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Migraine from the Patient's Perspective
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I'm Susan, I'm 28 and I'm from Dublin. I'm a long-term member of the Migraine Association and a migraine sufferer for many years. I'm here today to tell you a positive story about migraine. We've already heard from Dr. O'Sullivan how difficult it can be to treat migraine. I'm here to tell you that it is possible to live life to the full by managing your migraine.

I began to suffer with migraine when I was only 3 or 4. My poor mother didn't know what was wrong with me – at first she thought I had meningitis and had the doctor out. Whenever I had an attack she had to call the doctor or locum doctor whoever was available.

She tells a story about how when I was about 6 years old, I sat up in the bed and said "Mam, I don't know why you're calling the doctor all he's going to do is say 'take two paracetamol'". And that's exactly what happened – the locum doctor arrived said 'she's got a headache, go to your GP in the morning'.

This went on for years. To complicate matters I'm adopted so I didn't have any family medical history coming with me – I was just landed in this new home without knowing what had come before.

I just accepted my GPs word that I had these weird headaches that nobody else seemed to have. I accepted that they would come at inopportune times and that there was very little I could do about it.

My worst childhood memory was being 10 years old at my best friend's slumber party and waking up in the middle of the night with a ferocious migraine with the sleeping bodies of my friends all around me. I went into the kitchen and trawled through all the presses looking for medicine – our medicine press was in the kitchen at home and so I assumed everybody else's was too. I remember finding press after press of crockery and mugs. I had no medication myself. I wasn't wise enough at that stage to make sure I always had it with me.

Eventually I found some ordinary painkillers, some Paracetamol, that I knew I could take and after a while managed to get back to sleep. To have to, at 10 years old, go sneaking around someone else's kitchen trying to find drugs, well, it was an awful experience, one that has never left me.

And this became my usual pattern of migraine. Unfortunately I sleep through all the prodromal warning signs. I sleep through the initial pain and I sleep through any hint that I'm going to get a really bad migraine. As a result waking up at 4 in the morning with a vicious migraine is quite normal.

At that point your whole system has shut down. Your stomach has shut down so taking tablets at that stage is of no use to you. I end up trying to get down the stairs with half of one eye open, feeling the wall and try to make some tea and a slice of toast and take some painkillers. This is the usual pattern for me.

All the doctors tell you to take your medication early but because I don't get a chance to do this I end up stuck in the middle of a migraine and there's nothing I can do.

I also can't lie down, therefore I'm forced to walk up and down like a lunatic. Sometimes people say would you not sit down and relax. They don't seem to understand that me relaxing at that time is just not going to happen. All I can do is walk up and down until the pain eventually goes. If I could cry, if I could bother crying, I would. But the thought of all that's involved, the build up of tears and pressure that you just don't bother. At least if you could cry somebody would be able to empathise with you.

The rate of attacks in my teens was one or two a month. As I got older it got worse.

Eventually I took the plunge and looked up my birth family and discovered a huge link to migraine. My mother, 2 brothers and 5 of my aunties and uncles are all sufferers. It's quite prevalent among the men in the family too, which is quite unusual as migraine affects mostly women.

My birthmother suffers so badly with migraine that she has to get morphine at times. Roughly two or three times a year. She vomits all the way through her attacks. I'm lucky I don't get that with mine. Her GP knows her well enough to know the situations that are drastic enough for her to need a shot of morphine.

When I began to look into my trigger factors, my GP said, 'maybe its dairy, or maybe its chocolate or just cheese'. I cut them all out at one stage and moved to Soy. At another time I cut out all wheat products and ended up spending a fortune on all those organic products. None of this made any difference to me.

By all means try it but if it hasn't worked there's no point in punishing yourself and not eating chocolate and cheese.

It turns out my triggers are stress – any form of stress like exams or if you're busy in work. Irregular sleeping patterns – too much or too little sleep. At times I've tried to make up for too little sleep by sleeping on at the weekend but it does me no good – you're better to just get up as usual at the weekends.

Skipping meals is also a trigger for me. If my friends say 'Ah sure we'll skip dinner, we'll just get a sandwich at the pub' that would guarantee me a migraine. Some people I know have taken to carrying crackers or biscuits with them and bottles of water – whatever it is that works.

Hormonal changes are also a big one.

Environmental triggers also apply to me – smoke, strong smells, bright lights, anyone on the bus with really overpowering perfume etc.

Long periods in front of the television are a trigger – this is often a big one for children. Similarly working on a computer for a long time without a break can lead to an attack.

I'm susceptible to all of these triggers except food. Other migraineurs find food is a trigger for them – I have a friend who, after eating chocolate, can count down the hours to when she will get a migraine but it doesn't affect me at all.

Another thing I found very helpful was keeping a diary. You think you know yourself, you think you know what you're eating and what drugs you're taking but you don't until you see it written down.

Keep it for 2 or 3 months. The Migraine Association produces an excellent diary. It enables you to record things that may have induced an attack such as a deadline at work or if you're under stress. Write down the hours of sleep you think you got on particular nights. Also it's important to record the medication you're taking. Write down what you took to treat the migraine whether over-the-counter or prescription. I found it invaluable when I was trying to identify trigger factors because I didn't realize how many paracetamol I was taking on a weekly basis. I always seemed to be in the chemist or the supermarket buying another packet of paracetamol – no wonder the government brought in that we can only buy one at a time. You can end up going round like a junkie from pharmacy to pharmacy. When I saw it written down on a monthly and weekly basis how much I was taking it was really scary.

I've tried meditation, yoga, acupuncture, acupressure and various specific medications for migraine. I tried going on the pill to control my periods – then I read that the pill might actually contribute to migraine.

I've had PainGone Pens, Tiger Balm that you can rub on your temples. Short of decapitation there wasn't much left for me to try. I didn't find any of the alternative treatments helpful but that doesn't mean that it doesn't work, it just means it doesn't work for me.

Each individual with migraine has to go through everything and find what does work. I'm not going to say acupuncture is useless because there are people I know who swear by it. So try everything and see what works that's my big piece of advice.

When I met my birthmother she was a lifetime member of the Migraine Association and she encouraged me to join. This was when I really started to control my migraines.

I attended the Migraine Clinic under Dr. Orla Hardiman and there I met one of her team – an excellent doctor. She was a registrar, who recognised that I don't have a typical migraine. For me its not one-sided, its in the back and I also don't get sick. I'm susceptible to all the environmental triggers but not the food ones. The doctor tried me

on a drug called Propranolol, which is one of the Beta-blockers used to lower blood pressure. Given in half the dose its used for blood pressure makes it quite a good preventative for migraine.

It doesn't work for everybody but because I have a weird type of migraine it worked with me.

I take 1 every night. I started that 3 and a half years ago and I haven't had one migraine since. Now when I say that, I mean I haven't woken in the middle of the night with a migraine I couldn't control. I still get a migraine with my monthly cycle even though I'm on the pill to control it. When I stop my pill and I'm on the pill-free week my oestrogen levels drop and I get migraine like I always would have got it. But these migraines happen in the middle of the day and I know they're coming so I can take something – usually over-the-counter medication is enough and I don't have to resort to anything else.

The main side effect for me with Propranolol was dizzy spells in the initial stages after I began the treatment. They were caused by the lowering of my blood pressure but to be honest I don't care – I will take dizzy spells if it means I'm not going to get a migraine. I'm delighted that that's all I have to contend with.

To sum up briefly from a migraine sufferers point of view.

I think everybody here probably doesn't need to be told to talk to your GP. For anybody who hasn't taken any steps to control your migraine – your GP is your first port of call.

If your GP is disinterested or unsupportive or unknowledgeable as a lot of them can be as migraine isn't their area of speciality, find a GP who is. If this is affecting you and your life you have to do something about it. If you meet a GP who doesn't care, don't accept that that's something you have to live with – go and find somebody who does care.

Join the Migraine Association if you're not already a member. Support is vital so you know you're not alone, especially if you're someone inclined to wake with migraine in the middle of the night like me.

Become aware – if you're trying to manage migraine you must know your body – know its symptoms. Keep the diary and try to find the triggers and make an effort to avoid them.

Tell your employer about your condition but in a positive manor. Only yesterday somebody suggested to me that migraine is psychosomatic and I light up. I said do you mean to tell me that I've been making this up since the time I was 3? I was furious. So tell your employer – if your child has migraine tell their teachers and principal. Forewarned is forearmed.

If you explain in a rational, logical, non-moaning way to your boss that you suffer from this condition but you're doing everything you can to avoid getting migraines, the

understanding and sympathy is there already when you have to ring in sick because of migraine. If you haven't taken the time to explain your condition to your boss and ring up some day out of the blue and say you can't come in because of migraine, you could almost understand why they might be inclined to think 'I'll bet that's a hangover'.

If you find a medication that helps be prepared – have it with you at all times.

My friends laugh at me as I carry around this blue diamante cosmetic bag with all my medications in it and if anyone needs medication for anything from a headache to upset stomach the chances are I'll have it. But if you've found what works, keep it with you and don't be embarrassed about taking it.

Some people need to eat regularly so if that's you, have a snack with you at all times.

Finally migraine is controllable. I know a certain percentage of people suffer from migraine and it doesn't seem to respond to anything but for the majority of people it is controllable.

It takes patience from you and those around you and a lot of hard work to try and find what's causing it and how to manage it. If you explain what is wrong with you, they will recognise that its quite real and you're not making it up. But if you haven't explained to people and you hope to just get on with it they may not be as sympathetic.

My key message from one migraine sufferer is don't give up, please!