

"Migraine and me"

A talk by Eva Gaynor, Migraine Association Member at the Migraine Association's Spring Seminar 29/2/2004

Migraine is in my family - my mum has had migraine since she was about 7 years old and my granny has also suffered from it. I started to have headaches all the time when I was a child but it wasn't until I was about 16 that they started to turn into migraine. With mum the expert at home it was quickly 'diagnosed'.

To be honest for the first year or two it didn't really impact that much on my life. I was doing my Leaving Cert when I was 18 and I don't really have any recollection of it being a big worry that it was going to impact on my exams or anything like that. During college however, the attacks did worsen but they probably weren't helped by the fact that I was having an awful lot of good times down the college bar!

But with the irregular hours college holds it was easy to hide the attacks so it wasn't until I started to work fulltime that I began to realise the impact that migraine was starting to have on my life.

When I get a migraine it normally starts over my left eye. It starts as a dull pain and at the same time my stomach starts to bloat, in fact, sometimes I look like I'm 4-5 months pregnant!

My eyesight starts to go - first of all it can be kind of blurry, then I can get double vision. I'm sensitive to light and to noise. I don't want anybody coming near me or touching me and my co-ordination and my balance go out the window.

About two and a half years ago I decided I had better keep track of these migraines because they seemed to be getting worse. I started by keeping a manual diary myself. I joined the Migraine Association about a year later and I got one of their diaries and it was then when I saw written down in black and white that I really realised, 'God, I have to do something about this'.

To give you an idea: two and a half years ago, I was getting, on average, two migraines a week. I thought that was bad at the time. Last year however from the 15th of April straight through to the end of October, I can only count 8 migraine-free days. So essentially everyday last year from the 15th of April to the 31st of October, bar those eight days, I had a migraine.

My triggers are stuffy atmospheres and smoky rooms. I can get an attack if I get too hot or miss meals or don't get the right amount of sleep. Some of those things you can kind of manage yourself. There are others, things that somebody who doesn't have migraine would never even think of. For instance, if I'm feeling 'migrainey', I couldn't go to the petrol station to fill up my car because the smell of petrol would knock me flat. I definitely wouldn't even attempt to pluck my eyebrows. Also a trip to the hairdressers would be out of the question, as somebody pulling at my head for three hours would guarantee me a migraine as soon as I walk out the door.

However, I'm not sitting on my laurels at home feeling sorry for myself, I'm out there trying to do something. On the medication side of things, I am on my third course of preventative medication. First of all I started on amitriptyline, which is an anti-depressant used as a preventative treatment for migraine. I was on that for nearly a year but unfortunately it wasn't for me. I then switched to one of the

Beta Blockers and tried that for a good while as well but it turns out that they weren't for me either.

However, these treatments have worked wonders for loads of people. I have met people who have started taking Beta Blockers, for example and they haven't had a migraine since. Just because it didn't work for me, doesn't mean it won't work for you so do talk to your GP about treatments.

I started my third preventative just before Christmas, its one of the epileptic drugs and I'm taking it together with an anti-inflammatory. I'm actually afraid to say this out loud in case I jinx anything but they appear to be doing something. I'm not up at my full dosage yet but so far the frequency of my migraine has reduced somewhat so maybe, as I increase the dosage, it'll continue to go down.

On the other side of things, medication is not the only answer. The onus is definitely on me to manage my migraine and my lifestyle so I try to avoid missing meals and get as much sleep as possible.

You become super organised when you have migraine. If I have a deadline in work that's due on a Friday, I try to have it done by Wednesday because I know that come Thursday, something could happen that causes me to get a migraine and I'd end up putting myself under massive pressure on Friday to the point where I end up so completely whacked that I end up having another attack. So do try to have everything done by Wednesday so you know its ready for the Friday.

If I'm going to a meeting, I'll try to get there a couple of minutes earlier to make sure that I'll get a seat either by the window or by the door so that I'll always have air - that's a big thing for me. I never go anywhere without a drink, and never go anywhere without medication. If you're taking triptans or anti-inflammatories or anything like that, remember you don't know when it's going to strike so always have them on hand.

The other thing is that I have a folder and I always keep a bit of food in it. But if you're in a meeting and it's going on and on out comes the food and I nibble away! But I had to force myself to do this. It is very awkward to do when you're in a meeting and there are 12 or 14 people looking at you. But I make it clear that if I don't eat I'll get a migraine and therefore wont be able to concentrate on the meeting and wont be able to follow through on the work afterwards. Of course I also don't want to have a pain in my head and to avoid that you'll get over your inhibitions.

Unfortunately there's no "chill-out room" where I work so I've had to come up with my own combat measures for dealing with attacks that strike while I'm working. I have a big huge folder on my desk and it is filled with absolute gobbledygook. If you had to read that stuff you'd give yourself migraine (!) but I open it up while I'm waiting for medication to kick in and so if anyone calls me I can say 'I'm in the middle of something, I'll be with you in a minute'.

I also have a fan on my desk, as I said earlier, air is a big thing for me and put my phone on voicemail. It may take 15 minutes before I feel a bit better or it may take an hour but during that time I can put my hand to my head and wait for the medication to kick in. When it has helped me through the high point, the real intense point of the migraine I can then resume my work and even stay back an hour later to try and get through the rest of the work that I missed if necessary.

To finish up, I am 26 years of age, I got engaged just before Christmas and plan to marry next year. My mum had to give up work when I was born because she physically and emotionally could not work, care for me, be a good mum and have frequent migraine all the time. I do not want the same thing for my kids. Its now 2004 and things have totally and utterly changed. There are loads of new drugs and research. There is the Migraine Association and information on the Internet. There are people like Dr. Hardiman and Dr. O'Sullivan. I would urge every single one of you to use them. As I already said, get the migraine diary, I found it absolutely invaluable because for the first time, I saw in black and white exactly how bad my problem was and what I needed to do to try and change things. It also helps your doctor or your practitioner if you go for a complementary therapy. By looking at your diary, they can tell what medication/therapy you need.

The biggest thing is do not give up hope even it the first or second or even third or fourth thing doesn't work. If I had to go through everything I have tried I'd be here forever. I have swallowed the strangest herbs. People offer you the strangest advice but believe me when you have a pain in your head, driving you mad, you will do anything. If somebody told you to hang upside down like a bat you would do it!

So I'm urging you to please, keep trying. Join the migraine Association. Don't get isolated. Talk to as many people as possible. Talk to your GP and if s/he doesn't have the answers to your questions talk to the Migraine Association, there is a Helpline and then go back to your GP with what you've found out and work together to try and manage your condition. I'm sure someday we will find a cure but in the meantime there has to be some way of managing your life and believe me there is a way of doing it.