us" "Give us time to process what you are saying" "Remember we are trying our very best" "Remember we get tired easily" "Give us time to relax"

"Don't judge us"

"Learn about me and my FASD"

To start the discussion, here is what some members of our adults and young adults with FASD advisory committee said should be in the manifesto

## Merch



A visual tool to help people with FASD work through good and not-so-good situations, to help them identify different strategies and strengths that can help them.



#### **Calming cards**

A set of 50 colourfully illustrated visual cards with suggestions from more than 70 people with FASD about what helps them to stay calm.



The Misunderstoods

The Misunderstoods: Living FASD - a fun way for a young person to work with an adult to explore different aspects of living with FASD.

These are available to purchase on \_\_\_\_\_\_ https://tinyurl.com/MeAndMyFASDMerch



# Training

People can help you more if they know more about FASD.

The National Organisation for FASD was successful in developing national training packages for professionals to help them to understand FASD and how to help children and young people with FASD.

We worked with a charity called Seashell to make sure that the training is as good as it can be.

Our training uses a lot of the Me & My FASD materials. It was developed with a group of adults and young people with FASD as well as a national experts committee.

If you think that someone who supports or works with you would benefit from learning more about how your brain works and why people like you with FASD are awesome, they can find out more here.

We also have leaflets available that can be downloaded from our website that you could give to them about our training.







# Winter

Winter can be a hard time for people with FASD. The weather isn't always good. It's harder to get out because many people don't really like getting cold and wet. Or maybe you do?

Some people get colds and flu. That's not nice.

Others like winter, especially when it snows.

We asked people with FASD to show us some of their snow creations during the last big snow.

Here at Living FASD we would love to hear about what you like about winter.

You can draw us a picture and take a photo of it and send it to us at https://fasd.me/portal/

Making snowpeople can be fun! Awesome



Tiggy, 9, created this dignified nowman

Jim's snowman is looking comfy in that scarf





Look at Charlotte's smile when she was 2

Now at 15 Charlotte still enjoys snow-people



E, 17, created this in the dark after finishing college and work for the day! Brr!



Lilly, 10, got creative!

Tyler, 13, showed his focus and artistic flair

P, 11, used a a banana for the smile!



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# What's next?

YOU can be an 'awesome' star in the next edition of Living FASD!

We need your help to make the next magazine brilliant.

Our next magazine will be sent out in April 2023. It will focus on people with FASD who are awesome.

Please let us know what makes you awesome.

It will be a special holiday feature! Please also let us know what you like to do when you go on holiday, what your best ever holiday was like, or what your dream holiday would be.

To send us things, please get help and permission from your trusted supporter - usu a parent, carer, or guardian. If you send us photos, we will try to include them in the magazine. Remember, we need permission before we can use photos of you.



Awesome

#### Checklist of things you can send to us via our Me and My FASD portal:

Your FASD manifesto ideas, p20-21

Photos of your art or crafts, p14

Your FASD Doodle, p16

Your favourite community activities, p17

What do you like about winter, p23

What makes you awesome? p24

What was your best ever holiday and why? p24

Thanks for reading!!



Scan this QR code with your phone or go to https://fasd.me/portal/

