My Journey through Post Concussive Syndrome

By

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In January 2024 I had a head injury that caused Post Concussive Syndrome. I wrote this book because I want people to know about Post Concussive Syndrome and how to support people who have it so, they have a better experience than I did.

I also wrote it to help people who are suffering from it feel like they aren't alone and to let them know what helped me recover.

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2024 -The head bang

Hello

My name is Millie and I am 9 years old. I live in Dorset and I love to read and do art. I have two dogs, Wanda who is blind and tiny and Gywn who is massive and thinks she is the queen! I also have a pet Tarantula called Ghost, I used to have one called Fluffy but mama left the top of her pot open to give her air and she escaped, so is still somewhere loose in our house!

In January I was doing PE at school, and I fell and hit my head. I went home and we thought everything was ok and normal. My head still hurt that evening and I had some Calpol. The next morning, I didn't feel any better and I was seeing double of everything, so we went to A and E. The Doctor said I had concussion; I did not know what that was.

I did bang the top of my head again on a walk going under a bike barrier. It hurt a lot because I was already in pain.

A few days later I woke up and my head was hurting a lot more than normal. I was whispering because my head hurt so much and I couldn't balance properly, so I had to hold onto things to help me walk and stand. So, we went straight into A and E again and the Doctor said I would have to stay

overnight, they took me up to the ward on a wheelchair. I had dinner (which was better than school dinners) and I remember the ice cream had all melted, so it was all spongy like a cake! I was in a room with two other boys, who were both older than me.

When the Doctor came round, he said he didn't understand how I could have got concussion from such a small fall and that I did not have a bruise. He also said he did not believe I was in as much pain as I said I was. This made me feel he definitely didn't believe us. That night I couldn't sleep due of the noise of the nurses talking and I couldn't lie down because it made me feel horrible. The next day they thought I seemed better so sent me home.

About a week later I went in for an MRI scan. It was very noisy, and it took about 15 minutes. My mama could be in there with me and I took a cuddly toy. It was horrible because I knew I couldn't get out whenever I wanted. My head really hurt afterwards.

I started doing school again, it was very loud, and I was sitting right next to the white board (which is like a massive television fixed onto the wall) as I couldn't look at screens, it made me feel really sick.

That weekend I woke up and couldn't get out of bed, because it made me feel horrible if I lifted my head. So, I

went back into A and E and the Doctors said that it was Post Concussive Syndrome and sent me home.

A couple of weeks later we went to see a doctor at the hospital and she kept saying about unexplained symptoms. She said to the GP that she thought I might be autistic because I wasn't giving her eye contact, and I was whispering because my head hurt. It made me feel that she definitely didn't believe us, even though she had said she did.

One of our friends who is a concussion specialist at a school near us said I needed neurological physiotherapy. So, we went to London to see a Physiotherapist called Theo and he gave me some exercises. He believed us.

I started doing an hour and a half of school, which was better. I went in for maths and a play time. Unless someone helped me with the maths, I had to take it home and do it, as I couldn't read it and I found it confusing. Being in class was very noisy and overwhelming, it made my head hurt a lot. During playtime I stayed inside with a friend as the playground was too noisy and overwhelming.

I missed seeing all my friends at school and not being able to be there, be normal and do all the things my friends were doing. I wasn't been able to go on school trips, forest school or do sports day. I was sad that I couldn't do the

school play, in other years I found the rehearsals funny as some bits go wrong!

After a while, we found a Neurological physiotherapist in Winchester who worked with children and knows about concussion, called Debbie. I saw her every two weeks and we did exercises and games to help my movement and brain.

For a few months I also saw a physiotherapist called Becky at our local Hospital who helped with my movement. Seeing Debbie and Becky was tiring but fun.

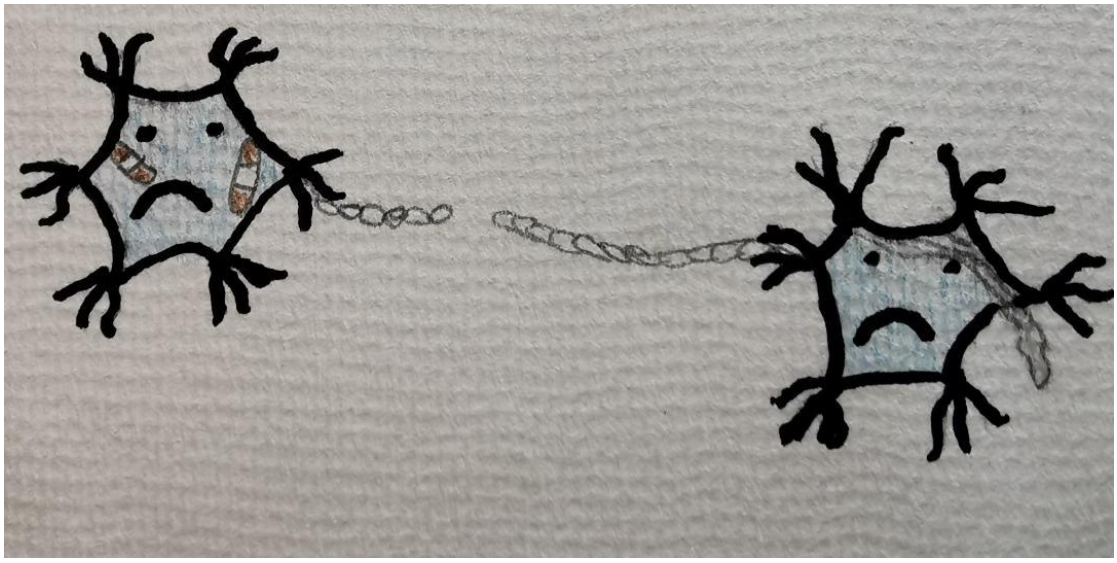
We went to Manchester to see a doctor who is a concussion expert. He believed us and gave me painkillers, which I hadn't got from any other doctors.

What is concussion?

When I fell over and hit my head, my brain got jiggled around inside my skull. This caused damage to my Neurons in my brain. Neurons are cells and they pass messages to each other along their arms, which are called Axons.

This is like holding hands with someone and passing information along. When you get Concussion, the Axons break and stretch, so it is harder for the neurons to communicate.

All the energy needed to heal my brain was going to the Neurons to help fix them, which means that there is less energy for the rest of my brain to work properly.



What is Post Concussive Syndrome

Post Concussive Syndrome is concussion that carries on. Here is a list of my symptoms –

- Headache – It is constant and doesn't get better. Sometimes it gets worse, for example, if I am in shop, or in a busy or loud place. It feels like my head is going to explode and no pain killers that we have tried have worked.
- Feeling sick all the time.
- Feeling dizzy sometimes, for example, after being in the car.
- I cannot read as it makes me feel sick. I can read handwriting because it isn't so jammed on a page like typewriting is.
- I cannot look at screens because they make me feel sick.
- I get overwhelmed in crowds and busy or loud places, for example shops or school.
- I have Insomnia so it takes me a long time to fall asleep. I am sometimes awake in bed until 2 O'clock in the morning.
- My balance is not as good as it used to be.
- My Short-Term Memory is not very good.

- I cannot answer some questions as quick as I used to be able to, for example maths questions. I call this "Mind Blank".
- I feel hot and cold even though I have not got a temperature.
- I feel like something is pressing on the front of my neck.

How it has impacted me

- I cannot listen to any music.
- I can hardly do any of the clubs that I used to do, for example, Gymnastics, dance, drama, swimming.
- I can't go to playgrounds because slides and swings would jolt my head, they are very noisy, and I am worried about hurting myself.
- I cannot run, skip, cartwheel, handstand, jump or walk long distances as it jolts my head.
- I cannot read because it makes me feel sick. Normally I would be reading all the time.
- I cannot look at screens because it makes me feel sick. I didn't realise how many things actually were screens and how many there are out and about, until now.
- I cannot get up from the floor because it jolts my head, so I use something that is taller than me to help me get up.
- I try to avoid going into shops and busy areas because I find it overwhelming. I cannot go to lots of the places I used to, for example, festivals or helping the homeless.
- I only do an hour and a half of school as it is very noisy and overwhelming. I cannot go out to the playground as it is very loud and busy.
- I get more nervous talking in front of people

- I get more angry and sad
- I worry about falling over

Sadness

Letter to my Post Concussive Monster

Post Concussive Monster,
Number 3,
My Brain,
AXON 23

7.7.24

Dear Post Concussive Monster,

I am writing because you are in my brain and I would like you to kindly leave. You have been in my brain since the 3rd January 2024, which has been hurting me.

I am not sure if you have realised, but you are hurting my head. I have got a constant headache, that is stopping me from doing most of the things that I used to do.

As well as the headache, I have got lots of other symptoms which you are causing (for example, overwhelm, feeling sick, not being able to read and not being able to do most of my clubs). I did not invite you

into my brain and it is not polite to come and stay without being asked. You have also hurt the Axons in my brain, which is illegal.

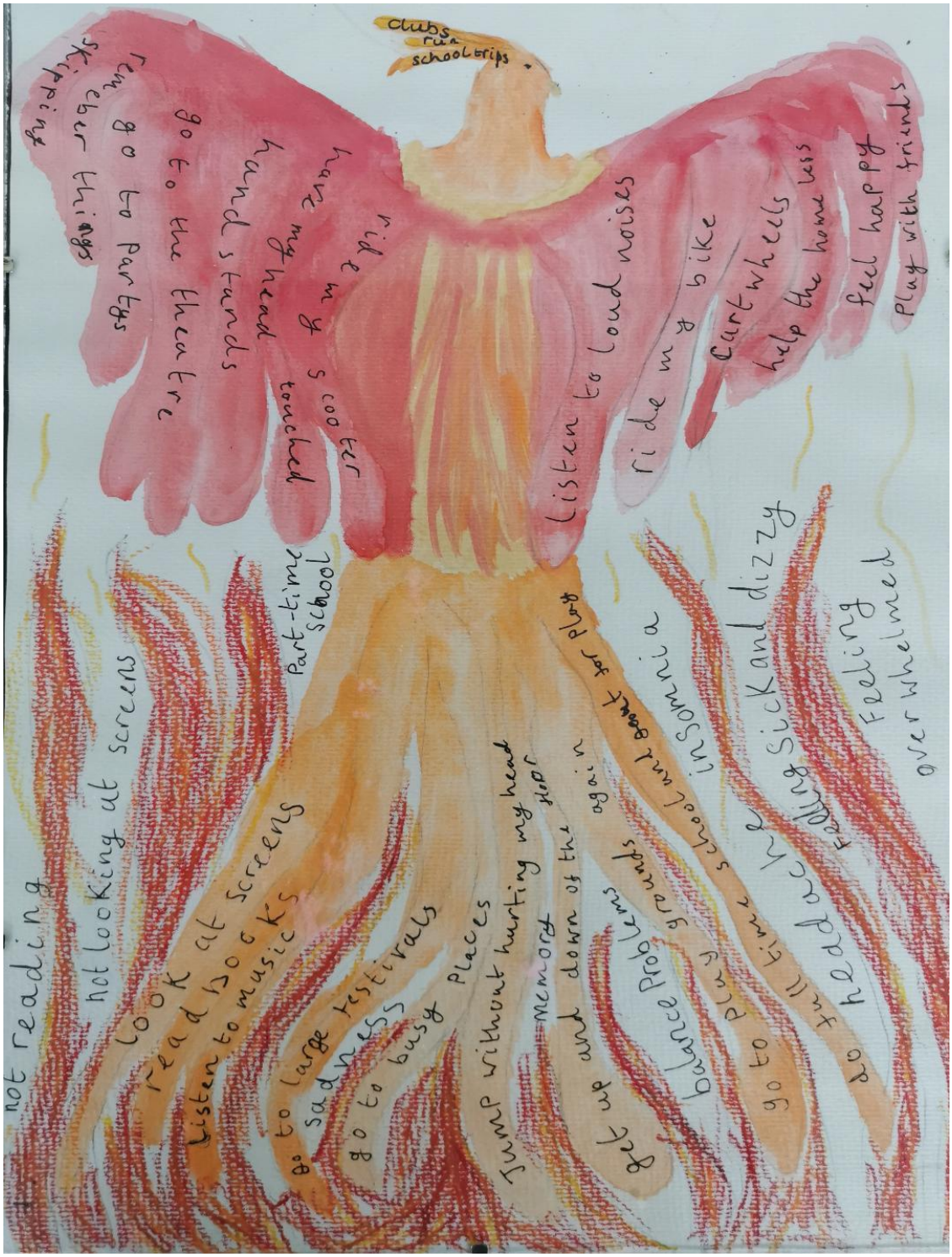
For these reasons, I would like you to leave by tomorrow morning. I also want you to fix the damage you have done before you leave. If you do not do this, then I will call the police who will make you leave and might put you in prison. In the future, you should not go anywhere you have not been invited.

Yours Sincerely,

Millie Osnowska-Salt

What I want to do when I am better

- Be happy
- Read books
- Look at screens
- Listen to music
- Go to large festivals
- Go to busy places
- Jump without hurting my head
- Get up and down off the floor
- Go to playgrounds again
- Do full time school and go out for play
- Play with friends
- Go to the theatre
- Clubs (dance, drama, gymnastics, swimming)
- Be ok with loud noises
- Cartwheels
- Handstands
- Go to parties
- Remember things
- Skipping
- Have my head touched
- Ride my bike
- Ride my scooter
- Help the homeless
- Go on school trips



Me rising from the flames, leaving all the Post Concussive symptoms behind.

What I want medical professionals to know about Post Concussive Syndrome

- Don't doubt symptoms in front of patients, so they don't feel they are not believed.
- Admit if you don't know about Post Concussive Syndrome and suggest somewhere else to go, for example, Neurological physiotherapy.
- Learn about Post Concussive Syndrome and the symptoms.
- Learn that any fall can cause concussion and it doesn't matter what height it is from and whether the person has a bruise.
- The MRI scan does not show any type of concussion as the damage is inside the cells. My scan was normal but that doesn't mean there isn't anything wrong.
- Have leaflets to explain what Post Concussive Syndrome is.
- Start more concussion clinics and have no age limits (lots of specialists only see children who are over 12 years old).
- Start more support groups so people can meet other people who have it and can talk about what it is like.

Advice for family and friends

- Learn about Post Concussive Syndrome.
- Try not to make the person think you are doubting them, it's hard when people don't believe your symptoms.
- Don't expect the person to do what they could do before
- Adjust to what the person needs and what they can do now.
- It's hard when people are loud.
- Try not to be so busy and have time to rest.
- Be calm and let the person do things in their own time.

Advice for schools

- Explain to the class what is wrong and what the child might need, because then they can help and understand why their classmate might be different.
- Let children bring fidgets in. I keep two quiet ones in my pocket that I have underneath the table in class.
- No timed activities.
- Don't ask direct questions in front of the class.
- Turn off the whiteboard whenever possible.
- Make the work bigger
- Have an exit card so children can leave the classroom if they need.
- Don't expect the child to do everything they could do before.
- Believe children when they tell you what they can't do.
- If possible let the child work in smaller groups as its less overwhelming and easier to understand things.
- No PE lessons
- Include children as much as possible
- Allow the child to stay in at break times because playgrounds can be very loud and overwhelming.
- Allow children not to go to assemblies because they are very loud.

What has helped me

- Physiotherapy – Exercises which are fun. We found a variety online and kept changing them.
- Playing Dobble is a fun way of doing eye movement exercises.
- Hydrotherapy – it is nice and relaxing being in the water and not having the pressure that I need to swim, I can just float around.
- Walking - It is nice to get fresh air, but the movement hurts my head. I find doing smaller walks throughout the day is better than doing one big one.
- Books – I like getting picture books with lovely drawings and photographs out of the library, (which don't have lots of writing) and at night I copy some of the pictures in them.

- Playing – I find playing with hard toys (Playmobile, Sylvanians, Schleich, Safari) relaxing and something I can do when I can't sleep.
- Crafting – I have learnt to needle felt and have done painting and diamond painting, which I have found helpful. I find colouring, drawing and painting calming. When I am cross because my Post Concussive Syndrome isn't stopping I have found drawing how I am feeling has helped.

(Angry)

- Shops – I have tried using fidgets, breathing to stay calm, and fidgeting with buttons on my clothes, but these have not helped me. When you do go, get more things, so you don't have to go so often. My Mama tries to go shopping without me.

- Playdates – I choose calm people and limit the amount of time they are here for.
- Trips out – We go to places during school hours, so they aren't full up with people.
- Magnetic white board on the fridge – so I can write what we are doing each day to help me remember
- Information sheets – we sent information sheets to family, school and friends about concussion and how it has impacted me, so that people understood what I can do and what I can't do.
- Clubs – I can't do many of the clubs I used to do, but I can do bowls with help getting up and down and I have started an art class, which it is nice and quiet.
- Find a font style that works for you. I liked Ink Free and Comic Sans, at the start I could read only size 70, but I worked back to normal size again.
- Finding other people who also have Post Concussive Syndrome and talking to them.

- Animals – I have a blind puppy; I find being around animals helps because I can cuddle them and they make me laugh. Since being unwell I have been grooming a friend's pony, Magic and also did 12 weeks of horse therapy, where I met Dude. Being around horses is calming and I have a connection with Magic and Dude. In December 2024 I started going to a bird of prey centre where I have learnt about the different birds they have there and how to care for them. It has helped me feel confident and I look forward to going.

- Get a bag of fidgets.

- Finding a good psychologist. I go to see Kelly, a psychologist who knows a lot about brain injury.
- We found you can order books in large print, with extra spaces and coloured pages, from Custom Eyes Books (Guide Dogs for the Blind), they have lots to choose from and are the same price as a normal book.
- **Find something you love and find calming.**

Update

Autumn 2025

- I got two more tarantulas!
- I do one to one gymnastics and soon will be going back to a class
- I go to the bird of prey centre every Friday afternoon and in the holidays, I have been going more.
- The pain medication didn't work
- I am seeing a Behavioural Optometrist called Sophie who gives me fun exercises to do at home and lets me borrow games.
- I have seen a Cranial Osteopath Called Tamara, though this did not help me, it did help a friend.
- After a year I have stopped seeing my neurological physiotherapist Debbie.
- I had another MRI scan
- I did an art exhibition of all the art I have done since being unwell and got in the paper
- I have met adults with Post Concussive Syndrome which I found helpful, but I would have preferred to meet another child.
- I do maths with just one other child in my class, which is far quieter and I can have more help.

- I went to Southampton Hospital to see the Neurologist there.
- I do swimming lessons weekly in a quiet pool
- I was in the school play!
- I have increased my time at school and am nearly full time
- The doctor who thought I had autism apologised and has learnt more about Post Concussive syndrome.
- I went to a hot air balloon and firework display
- I have started reading a book with bigger text but can read smaller writing when it is spaced out.
- I can now run, jump, skip, go on playground equipment and am soon going to do a big zip wire!
- I can watch television again and look at screens
- I can listen to music!
- I have a tortoise called Jaws.

Update 2026!

My brain decided to celebrate the two-year anniversary of my fall by being totally better!

After having to rearrange many times I finally got to London to see the Harry Potter Play and went to Legoland!

I am back at dance and gymnastic classes again. I am reading normal size text and am a bookworm again!

I have caught up with all my learning and go to secondary school in September, I cant wait!

Recently I have been on a year 6 residential at Land and Wave in Studland for two days. I managed to stay both nights and climb up a cliff!

I have got an 8-month-old English Bull Terrier puppy called Frank, who is keeping me entertained.

Thank you

I want to thank mama for typing the book for me and everyone who helped me get better.

I also want to thank my friend for staying in with me at playtime.

I would like this book to give people hope that they will also get better.

If anyone wants any advice or has questions or feedback please email us
postconcussivemonster@yahoo.com

THE STORM WILL PASS

Recommended professionals

Dr Theo Farley

Physiotherapist specialising in Concussion and neck injury

theo.farley@hcaconsultant.co.uk

Hobbs Rehabilitation

We saw Debbie for specialist children's neurological physiotherapy near Winchester

https://hobbsrehabilitation.co.uk/services/paediatrics

(Specialist Neurological and Amputee Rehabilitation services for adults and children)

Kelly Camilleri

Psychologist specialising in brain injury

Based in Newton Abbott Devon

kelly@camilleripsychology.com

Dr John Rogers

Specialist in Sports medicine

Based in Manchester

07852 918631 (Susie his secretary)

Behavioural Optometry

https://www.babo.co.uk/ this has a list of all the practitioners in the UK

We saw Sophie at Sophie Rose Optometry near Basingstoke

07518 898134

The child Brain Injury Trust

They offer amazing support.

We had Debbie allocated to us, she stayed in contact with Mama and came to my first hospital appointment in Southampton

https://childbraininjurytrust.org.uk/

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