

## Functional Somatic Symptoms (FSS)

Information for children, young people and their families





This book is all about Functional Somatic Symptoms – or FSS for short. If you have been given this book to read, then you or someone you care about has been told they have FSS. This is often worrying or confusing, but most children and young people with FSS will make a good recovery and return to doing the things that they enjoy.

If you have been diagnosed with FSS it means that the doctors have made sure that there is nothing harmful happening in your body to explain the symptoms.

It is possible to have FSS at the same time as another medical condition. It is important to know about both as they will need different sorts of help.



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Children's Health Queensland pays respect to the traditional custodians of the lands on which we walk, work, talk and live. We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders past, present and future.

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### What are FSS?

FSS are like a big umbrella that includes a lot of different types of symptoms that affect different parts of the body. Many people have more than one type of symptom, but they are all part of FSS.

In this book there is information about:

- What FSS are and how FSS can present differently for different children and young people
- Why FSS happen
- How to get better.

Functional gut symptoms

Persisting fatigue

Functional neurological symptoms (FND)

#### **Autonomic symptoms:**

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Dizziness
- Hot and sweaty
- Nausea and vomiting

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Functional cough
Irritable bladder
Functional chest pain
Chronic/complex pain



There is also extra information at the end of this book if you or someone else wants more details. Just look for the symbol.



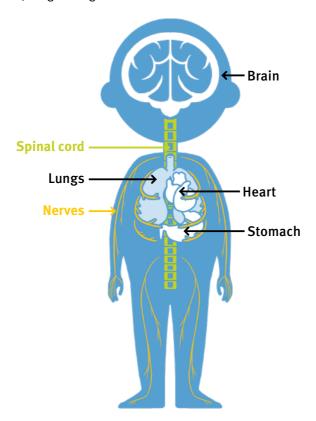
Lots of people have heard of FND or Functional Neurological Disorder. There is more information on the relationship between FSS and FND in one of the 'extras' on page 25 of this book.

## The nervous system

To understand FSS, we need to talk about the nervous system.

The nervous system is made up of your brain and spinal cord as well as nerves throughout your body. The nervous system controls everything that you do.

The brain is like a big computer that controls the way a person moves, speaks, thinks, and feels. The brain and other parts of the nervous system also control a lot of things that we aren't aware of, like the way our heart, lungs and gut work.





Find extra information on page 26

## The brain-body stress system

Another job for the nervous system is to protect you and your body when your brain thinks you are in danger.

The nervous system is part of our brainbody stress system. When there are threats or danger, your stress system switches ON to protect you. This is like your body's alarm warning you you're in danger.





For example, if a big spider crawls on your foot – your stress system will switch on to protect you.

The stress system will send your body a message to move away from the danger. You might notice that your heart is beating faster, and you may be breathing more quickly. You might also feel 'butterflies' in your tummy.

When you are safe, your stress system should switch off until it is needed again.



### The stress response

The stress response is also often called 'fight, flight or freeze'. This is a normal thing that everyone's body does when their brain thinks they are in danger.





Find extra information on page 28

# What causes the brain-body stress system to turn on?

The body-brain-stress system can be turned on by anything that seems like it might be dangerous to you or your body.

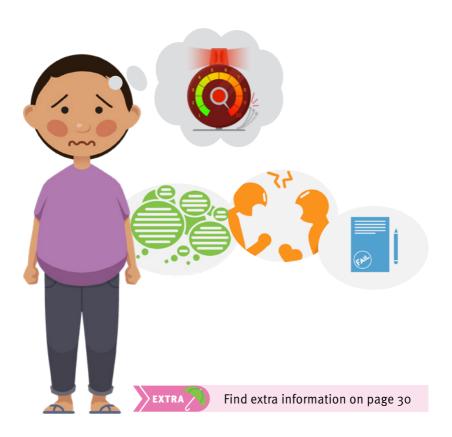
The stress could be a range of different things for different people such as an injury, an illness, or an upsetting experience. Some examples might include breaking your arm, a vomiting bug or being bullied at school. Everyone's reaction to stress is different.

Usually, the stress system will turn off again once the stress has passed.



If the stress system is turned on too often, too much or for too long, it can get stuck and not turn off. It's like the volume dial gets turned up too high and the nervous system becomes more sensitive.

When this happens the stress system can get turned on by things that can seem like small, everyday events that you might not even notice. These events can be something from inside or outside your body and something physical or emotional. The stress system can even switch on when there is no obvious threat or danger.



## What happens if the stress system is turned on for too long?

A stress system that is turned on too often, too much or for too long can result in symptoms such as:

- pain (in one place or many places in your body)
- nausea (feeling sick in the tummy) or vomiting
- events that look like seizures
- weakness or not being able to move your arms or legs
- loss of feeling in your body or changes in your eyesight

fatigue/tiredness

dizziness



### FSS are real

We know that FSS can look like lots of other medical conditions.

It is important that your doctor has made sure that FSS are the right explanation for what is happening to you and your body. Your team is confident you have FSS.

Although FSS are related to an overprotective nervous system, we know that the symptoms are very real!

We know that it might be hard to work out what is causing your brain and body to be on high alert and to activate the FSS. It might be one big stressor or lots of little stressors all building up together. Sometimes the stress that started the FSS has gone, but other things keep the FSS going. Working this out with your team is part of getting better.



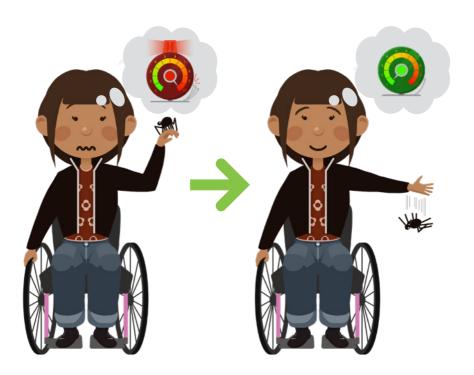
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### **Getting better**

The good news is that you can get better from FSS! You do this by retraining your brain. You can learn ways to turn down the volume dial on your stress system.

As you begin to retrain your stress system, the alarm switch will learn to turn on only when there is true danger and to switch off when that danger has passed. The more the stress system is retrained, the better it will get at sending the right messages at the right time.

Retraining your brain is not easy, but it is possible when you have the right help. We know that FSS can cause a lot of distress. It is important that your doctor assures you that your body is safe and that there is no damage happening, so you feel ready to start treatment.



### The treatment plan

Recovering from FSS is easier once you have a treatment plan to follow. This is the plan that helps retrain your brain. The plan will involve:

- understanding anything that might be keeping your nervous system switched on.
- finding ways to turn down the dial on your nervous system.
- returning to normal everyday activities such as going to school, hanging out with your friends, or playing your favourite sport. (This is a great way of sending a message to your nervous system that you are safe).
- knowing what to do if any symptoms come back again in the future.

Retraining your nervous system can take time, just like training for a race.



If you are back doing the things you like to do, the FSS won't have as much impact as they do now.

Research tells us that the following things (listed right) are helpful and should be part of the retraining plan.



- Learning about FSS. You're off to a great start with this book!
- 2. Understanding your FSS and some of the things that might have played a part in it.
- Learning to retrain the nervous system and turn down the volume on the alarm so it is not so sensitive.
- Getting back to your normal routines and everyday activities.
- 5. Seeing different health professionals to help retrain your stress system and help your body's function return to normal. This may include an occupational therapist, a physiotherapist and a psychologist. You can take this booklet with you to any of your appointments.
- 6. Working together with your family and school as part of your recovery team.

There are lots of things that can help you start to retrain your nervous system. Different treatments work for different people so you may have to try some and see what works best for you.

Right is a list of strategies recommended by experts and other young people.

These brain retraining tools work best if you practice them. Try practicing them when you are feeling happy and well so that your brain learns what it needs to do when you are feeling stressed and your FSS may be stirred up.

It also helps to practice these skills with a parent/carer or friend so that they can help remind you how to use the skill at the right time.

Your brain will do everything it can to switch on its overprotective alarm system, so you may need help with this.

You might have used some of these tools before and feel that they haven't helped. That's ok. Your team will work with you to find the best way to dial down your stress system.

My list	
1. Breathing	1
2. Grounding	
3. Sleep and sun	
4. Everyday activities	
5. Move your body	
6. Noticing stuff - mindfulness and meditation	
7. Find your thing!	

# 1. Breathing

Taking slow, regular breaths may sound too simple to be helpful, but it really is one of the most effective things you can do for FSS symptoms. Breathing is simple, easy and always available – everyone knows how.

When our brain-body stress system has the alarm turned on high, it is natural to take short shallow breaths. When this happens for a long time, it is called hyperventilation.

Hyperventilation leads to major changes in the body and the brain. This can include: tingly sensation in hands and feet; muscle twitches and spasms; dizziness and fainting; difficulty thinking clearly; and pain and tightness in the chest. These are all common functional somatic symptoms!

Taking slow, regular breaths is like first aid for your nervous system. It immediately helps your whole system calm.

Steady breathing slows everything down, triggers the relaxation response and deactivates 'fight, flight or freeze'.

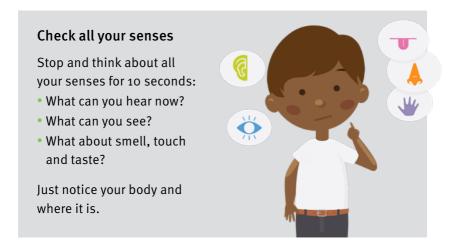
Even one big deep breath that goes all the way down to your belly will help your whole brainbody stress system.



# 2. Grounding

Grounding is simply just reminding yourself where you are and what is happening right at that moment – like reattaching yourself to the ground. This distracts your brain from the alarm going off and reminds your system that you are currently safe.

There are a lot of ways to practice grounding. Below are examples.



#### Talk to your brain

This feels weird, but it can work. Try thinking of a short sharp sentence you can say to your brain (out loud or in your head) when things get tricky. This might be something like "I'm safe right now, alarm system turn off" or "hey brain, time to stop!"

You could even give your brain another job to focus on like counting backwards from 100 by 7 - 93, 86, 79, 72 etc.

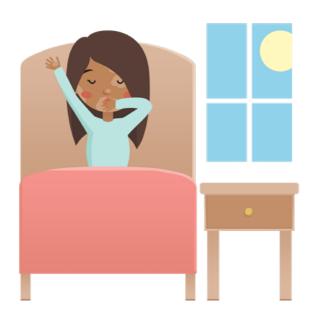
## 3. Sleep and sun

I'm sure you've heard it before, sleep is so important, and it is particularly important when you have FSS.

A simple thing to do to support your brain retraining is to have a consistent sleep routine – try to go to bed and get up at the same time every day. This doesn't have to be exactly the same to the minute, but your body and brain will cope better if it knows when it is getting rest and how much.

Doing this helps the alarm system turn down and makes all the other tools work better.

What you do when you wake up can also be really important. Try sitting in the sun in the morning, even just for a few minutes. This helps your body clock and gives you a boost of important brain chemicals like melatonin and serotonin. These amazing substances are awesome for your mood and your sleep.

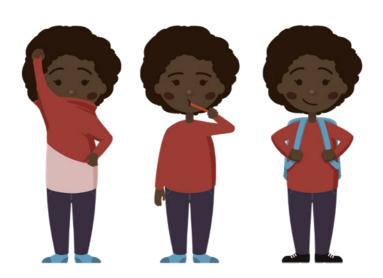


# 4. Everyday activities

A really great way to remind your brain that it is safe is to do everyday things. If you get up and do things like get dressed and brush your teeth your brain will be reminded that it does not need to be in protection mode. Your body and brain are capable!

#### Try:

- Getting dressed every day, even if you aren't leaving the house.
- · Brushing your teeth and hair every day.
- · Having a shower or bath every day.
- Making your bed, feeding a pet, or do other simple household chores you would normally do.
- Sitting at the table with your family for meals if this is what your family normally does.
- · Going to school, even if only for a short time.



## 5. Move your body

Exercise is incredible at helping retrain your brain. Whenever you exercise, your system releases hormones called endorphins. This is awesome because endorphins can reduce your experience of pain and also create positive feelings. Not only is this good for retraining your brain, but when you have FSS it can be nice to just have times where you feel good.

Exercise doesn't have to be long or strenuous. You just need to move regularly. Try:

- · Walking your dog around the block.
- Walking to the corner and back if the whole block is too far at first.
- Throwing and catching a ball 10 times.
- Doing a quick gentle yoga class from YouTube (yoga is really helpful but it's not for everyone).
- · Gentle dancing to your favourite song.



# 6. Noticing stuff (mindfulness and meditation)

Mindfulness and meditation are excellent tools for retraining your brain. Mindfulness doesn't have to be complicated, it is basically just 'noticing stuff'. This allows so many great things to happen in your brain and body – your whole brain calms down. It makes your brain release chemicals that work against fight, flight, or freeze.

Although 'noticing stuff' is really powerful, it works best if you practice it every day. It also works well when you practice at times when you feel calm and settled. Then your system will know what to do at tricky times.

Try one of these every day:

#### Notice your breathing

Stop and focus on your breath going in and out 20 times. You might start to think about other things but just say "oh well" and go back to noticing your breathing.

#### Notice your body

Stop and focus on how your body feels for 1 minute – Where are your hands? What are you sitting or lying on? Is your belly tight or relaxed?



#### Notice what's around you

Stop and focus on what's around you – what can you hear right now? Birds, a lawnmower, the TV? What can you smell right now? Mowed grass, your moisturiser?

You may also find a good app or podcast that helps you work on grounding and noticing stuff like your breathing.

# 7. Finding your thing!

Although these are the top things that we know can help retrain your brain, there are many others that kids and young people have discovered for themselves.

An important part of recovering from FSS is finding tools that help your nervous system feel safe. We know that FSS are a sign that your nervous system is feeling stressed and in danger. So, look for the things that remind your system it is safe. The six ideas above in this book will help, but you might discover something else that works for you. It could be:

- · Listening to music
- Singing
- Colouring in
- · Patting the dog
- Going for a walk
- Fishing
- Anything that helps you feel calm and safe.



Remember – the focus of recovery from FSS is all about retraining the brain and getting back to your normal daily activities. Reducing the symptoms often takes longer.

It is a lot of work to get control over your super protective brain, but it will be worth it.

It will feel hard at times, and it won't happen straight away, but you can do this. You'll probably have good days and bad days. Just keep going. You've got this!





Functional Somatic Symptoms can be anything that causes someone to experience:

- 1. Physical discomfort or disruption to the body (e.g. pain, nausea)
- 2. Changes in motor abilities or in sensations in the body (e.g. paralysis, loss of vision)
- 3. Feelings of general poor health and wellbeing (fatigue, exhaustion).

Or, all of the above.

They are symptoms that cannot be explained by anything harmful in the body, even after doctors have done tests to make sure.

As mentioned earlier in this book, the symptoms come about due to the brain-body stress system being turned on too often, too much or for too long.

There are many common difficulties that can be identified as functional somatic symptoms and many people experience more than one. That is why we use the term FSS as an 'umbrella term' that covers all different symptoms.

Part of the brain-body stress system is the Autonomic Nervous System (ANS). This is the part of the nervous system that controls all the automatic actions in our bodies. This includes heart rate, breathing rate, sweating and the need to go to the toilet. The ANS is part of the alarm system that gets dialled up too high or for too long in FSS.

As such, many functional somatic symptoms impact these automatic actions. This can be scary because it can feel like you have no control over what your body is doing.

The most common functional somatic symptoms are outlined following, but this is not a complete list of every possible symptom. FSS are as individual and unique as you are.

## Functional Neurological Symptoms (FND)

Functional motor disorders or functional seizures. See Extra: FSS and FND. The same or different? on page 25 for more information.

#### Irritable bladder

Regular or increased need to suddenly go to the toilet. A common symptom that occurs with 'fight or flight' as the body gets rid of any extra weight, so it is effective to fight or run away.

#### Postural Orthostatic Tachycardia Syndrome (POTS)

Changes in your autonomic nervous system that result in your heart beating too fast when you sit or stand. This can often result in lightheadedness.

- Common in FSS as lightheadedness can result from periods of reduced activity.
- POTS can also be associated with other symptoms of the autonomic nervous system. See 'Other autonomic symptoms' on page 24.

#### Chronic/complex pain

Chronic/complex pain is long term pain that persists.

When there is persistent pain, the body's alarm system is in a highly alert state. When it is in this state, even normal information can be processed as a danger signal which can lead to the brain creating pain as a protective output.

#### Persisting fatigue

Persisting fatigue is a common symptom for everyone with FSS.

- When the brain-body stress system alarm is dialed up high all the time, the nervous system tries to 'fix' this by encouraging rest. But, the less you do, the more deconditioned you get which helps other FSS appear (e.g. dizziness).
- Persisting fatigue can also result after an illness or infection where the body's recovery response is turned on and it then gets stuck on high alert.
- Stress and anxiety often make it difficult to fall asleep or stay asleep.
   This only adds to the feeling of constant fatigue.

#### Functional chest pain

Pain and tightness in the chest, often happening at the same time as heart beating fast and dizziness.

- Changes in feelings in the chest can happen as a normal part of 'fight, flight or freeze' and are intensified when the stress system is dialled up too high for too long.
- Tightness in the chest and dizziness is also common when you breathe in short, shallow breaths. This is called hyperventilation and breathing this way is common when the whole nervous system is on high alert.

#### **Functional gut symptoms**

Functional gut symptoms may include feelings of nausea, food sitting like a 'rock' in the stomach, lack of appetite or vomiting.

- Internal body changes that happen as a normal part of 'fight, flight or freeze' can result in any of these feelings in the gut.
- These feelings intensify when the brain-body stress system is dialled up all the time.
- Also known as Disorders of Gut-Brain Interaction.

#### Functional cough

Interferes with everyday activities, impacts on sleep and in some cases leads to vomiting.

#### Other autonomic symptoms

Such as being sweaty, hot, dizzy or nauseous.

- These are all signs that the ANS and brain-body stress system are on alert.
- These are all common things that happen in the body when it goes into 'fight, flight or freeze', which is what is happening when the alarm system is turned up too high or for too long.

So, remember that even though these symptoms might feel scary, if you have been told they are functional somatic symptoms we know that your body is safe. It means that your brain-body stress system is working hard to protect you, but the alarm has gotten stuck on high alert. It also means that you can recover from these symptoms that are impacting on the things that are important in your life. You've got this.



As we have learned through this book, FSS occur when the brain-body stress system gets stuck in protection mode. FSS can happen in all parts of the body and look different for everyone. Some people experience one FSS, while others experience many different symptoms. Some people experience FSS on top of an already existing medical condition.

Functional Neurological Disorder (FND) comes under the FSS umbrella. It is one type of FSS. We call it FND when the symptoms are mainly neurological in nature. People with these neurological symptoms might be referred to a neurologist.

As well as the neurological symptoms such as weakness or loss of sensation, a person with may have other FSS such as nausea or fatigue. This is all part of the FND and the symptoms can be treated together.

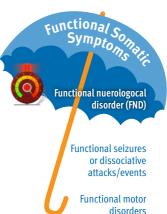
The two most common types of symptoms are:

1. Functional seizures or dissociative attacks/events

These are different names for the same thing. The event looks like a seizure and can include shaking, unusual movements in the arms and legs, and a loss of consciousness. However, this is not caused by abnormal electrical activity in the brain, or abnormal brain anatomy.

#### 2. Functional motor disorders

These include a range of movement difficulties that can make normal movement and mobility really difficult. It can include weakness in the arms and legs, shaking, and unusual positioning of the body that get in the way of normal movement.



Functional seizures and functional motor disorders are also symptoms that arise in the body, are caused by an overprotective stress system and that need to be treated by a different approach – like the one described in this book



We all have a brain, and they are all completely incredible. Your brain controls absolutely everything that happens in your body, and it does most of it without us noticing!

Although the brain is amazing at doing all the things it needs to do, one of its main jobs is to keep you safe. Your brain really wants to protect you at all costs.

As discussed in this FSS book, your brain has an alarm system that switches on and dials up the volume to protect you. This 'extra' will help you understand more about the amazing brain and how it works.

The brain is made of up three main areas and in FSS we are particularly interested in two of them – the Pre-frontal Cortex and the Limbic System. These areas can also be known as the 'thinking brain' and the 'feeling brain'.



#### The feeling brain (the Limbic System)

The Limbic System is made up of different parts of the brain, but in FSS we focus on a part called the Amygdala.

This is a tiny little area in the middle of your brain, and it switches on an alarm when it thinks there is something to protect you from.

The 'Alarming Amygdala' protects you by starting 'fight, flight or freeze'.

The problem is that the more the Alarming Amygdala gets turned on the bigger it gets, the stronger it gets and the quicker it gets at turning on.

Before you know it, your Alarming Amygdala is the boss of your brain, which means it's the boss of you.

The Alarming Amygdala is what makes you feel stressed and anxious – and can cause FSS if it gets too strong and too protective.

#### The thinking brain (the Pre-frontal Cortex)

The Pre-frontal Cortex is right at the front and top of your brain, and this is the part of your brain that can turn off the Alarming Amygdala.

The Pre-frontal Cortex is like the clever professor in your brain that solves problems, makes plans, and works out what to do when things go wrong.

Professor Pre-frontal Cortex loves to be friends with the Alarming Amygdala, but it also knows how to help it calm and dial down the alarm.

As the Alarming Amygdala gets bigger and stronger, Professor Pre-frontal Cortex needs help to work out how to calm the Alarming Amygdala.

All the strategies and tools in this FSS book, like grounding and exercise, work really well to help Professor Pre-frontal Cortex do this and that's why we've told you all about them.

# Fight, flight or freeze

Lots of people have heard of 'fight, flight or freeze'. This is what everyone's brain and body does when it thinks you're in trouble. This is exactly what the Alarming Amygdala likes to set off whenever it gets worried.

'Fight, flight or freeze' is normal. It happens to everyone. In FSS, it happens all the time so we need to understand what is happening.

The idea of 'fight, flight or freeze' comes from way back in prehistoric times when we were all cavemen (and cavewomen and cavekids). At these times, there were lots of dangers around all the time. It was life or death whenever you stepped out of your cave. Our lives are pretty safe now, but the **Alarming Amygdala** doesn't seem to realise this.

Imagine you are a caveperson and when you step out of your cave in the morning to go and look for breakfast, a sabre-tooth tiger comes running straight for you. This is definitely something to worry about and your **Alarming Amygdala** kicks into high gear. There are 3 options:

### 1. Fight



You could decide to stop and fight the sabre-tooth tiger. Maybe your breakfast has come straight to you! In order to give you the best chance, your brain and body work together and things start to happen:

- blood is pumped to your muscles to make you strong,
- your heart pumps this blood faster and gets your lungs pumping as well,
- adrenaline flows throughout your body to add to your strength and confidence, and
- you stop digesting anything in your stomach so that all your body's attention can go to your heart, muscles and blood.

### 2. Flight



Also known as 'flee'. You might decide that your best chance of survival is to run as fast as you can back to your cave to safety. Once again:

- blood is pumped quickly by your heart to your muscles, but this time straight to your legs for fast running,
- your body might decide that it needs to be light to run faster so suddenly you really need to go to the toilet,
- you start to sweat so you don't overheat and
- you can't think of anything but getting out of there as quickly as possible.

### 3. Freeze



Maybe you decide that if you stop and stay perfectly still, the sabre-tooth tiger won't notice you.

Freezing happens because sometimes, your brain and body is so overwhelmed by the danger that it just decides to stop and shutdown. It quickly turns off everything that is happening and you will be still, quiet and immobile.



These are just some of the things that happen in your body when it when it thinks it's in danger and goes into 'fight flight or freeze' mode. You can see that any of these would be helpful back when we were trying to stay safe from sabre-tooth tigers. However, for most people now, things that turn on this stress response tend to be everyday things that happen to your body and emotions.



#### Everyone is unique, which is what makes the world wonderful

We all have different likes and dislikes, have different coloured eyes, skin and hair, and are good at different things. Even our closest family and friends are different from to us.

#### We all have different brains as well

We all get information from the world around us – what we see, hear, feel, taste and smell. However, the way our brains take in this information and interpret it is different to everyone around us.

Some people love bright lights and loud music, while others like quiet and calm. Some people love spicy food while others find it too hot to even put in their mouths. The food is the same, different brains just understand it and experience it in a different way.

#### Things that cause stress are also different for each of us

Some people feel really worried about school, while others love it. This might be because learning or making friends has been hard for the first person, and so their brain has gone into protective mode around school.

Plus, worried brains are very good at remembering all the past negative things that have happened and this adds to the worry. Their brain sees anything to do with school as a threat. School hasn't changed but the brain sees it differently.

#### Worries or 'stressors' are a big part of FSS

If the brain-body stress system is dialled up high and FSS symptoms appear, your nervous system is telling you it is stressed. So, we need to be curious about why that may be happening. That is why it is so important to try and work out what your brain sees as stressors.

Try and have a good think about this and remember, it doesn't have to be something big and extreme, lots of little things cause stress too:

- What is happening in all your environments at home, school, sport, part time job?
- Do you have any memories of things that worried you in the past?
- What do you honestly think is making your brain and body stressed?
- What about emotions? Are you good at recognising them? At talking about them?

This is an important part of recovering from FSS.





It seems like everyone is talking about mindfulness, you might have even done it at school. The thing about mindfulness is that it works – there is so much scientific evidence that it changes your brain and the way your whole nervous system functions.

Mindfulness doesn't have to be complicated, it is basically just 'noticing stuff'. It is all about paying attention on purpose.

Doing this allows so many great things to happen in your brain and body:

- it turns the dial down on your brain-body stress system.
- your whole brain calms down.
- it makes your brain release every chemical that works against 'fight, flight, or freeze'.
- it helps Professor Pre-frontal Cortex to work out how to get bossy with the Alarming Amygdala.

Mindfulness works best when you practice a little bit quite often. Paying attention to the stuff you are noticing is tricky when you first start.

When Alarming Amygdala has been the boss of your brain, it is very good at distracting you when you try to pay attention to something else.

There are two easy ways to start practicing mindfulness:

#### 1. Notice your breath

Just simply paying attention to your breath and noticing how it feels as it goes in and out of your body is really powerful.

#### 2. Visualise

Focussing on the breathing doesn't work for everybody, but visualisation works just as well. Try closing your eyes and imagine being in your favourite place. Notice what you can see, what you can feel and what you can hear in this place.

Even if you only practice mindfulness for 5 seconds, that is 5 seconds where your Alarming Amygdala is not dialling up the volume on the alarm. It is 5 seconds of chemicals being produced to deactivate 'fight, flight or freeze'. It is 5 seconds that your whole brain-body stress system calms.

If you practice for 5 seconds a day for a week, you may then find that 10 seconds becomes easier and the week after, 20 seconds is possible.

Before you know it, you can stop and do a few minutes of mindfulness every time you feel Alarming Amygdala starting to cause trouble.

There is a lot of help when you are learning how to 'notice stuff' in order to help your FSS. There are books, apps, podcasts, YouTube videos and audio books galore. Try a few different ones and see what works for you. Your occupational therapist or psychologist should be able to help you with ideas.





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