



VIRAL MENINGITIS AWARENESS WEEK



HEADACHES, SPEECH DIFFICULTY, TINNITUS, MEMORY LOSS AND ANXIETY. LILY MORL HEARS FROM PEOPLE ABOUT LIVING THROUGH THE NIGHTMARE, MONTHS AND YEARS AFTER CONTRACTING THIS VIRUS



I *JUST THOUGHT it was a bad migraine.* Many describe this migraine as feeling like ‘putting your head in a vice and slowly squeezing it until you pass out.’ Instead, it was a virus, viral meningitis, which becomes a nightmare for 6,000 people each year in the UK, according to the charity Meningitis Now. Almost always the victims of this virus whom suffer serious effects will require emergency medical attention within days. The 4th to 10th of May is Viral Meningitis Awareness Week, which many hope will bring attention to how the disease wreaks havoc and leaves a perpetual ripple of after effects in its wake. With the current coronavirus pandemic, people can only hope it highlights the severity of the nightmare that many people have to live with for years after.

VIRAL MENINGITIS IS an infection that causes inflammation of the membranes – called meninges – that surround the brain and spinal cord. The meninges protect the brain, however, when they become inflamed this causes pressure around the brain, which can cause nerve damage. This leads to a traumatic experience for the victims of the disease, who will suffer with a severe headache, stiff neck, sensitivity to bright lights, nausea, loss of consciousness and confusion.

Viral meningitis is the most common type of meningitis (36%), but VM sufferers worry it is not taken seriously because it is not bacterial, which can be deadly.

A recent study published in *The Lancet Infectious Diseases* focused on the delayed diagnostic testing of VM and how it led to longer stays in hospitals. They identified only two long-term effects: short-term memory loss and concentration problems. However, these are only two of the devastating impacts VM sufferers list.





“IT FELT LIKE I HAD BEEN HIT BY A BUS”

GEMMA MANSFIELD, 23, IS A NURSERY PRACTITIONER FROM ESSEX

F&W
REAL LIFE

A WEEK BEFORE I was in hospital, I felt really tired and it just felt like I had a bad cold. I was shivering and had a temperature. I just thought it was a bad migraine. The pain was unbearable even if I closed my eyes. I tried putting a cover over my head and a pillow, but it was still there. I remember my curtains were open. I couldn't look at the light.

I managed to go to sleep, which was surprising. But I remember waking up, honestly, I can't describe the pain. Touching the top of my head, it felt like a sponge where it was so inflamed. It was soft. The pain was thumping. It felt like I had been hit by a bus.

I had to crawl to my mum and dad's bedroom because I couldn't stand up. I was crying because I just didn't know what to do with myself.

My mum got me into bed and I was being violently sick. I was shaking and had a really high fever. She couldn't turn the light on, I'd scream because the pain was so bad.

Mum called 111. They asked me to do certain things. Could I move my neck to my chest? I could barely move my neck. We waited two hours for the ambulance.

It didn't turn up.

Mum called them again and the responder said, "You've got another half an hour. If you don't think she can wait that long just take her to A&E and we will let them know that you are coming."

I went outside and had to have a blanket over my head because of the streetlights. I couldn't look at them. Mum was holding me in the car while Dad drove. I went straight to the emergency department. They had to get me into a wheelchair by this point as I couldn't walk.

I was taken straight to a room where I was given an injection in my bum, because if it was bacterial meningitis you can die from that.

I had a drip where I was so dehydrated because I kept being sick. They gave me morphine. It didn't touch the pain in my head. It just sent me to sleep. I was on so many drugs, I can't remember a lot. Above my bed was a window. They had to move my bed to the wall because I couldn't stand the light on me.

They didn't know whether I had meningitis or a brain haemorrhage. They said if it was a brain haemorrhage there's nothing they could do. I'd die. By this point I was crying and mum was crying. I just didn't really know what was going on. It felt like I was in there for ages.

I had to go for a brain scan. I had to lay still while I had the camera moving around me, which was hard when you're in that much pain. You just want to hold your head.

The scans came back all clear. I had to go onto a ward and wait hours.

In the evening I got my lumbar puncture and I wasn't allowed anyone with me. I had to sit at the end of the bed, with my head in my knees and they put the needle in my spine. It was like someone got a knife, put it in a little bit and twisted it. I just wanted my mum. I couldn't move because it could hit a nerve and I could be paralysed. Afterwards, I had to lay still for an hour.

I started getting a rash when I had a really high fever and they panicked because they thought it was bacterial [meningitis]. They stripped all my clothes off, but it was just heat rash. I couldn't control my temperature.

At 9pm they said, "You've got viral meningitis." I spent a night in the ward. I don't know what drip I was on, but by the morning I didn't have the pressure in my head like the previous night. It was still there but it was more bearable. Where I had the fluid taken out of my spine, I could hardly walk. I couldn't get my trousers on or lift my arms up. Mum had to help me get changed.

I was only in there for one night. I didn't really get any help. They didn't really tell me how long it would take for me to feel better, the seriousness of it or what could happen after. It was like, "Oh, you've got viral meningitis."

SPRING
Viral
Meningitis
SPECIAL



GEMMA, TWO YEARS after contracting viral meningitis, hugging her mum who helped get her urgent medical attention

“GOING INTO HOSPITALS IS NOW ONE OF MY FEARS BECAUSE IT BRINGS BACK MY WHOLE VM”



+ LIFE AFTER VM

FOR WEEKS I felt tired. Just walking to the bathroom was an effort. I had no energy and I had really bad headaches. In the mornings, you check your phone and you see what the time is. I couldn't do that because if I looked, the pain in my eyes would really hurt. I'm still really sensitive to lights.

The tiredness was frustrating. It's hard to explain it if you haven't had it. It's not like a tiredness after a long day at work; it's a mentally and physically drained tiredness. As much as you sleep, you're still tired.

I was signed off work, but I went back too soon and made myself worse. I thought I felt better because when you're resting at home, you feel better... until you get put back into the environment of work. I don't even know why I went to work if I'm honest. I felt guilty and a bit under pressure. I don't think they realised how ill I was. In the end, I was off work for four months.

I had really bad dizziness, like when you have a bad hangover and the room spins. When I lay down, the room would spin. When I stood up, the room would spin.

Anxiety for me was the worst. I had it for about a year. It got so bad where I couldn't go out of the house. If I went out, I'd have panic attacks. I remember I had a panic attack in my boyfriend's car because I couldn't go in to his house, even though I'm a sociable person. The thought that I had to go and speak to his mum and sister scared me so much. I just couldn't breathe. I just couldn't do it. In your head you're like, "Why am I like this?" You can't control it. I couldn't even drive my car because of this fear and it still happens now. I still get anxious but now I know how to control it.

I was also emotional. I would literally cry over anything. I still am. I overthink everything. I think of every negative thing that could happen and then I'm like, "I can't do it."

Last year, I had to go into hospital again. What I didn't realise was how traumatised I was by hospitals. As soon as I walked in and knew I had to stay overnight, I started panicking; my heart was racing. It freaked me out. Going into hospitals is now one of my fears because it brings back my whole viral meningitis.

PROBLEMS
FACED BY
VIRAL
MENINGITIS
SUFFERERS

F&W KNOWLEDGE:

★ 80% OF SUFFERERS do not receive a follow up appointment after contracting VM, according to Meningitis Now and a Fit & Well survey.

★ THERE IS NO specific guidance for hospitals on follow-up care and therefore, many face their recovery alone with little information.

★ NO STUDIES HAVE specifically looked at the wide range of after effects of viral meningitis.

★ LIFE AFTER VM: memory loss, headaches, anxiety, depression, exhaustion, tinnitus, dizziness, personality changes, speech and language problems, photophobia (light intolerance) and aching joints.

★ LUMBAR PUNCTURES, ALSO known as spinal tap, is the procedure in which spinal fluid is taken from the lower back in order to diagnose VM.

★ SUFFERERS ARE FORCED to go back to work when they feel they are not ready to; but return either due to financial difficulties, pay cuts or guilt for not being there.

MENINGITIS NOW IS a charity based in the UK, and their work has been praised by VM sufferers for providing a lifeline and support on the stage of recovery. For more information go to, www.MeningitisNow.org



“YOU GRIEVE FOR THE LIFE THAT YOU HAD”

JONATHAN DAVIES, 57, IS A FREELANCE PROJECT MANAGER FROM ESSEX. HE HAS MOLLARET’S – RECURRING MENINGITIS

ABOUT TEN DAYS prior to being admitted to hospital, I had the mother of all headaches. Over the week, I got progressively more ill, with stiff neck and confusion. I’d been in four different cities and four different hotels for work and woke up in Darlington and didn’t know where I was. I went down to reception and said: “This is going to sound really stupid, but can I ask where I am?”



She said, “Yes you are in reception.” Saturday night, I went to bed dosed up to the eyeballs on the strongest painkillers I could get my hands on. Nothing touched it. It felt like putting your head in a vice and slowly squeezing it until you pass out.

The next thing I remember is the outside air hitting me as I was being taken into the ambulance. I really didn’t know where I was or what I was doing.

I came round in hospital as they were doing the lumbar puncture with the doctor saying to my wife, “I’ve never done this before. I’ll try not to paralyse him.”

The A&E assistant was standing next to him saying, “No. Go left a bit. Up. Up. Left a bit.”

It was the most excruciating pain. I passed out again.

Next thing I remember is coming round in hospital in the morning when one of the day shift nurses came on and said, “Oh, you’re still with us then.” Which I thought was a bit odd. It transpired I nearly died the previous morning at ten to four. My notes said, “If not rallying by four, call the relatives.”



F&W REAL LIFE

They got me up at about 3pm. For some reason, they walked me up and down, though I couldn’t walk at all. I had no strength in my legs. But, they discharged me

the next day because they said I could walk.

Three days later, I was rushed back in. I can remember going around a corner in the ambulance and the ambulance tech saying to the driver, “You better put the noise and lights on, we’re losing him.”

I remember thinking, “I wonder who they are talking about.”

On the way to hospital, I had no discernable blood pressure and a heart rate dropping to 27. They kept squeezing my ear and saying, “Do you know where you are?”

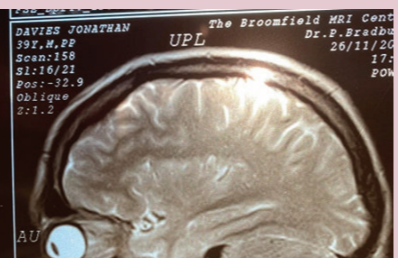
Apparently, I said to the ambulance tech, “Why, don’t you know where you are? Stop asking me where I am.”

I was sent home later that day. They said I’d be better off recovering at home.

I had nearly six months off work. I had to learn how to walk and talk again. I had enormous difficulty processing simple requests like, “Do you want a cup of tea?” I would sit there looking blankly at my wife.

My wife was incredibly patient with me. It was very difficult for her because

“IT FELT LIKE PUTTING YOUR HEAD IN A VICE AND SLOWLY SQUEEZING IT UNTIL YOU PASS OUT”



“WHEN I’M TIRED I STRUGGLE TO STRING A SENTENCE TOGETHER”

MARY HANNAFORD EVANS, 51, TEACHER OF THE DEAF FROM SHROPSHIRE. SHE HAS MOLLARET’S AND HAS HAD VM NINE TIMES



MARY CELEBRATING HER engagement, and married on Christmas Day. She said one thing VM has taught her is that there is no time to lose.

INOW SUFFER from constant tinnitus, pain in my neck and shoulders which apparently is due to nerve damage and constant tingling in the palm of my left hand. My memory is awful, although I am now masterful in disguising this with lists. When I’m tired, I struggle to string a sentence together, which can be very frustrating so there are times when I choose not to socialise because it is embarrassing.

Doctors have often asked me how I know it is viral meningitis and not just any headache. The pain is quite unique; it starts with a headache that sends jarring all the way down my spine, as if a metal spike is running from my skull through the centre of my backbone. The sensitivity to light is so bad it makes me want to kill anyone who shines a light in my face - probably just as well that by this stage I am too weak to even lift my head off the bed and the stiff neck means I can barely move anyway.

Each time, the recovery period seems to take longer, quite possibly because I am getting older but also due to the recurrent nature and ‘build up’ of damage done. With every occurrence, I have very little recall of what actually happens and I rely on my family to fill in the details. After my second bout, I started noticing random events vanishing from my memory, things that had happened years ago but also more recent events. I have been able to mask the worst of it by doing lists, particularly at work, and as a result become more efficient as I’m so paranoid that I will forget something important.

it was like having another baby in the house. My eldest said to me that I once asked her, “I know that you’re one of my children, but which one are you?” For six weeks I was bed-bound, other than getting up to go to the doctors.

I battled with my GP to sign me off after three weeks. My wife had to come with me because I couldn’t string a sentence together. He said, “You’re just malingering.” I had to ask him, “How many cases of viral meningitis have you ever treated?” He admitted he had never dealt with any cases of viral meningitis.

+ LIFE AFTER VM

I’VE GOT BIG gaps in my memory from that year. My short-term memory has gone walk about; I don’t remember names or places. I used to be like a human sat-nav. I get permanent headaches varying in intensity. I’ve got a dent on my brain which was only discovered after a brain scan. It’s around the bit that deals with metabolism. I was told if I had things in a too high concentration, I would develop intolerances: caffeine, alcohol, cocoa and nuts. If I sniff about 75% organic chocolate, I get a blinding headache within 30 seconds. It’s that acute. Alcohol makes me almost suicidally depressed the next day. That’s just to do with the dent on the brain – the brain damage.

What was normal for me before, is not the same. There’s no predicting what

normal is going to be. You may not get back to normal. My wife has said my personality is different. I am less patient.

The trouble with viral meningitis is you rest and rest a bit more and when you’ve done that you feel better and think you can do things now, but then you do things and it knocks you flat. If you’re an active person, then it’s a complete nightmare. Rest is the only thing that you can do. If you don’t rest, it forces you to rest.

I wasn’t ready to go back to work, but they had cut my salary by 50%. There’s only so long that you can keep going when your salary is being cut that much. I went back to work, but I was in no fit state.

If I allow stress to get to me, that allows my meningitis to recur for a period of two or three days. Apparently, I look like I’m drunk, which is ironic because I can’t drink.

I don’t like bright lights. It’s like someone sticking pins in your eyes.

I’m really angry at what viral meningitis has done to me. But, 18 years on, I think I got away quite lightly. I’ve been left with some after-effects, which are a bit unpleasant and unpredictable. Yet, I count myself lucky.

It took me a long time to get over the fact that things were going to be different. I couldn’t head out for a run whenever I felt like it and I get tired very quickly.

You grieve for the life that you had.



MANAGING Meningitis

AFTER EFFECTS CAUSING YOU GRIEF? HERE ARE SOME SMALL CHANGES YOU CAN MAKE TO YOUR LIFESTYLE. VIRAL MENINGITIS SURVIVOR AND PERSONAL TRAINER CHARLENE HUTSEBAUT, AND FORMER ACUTE LIAISON PRACTITIONER SARA DONNELLY HAVE ALL THE ANSWERS

Q. Are there any home remedies that could alleviate headaches and how can I reduce stress which exacerbates them?

A “LAVENDER WILL ASSIST with headaches and also sleep. I would recommend a lavender balm to be applied to the forehead. There are also lavender essence sprays and room diffusers which can be used.” SD

“Manage your stress in a way that best works for you, but try: meditation, Thai Chi, slower forms of pilates or yoga. These can help with stress relief and can push you towards the calming side of your nervous system. Breathing techniques are wonderful.” CH



Q. ANY SUGGESTIONS FOR FATIGUE, AS IT'S BEEN A COUPLE OF MONTHS SINCE I HAVE HAD VM?

A “EXERCISE. THIS SIDE of recovery needs a slow intelligent approach. Mentally, that’s going to be really hard, but you must be patient. For the first eight to twelve weeks use low to moderate intensity exercise. Think of this as fitness building. We have two sides to our nervous system: the parasympathetic and the sympathetic side. The sympathetic nervous system is the fight or flight. The parasympathetic is our calming side. However, our bodies need inflammation because when you work out, you tear muscle fibres and the body sends inflammation into the area to heal the muscle fibres. Our bodies are always trying to move us between the two, but you need to find a balance in the middle. The problem of doing high intensity workouts too often, means it will keep you in the sympathetic fight or flight side and will keep us chronically inflamed. This is not going to help you recover. The grounded workouts of low to medium intensity choices of weight training are going to keep you closer to the parasympathetic side. So, you need to be doing sessions such as weight training that aren’t part of hit training, for example: yoga, Thai chi, and pilates.” CH



Q. I’m exercising again, but I’m feeling more drained than I did before?

A “REST IS ABSOLUTELY vital if you are recovering from meningitis. Your body’s going to tell you that you need rest by exhausting you, so you’ll need to take a nap or don’t work out for a few days. There’s no way that anybody can do high intensity work outs every day and recover. Your body can’t deal with the inflammation and then repair the tissues, so something will suffer. You will either get sick again, a muscular injury, your brain won’t function properly and your concentration and mood will not be good. If you wake up with heavy legs every morning or just constantly fatigued or just not getting the power out of your muscles, you are probably doing too much. You just need to pull back. There’s a big element about getting to know yourself really well.” CH

Q. Should I make changes to my diet or eliminate any foods or drinks?

A “EVEN THOUGH I work in this industry, I didn’t realise the power of the food approach in my recovery. I do now from the many things I’ve learned in the last decade and also working with people who have had meningitis. We are looking for an anti-inflammatory approach, so we need to aim to eat anti-inflammatory type foods. This means staying away from fried food, processed food, refined sugars, alcohol and caffeine. However, I’d never tell someone to cut these completely out, but keep those things to an absolute minimum. Think about going for a plant-based foundation but also including good oils because oils like Omega 3’s help us to keep inflammation down and help to support our immune system. Also, target supplements like vitamin C, D, E, Selenium and Zinc. For vegetarians and vegans, take some fish oil supplements.” CH



Q. I’M EXPERIENCING GAPS IN MY MEMORY AND STRUGGLING TO REMEMBER THINGS. WHAT CAN I DO?

A “DOING PUZZLES AND self help mind exercises with encouragement from family and friends, the memory will gently return. Just be present and be patient.” SD

