Dealing with migraine

[00:00] [music]

Leigh Hatcher: [00:05] Hello, and welcome to another nerve podcast. I'm Leigh Hatcher. This time, a condition experienced by an estimated three million Australians. Migraine. I can tell you from personal experience, it can be a debilitating distressing condition, sickening. Headache, nausea, a sensitivity to light and noise, and much, much more that can last for days.

[00:26] Joining us is Dr Alexis Selby, a neurologist with Sydney Cognitive, with a special interest in headache and migraine. I'm so glad to say that one of Dr Selby's patients is also with us, Sam Mostyn, who's had a significant and high powered career on a number of boards in the corporate world and in sport.

[00:45] We begin with Dr Selby, for the uninitiated. When we talk about a migraine, what is it?

Dr Alexis Selby: [00:50] It's not just a headache. It's actually a primary brain problem. It starts off with a neuronal dysfunction. The actual neurons of the brain become dysfunctional. You have what we call a cortical spreading depression, which is where you have an abnormal reaction in those neurons which spreads across the brain.

[01:10] This then spreads to the trigeminal nerve, which is the nerve that innovates the face. That then feeds back into other centres in the brainstem, and then leads to further hyperactivation in other areas of the brain. You have this cycle and propagation of hyperactivation and hypersensitisation of the nerves in the face, and the lining of the brain, and all of the brain structures.

[01:34] This is why you have this characteristic four phases of a migraine. You have the prodrome, which some people notice for a few days beforehand. Some people don't. A very characteristic feature of that is yawning. Some people feel just a bit off. Some people have food cravings.

[01:52] They'll often crave chocolate, and then mistakenly associate the chocolate with the migraine. That's quite common. You can have the aura phase, which is the second phase. Most common is visual aura. More than half of the people with a migraine will get a visual aura.

[02:07] Visual aura is completely individual and is very heterogeneous. Some people have flashes of light, some people have zigzags. You have an expanding, what we call a scintillation or expanding scotoma, where it starts off in the middle and then expands outwards. You can have bright coloured lights.

[02:23] I've had one patient describe to me a rainbow snake, which was very, very good, and various types of aura. You can also have sensory aura, or motor aura, or speech aura,

where people actually have difficulty speaking, slur their words for a brief period of time. All of that is part of the migraine syndrome.

[02:42] The third phase of that is the headache, which we're all familiar with. Usually, the most debilitating part of a migraine, due to the severity of the pain. The fourth phase is the postdrome, where people will feel foggy, off, not quite themselves for a couple of days even after the migraine.

[02:58] All of these parts of the four stages of a migraine can last various amounts of time, in the individual patient.

Leigh: [03:06] From when to when?

Dr Selby: [03:07] For example, the prodrome can last a day or so. The aura can last 5 to 60 minutes. The headache itself can last anywhere from half an hour to three days. The postdrome can last usually a couple of days. It's very individual.

Leigh: [03:22] Great explanation. Sam, can I ask you? I'm so grateful for you joining us in this. From the sufferer of a migraine, what's it feel like? What's the migraine experience? Describe it to me.

Sam: [03:33] When I listen to Alexis give us that medical description, I was imagining where my headaches and migraines sit within that end. Mine take a very certain pattern most times. I'll start to get the pre-migraine feeling. I don't know if it's called a prodrome.

[03:50] What that feels like is I begin to get a little bit sparkling around the end of my peripheral vision, and then I'll often lose bits of my vision. There'll be holes in what I'm seeing. If I was looking at you, I might not see one of your eyes. It might just disappear, and I know that I'm now into a pre-migraine phase.

[04:08] At that point, what I try to do is take pain relief medication. If I can get that in quickly, then I can generally stave off a major migraine, or at least hold it for a while. It might come back another day, but certainly, that feeling of sparkles, and losing some vision.

[04:23] Occasionally, I'll begin to realise I can't grab for the words that I need. It's not some slurring, but I know there's a word I need, I just can't get to it.

Leigh: [04:31] If you're unable to hold it off, what then happens?

Sam: [04:34] What then happens, if I then take the pain medication a bit too late and I'm into it, I feel a sense of...first of all, it's an annoyance that I've missed the queue, so I know what I'm heading into. There's a sense of not dread but sadness almost. You almost feel your body going to this, "Not now. Not again."

Leigh: [04:51] Here I am again.

Sam: [04:52] Because you know where it's going. Once you're in, I think, as Alexis has described, it has its own pathway. You know what was going to happen over the next little while. For me, I'm best often taking the pain medication and then lying down, dark but doesn't have to be totally blacked out, but away from bright light.

[05:10] I like to get a warm wet bag over my head. Some warmth on my head always helps. I face this headache pain. It just doesn't describe what it is. My migraines have changed a bit over time. Now, I can get a bit of stabbing pain, and actually quite painful. Generally, mine it's an ache or a sense of dysfunction in my head.

Leigh: [05:30] It's more than just a headache.

Sam: [05:32] That's right.

Leigh: [05:32] This is what I'd like to convey.

Sam: [05:34] That's why I very rarely say I've got ahead.

Leigh: [05:36] Totally.

Sam: [05:36] It's debilitating. I immediately go into, "What am I missing, by now having to waste these next few hours or day?" You begin to set up in your own mind all the things that were pending, that now become almost urgent. It is a mind game in a way, once you're inside a migraine. You're managing the pain, you're managing this sense of heaviness in your head.

[05:58] You're waiting for signals to say the pain relief is coming or that you're coming out of it. There might be a bit of nausea, occasionally, it means taking some anti-nausea medication. Then there's some craving. I crave coffee. I need caffeine. That makes me feel much better.

[06:12] I know I take a lot of coffee during that little period, and then I just need to be left alone, to being almost knocked out. I was using pain relief that had stronger parts of almost sedation in it, for a while. Now, I just use what Alexis has taught me is the right way to treat the pain.

[06:27] You're in this fog. You're in a tunnel. I know other migraine sufferers will know exactly what it is. Any being would think this is ridiculous. I could just get up, I think. If you try to do that, you realise that actually you're just debilitated. You just need to be in this state, for as long as it takes to come out.

Leigh: [06:42] How long?

Sam: [06:43] Mine range from sometimes I can lay down in a couple of hours. Again, if I've got the pain medication in quickly, I can get up and I feel OK, a bit foggy. I've had migraines that have gone for two and a half, three days. Getting up and down, and trying to reconnect often with this family life thinking you're OK and then knowing that it hasn't gone yet. That's at its most extreme.

[07:05] If I can manage it well, lying down and do the things I need to do, it's probably generally a day, which may be overnight, as well. That's why when you go into it, you have this sense of dread and annoyance...

Leigh: [07:20] I can just totally get that.

Sam: [07:21] and, "Not now." It's not, not now, just, "Not again."

Leigh: [07:25] I get it. As a kid, I suffered from a migraine, and I know exactly what it feels like. Blessedly, I could probably count on my one hand the number of episodes I've had as an adult, which is a bit curious. It always started for me, over my right eye. Alexis, is that common?

Dr Selby: [07:41] Yeah, absolutely. Your typical migraine, as we call them, is a unilateral throbbing pain. In practice, not everyone has the same, that typical unilateral nature of the headache. Absolutely, commonly can start behind the eye. Sometimes, people find it starts at the back of the head, and that's to do with whether the nerves will run. A throbbing nature.

[08:01] Other symptoms typically with an acute migraine, will be what we call photophobia. That irritation to light. That actually persist in between migraines, as well as a hypersensitivity to light, particularly fluorescent lights. Sounds and smells, particularly, they can be hypersensitised and they can often trigger migraines, as well.

[08:19] Other symptoms, nausea, vomiting. Nausea is very common, apart from the visual aura, which Sam has very well described there. That will be some of the common things. Other people can have a sense of disequilibrium or imbalance, as part of their migraine itself.

[08:33] The pain itself usually is of a throbbing quality, very intense pain. We can sometimes have watering of the eye, and irritated feeling, sensitivity of the skin, of the face. A huge range of symptoms people can experience.

Leigh: [08:47] It's why I wanted to convey the sense that this is just not "a headache." It's costly for Australia.

Dr Selby: [08:55] It is the leading cause of adult disability in Australia, more so than stroke or dementia, mainly because of the indirect costs. You have the medical costs acutely of people seeking treatment, but more so the indirect costs. Hundreds of millions of dollars in Australia are lost because of lost productivity.

[09:17] When you have such a debilitating migraine, such as what Sam's described, a lot of people will soldier on, but a lot of the time you just can't. The symptoms are just so severe and the pain is so severe. It's a huge economic burden on Australia.

Leigh: [09:30] Sam, when did you first start to experience migraines? Is there any family connection, history?

Sam: [09:36] I remember getting my first migraines. I wouldn't have called the migraines at the time. The first symptoms in my late teenage years, early University years. There is a history of migraine in my family, both up with grandparents, and then I have members of my immediate family who have migraine issues.

[09:55] I'm just discovering it in my daughter, who's at university now. She's just showing some signs, which we're trying to get ahead of. The conversation she can have with Alexis and a good neurologist is completely different to what I did back then. There's always been a bit of a stigma about this thing of a migraine, or headache.

[10:13] I think it's less so now. I think the more we talk about it, the more we explain that it's not goofing off to have a day off work. [laughs] It's not overreacting to something that others have been able to get through, by taking a couple of discipline or whatever.

Leigh: [10:25] It's why this conversation is so important. Is it likely to run in families, Alexis?

Dr Selby: [10:29] Absolutely. 50 to 60 percent of migraine sufferers will have some family background, usually a first-degree relative. The actual genetics of that are very complex. We've not really elucidated any specific gene that contributes, although there have been many studies of many people that have tried.

[10:46] Yes. There definitely is a family predisposition. 50 to 60 percent of the people will get that. Their migraines typically start in late teenage years. Of course, they often will then a beige or change character. In your 40s to 50s, women have specific changes, in terms of their hormonal profile.

Leigh: [11:07] Are they more vulnerable?

Dr Selby: [11:09] Women? Absolutely. Up to 18 to 20 percent of women will suffer from migraines. That's a huge number of people. With men, it's probably more like, we think around, 10 percent. Overall, we say about a quarter of women may experience a migraine or migraine like symptom at some point during the life.

[11:28] A quarter of families will have one migraine sufferer in their household, as such. It's a big problem. Of course, that's all the working population, as well. That's part of the reason why it's such a problem. Yeah. It absolutely starts in teenage years. A lot of people find it gets better. Some people find it doesn't. It can transform into chronic migraine. It can change character throughout their life.

Leigh: [11:50] You spoke about triggers before. One of my triggers, I'll never forget, was the smell of an old incinerator down the back of our high school, which always set me of. Sam, are there triggers for you?

Sam: [12:01] Not so much, Leigh. I'm interested in Alexis' discussion about women and it changing. I didn't have a migraine for the entirety of my pregnancy with my daughter.

Leigh: [12:11] It's interesting.

Sam: [12:11] That was in my mid-30s. During that whole time, I was completely migraine free.

Leigh: [12:15] Blessed [inaudible] . [laughs]

Sam: [12:15] It was wonderful nine months. The character of mine have changed over time. It's not about triggers for me. I have quite a busy life. I think I manage that stress very well. I don't find that if I'm leading up to something stressful, I suddenly get a migraine. There's nothing that I can point to that would be a trigger.

[12:33] That's often what's so annoying about when I feel one coming on. I haven't thought, "I've taken a risk in eating something bad," or putting myself in a difficult position, or a position that makes me vulnerable. Although, I think I've probably been aware of the fact that I've avoided things, just in case.

[12:49] Mine, I think don't have a particular trigger, although, I think there'll be a hormonal link. I'm working on all of those things at the moment.

Leigh: [12:58] I bet. Self-interest rules.

Sam: [12:58] That's right.

Leigh: [12:58] In the midst of a very busy and demanding corporate board sport life that you have, how do you juggle all that with the ever-present risk of a migraine, and the reality of it sometimes?

Sam: [13:09] I think I'm a pretty good soldier on type person. I've got plenty of practice of managing and fixing the migraine, once I've got some pain relief. Even if I'm really suffering, I can push through. I know that that has a consequence.

Leigh: [13:23] It has.

Sam: [13:23] Once I've pushed through, it may be a worse set of period where I'm going to have to really lie down and deal with the consequences of almost actively stalling the impact. I very rarely have to cancel things or not turn up.

[13:36] I have had a couple of occurrences where I've been in the middle of something, after a long being very focused on something or leading a meeting, where I can feel I can no longer go on. I just have to make my excuses. Fairly rare. I think I've got almost like a capacity to manage through when I need to.

[13:51] I'm also very careful about preparation in the lead up to a stressful week. I'll extra check myself. I'm learning that more exercise would actually be helpful, the more I can get out. I always feel better after a walk. I always feel better clearing my head in the lead up to a busy time.

[14:06] I've got to now be much more active about that, I think. When I don't do it, I think I'm setting up preconditions for a migraine coming at the worst times.

Leigh: [14:13] Do you have a sensitivity about people knowing that you are a migraine sufferer?

Sam: [14:18] I think that's the heart of this conversation for me. The idea of saying to someone, "I can't make it today because I have a headache," and to a certain extent saying migraine, when it feels like it might have been grabbed at as a more forceful idea of...

Leigh: [14:33] I mean a migraine. That's the thing. [laughs]

Sam: [14:35] Then someone who doesn't know migraine thinking, "Oh, what? This is the latest RSI kind of excuse."

Leigh: [14:40] Oh, my goodness. Yeah.

Sam: [14:41] When I was an executive, often, people would be very nervous about talking about their RSI. That became the that's how you get out of work.

Leigh: [14:48] Cop out.

Sam: [14:48] Yeah. The cop-out. For those that suffered from carpal tunnel syndrome and other things, it was real, but in the same way that I think a migraine has that stigma attached to it. I don't like talking about it. Also, it does make you feel weak. There's a piece of me that says, "Why can't you just battle on?"

[15:04] Even though know what that means, in the thoughts of others, you think they're going to say, "Oh, well. Poor you," or "is that women's hormone issues?" or "here we go. This is why we don't need women in big jobs and stuff."

Leigh: [15:16] Just get over it.

Sam: [15:17] Yeah. Get over it. I know that's not the case. Whether it's a full stigma or a degree of concern about saying exactly how does affect me, I've certainly not talked about it very much publicly. I don't talk about it very much with people outside my family. They take the greatest impact of it, generally. You're often out of action during some home life.

Leigh: [15:35] Which is why I'm so glad you're here for this conversation. It's really important. Alexis, it is a condition that's often brushed aside?

Dr Selby: [15:42] Absolutely. I really feel that it's often trivialised. The experience of the patient, and often women, as women are the predominant sufferers of a migraine, is minimised. I see a lot of patients who just stick it out and just keep going. That can lead to obviously severe debilitation, psychological impact.

[16:02] It can lead to significant loss of productivity at work and at home. Home life can become quite disrupted, as Sam's mentioned because the symptoms are so severe. I do feel that now we are...I agree. We're now getting better awareness of migraine. People are becoming more aware of the fact that there are good treatments out there.

[16:21] Yes, it is a condition. It's not a cop-out. It is a neurological dysfunction or disorder, which is treatable. There is hope. There is treatments out there.

Leigh: [16:31] It has been undertreated.

Dr Selby: [16:32] Absolutely.

Leigh: [16:33] I never went to a doctor about this.

Dr Selby: [16:34] No. A lot of people don't. They will just, "Oh, it's just a headache," or, "It's just my monthly headache around when I get my period." They just put up with it, take a few painkillers, and that's that. It can then change over time, etc, and they don't seek help. Absolutely. It's definitely been undertreated historically, less so now.

Leigh: [16:53] What can you do now?

Dr Selby: [16:55] Treatment these days, so it really depends on the form or the patent of someone's migraine. You have episodic and you have chronic migraine, which are very different disorders on the same spectrum.

[17:07] The episodic migraine is usually how migraines start off, which is intermittent migraine. That's got a different treatment pattern, more based in acute treatments. Once you have a chronic migraine, or often you get transformation to chronic migraine, about two to three percent of people transform from episodic to chronic every year.

[17:27] That is a different sort of treatment. You basically have your acute treatment and your chronic treatments, and you have your non-pharmacological and your pharmacological treatment. You have a drug-based treatment and the non-drug based if you like.

Leigh: [17:41] The drug-based treatments are a bit tricky, aren't they?

Dr Selby: [17:42] Yes, they are. In terms of the acute drug-based treatments, the first line usually I recommend is a combination of things. For example, a combination of paracetamol and aspirin, or paracetamol and ibuprofen, or paracetamol and naproxen for a starter. Different people have different regimes. Different patients respond differently to different anti-inflammatories.

[18:03] Avoidance of codeine is very important. There's often been this belief that the codeine is the only thing that works for my migraine. That, you need your own special attention, as codeine is really actually very ineffective for a migraine. It is good at sedating you. It is very risky medication, in terms of you can easily develop a dependence.

[18:24] In fact, codeine makes a migraine worse over time. People will often say, "Oh, you know, my migraines are getting worse." In fact, it's related to the codeine, and teasing all that out is a very important part of someone's management.

[18:36] In terms of other medication based treatments, drug-based treatments, there are lots of different preventatives which have been tried over the years for a migraine. Some of which works, some which don't. It's extremely individual. As to what happens for each patient, is very individual.

[18:50] There are lots of different medications we've tried. There is some new medications coming on the market, which are specific for a migraine. They will be the first migraine-specific preventatives. It's been approved in Australia. We're still working out exactly what it's going to cost to the patient, and how that's all going to work.

Leigh: [19:07] There's optimism about that.

Dr Selby: [19:08] There is. Absolutely. There's a huge amount of research at the moment, mostly overseas at this stage, in terms of designing migraine-specific treatments. It's a burgeoning area. There is a lot of really interesting things going on for migraine.

Leigh: [19:22] Lifestyle factors for treatment or dealing with a migraine?

Dr Selby: [19:25] They are huge and not to be underestimated. A lot of people's migraine severity and frequency can be drastically reduced with lifestyle changes.

[19:33] The main triggers for a migraine, as we know, are things like stress, neck tension, hormonal changes, weather patterns, smoking, smells, lack of exercise, a sedentary lifestyle, obesity, high alcohol intake, high caffeine intake. Sometimes going from high to low caffeine intake can really have an impact on someone's migraines, as well.

[19:56] A lot of that stuff can be changed. The exercise is not to be underestimated. Getting good sleep. Sleep deprivation is a huge trigger for migraines. We all often suffer from a bit of that now and then.

Leigh: [20:08] Yes. [laughs]

Dr Selby: [20:06] That is something that if you get a regular sleep pattern going, regular meals...I find that a lot of particularly younger patients have issues with irregular glucose. If you're having regular meals or long periods of fasting, that's a big trigger for migraines, as well. There's a lot of things that can be looked at and changed. That's before we get to any medication at all.

Leigh: [20:24] Sam, how long did it take for you to seek medical help?

Sam: [20:28] I certainly sought help in the early years. In my 20s. I think pro what happened, it was treated not as well as it is today. I was given some fairly simple advice about pain management. I was put on a trial for what was then the prophylactic, which was Imigran. I had a bad reaction to that with my heart palpitations.

[20:50] My immediate thought was, everything that you take that prevents a migraine will not work for me. I then had a period of, a couple of decades of not really thinking much about it, thinking that was the extent of prevention.

[21:01] It was only when my migraines really changed their profile, in the last year or so, that I went back to my new GP. Then had a referral to a neurologist to have a proper conversation. I really was both delighted and annoyed with myself, but delighted at the amount of progress that's been made.

[21:18] To hear Alexis talk about the range of things that are now available, and I'm now trialing for myself a prophylactic medication, I hope that will give me some relief. It will be new for me. It doesn't have the side effects that the Imigran had with me, way back when.

Leigh: [21:33] There have been really concrete measures that you've been able to take, say over the last year?

Sam: [21:37] Absolutely.

Leigh: [21:37] That's made a difference?

Sam: [21:38] I think it will make a difference. I'm still in that early phase and trialing of things. I think my migraines have been affected by menopause, I've got some other things going on. I think it's Alexis that said, it's a very individual set of circumstances, and finding the things that I've got to do that will help me.

[21:54] I'm very confident about that. Now, I've had an MRI. I know that I don't have as many migraine sufferers think. You think, "Actually, maybe I've got a big tumor in my head. Maybe that tells me the story." When you get things that are fairly clear and you go, "OK. It's actually about treating this migraine."

[22:09] As Alexis said, the environmental things that I can do. I can do more exercise, not let myself get dehydrated, watch my diet. Watch those periods of time where I might go for a whole day without eating without realizing it, not to drink, and to make sure that my caffeine intake isn't something to become a crutch, and treating migraine doesn't then becomes something that has a feedback loop.

[22:29] I've got now people talking to me about this in a way I understand. I do have faith that there's a prevention strategy that I can feel good about.

Leigh: [22:36] A question to you both. You've covered a bit of that. What's your best advice for someone, if they're listening, thinking, "I've been experiencing this or sometimes over a long time." What's your best advice to them? First, Alexis.

Dr Selby: [22:50] I suppose I would say that it's not all in your head. [laughs] The symptoms are real. They're debilitating. There are treatments out there. There are things that we can do to help you. You don't need to just put up with it and suffer. We can make a real difference.

[23:04] With the involvement of the patients, we can really see some changes in the landscape of migraine treatment and prevention in Australia.

Leigh: [23:11] Sam, what would you say would your advice be? Wisdom.

Sam: [23:15] I think pursue more specialist advice. Not to rely on the first point of call, maybe a GP just saying, "Here's your pain medication, and really you're a migraine sufferer. Manage it." I think to then go and see a specialist. I've got a lot out of coming here and seeing you Leigh and Alexis.

[23:30] Actually, talking through what might be the unique treatment for me, and not making me feel guilty for not getting onto it earlier, and managing it the way I thought I could. If you think your own treatment works, you'll probably come unstuck at some point. I was someone who had in my back of my mind, that those strong codeine-based painkillers were actually quite good.

[23:49] I now know they weren't, that there was a sedative effect as opposed to dealing with the pain. I've learned dramatically about the combination of things like aspirin and paracetamol, which I would never have thought those two things could work. To hear a professional telling me that's what you need to do, and giving the physiological background to that, has been really important.

[24:08] I think the other thing about migrants suffering...I don't know about others. When you finish a migraine, there's almost a period of euphoria. I always feel like when I've got a clear head, that there is nothing I can't do. It's this thing about this dramatic comparison with how you felt when you were in the middle of a migraine.

[24:23] I think what that means is that you almost convince yourself you're fine now. When you're feeling that semi-euphoric state, and then a couple of weeks of no pain, you don't let yourself prepare properly...

Leigh: [24:29] For the next one.

Sam: [24:33] for the next one. Part of my environmental changes has to be not to suddenly think I'm through it and clear, and forget to do either the prevention things, or keep an eye on those things I've got to keep doing to really act as a prevention aid. You've got to be consciously dealing with this.

[24:50] I guess the other advice I'd say is I think you can share this story with colleagues. Certainly, family knows because they see you in those moments, but colleagues, and bosses, and others, in the same way, we talk better about mental health now.

[25:03] I think talking about how you suffer a migraine, what it does to you, preparing people for it rather than it being something that you get caught out in with people saying, "Oh, she's got another headache." That's code for, "We don't quite know what's going on, but she's just not here."

[25:17] I think there's an honesty in that, there's an integrity about that, and explaining how you manage it. I think most people nowadays, with the help of things like this, and great professionals, say, "We get that it's a medical condition, and we want you to get better," and create the work environment.

[25:31] That's why I think flexible working is a wonderful part of our modern economy, that you don't need to get dressed up and go into an office. You can do your work occasionally from home or in a different way. That flexibility will help someone who's managing bad migraines.

Leigh: [25:44] There's such wisdom in this conversation from two very important perspectives. I'm so glad, Sam, you've been up for this conversation. Thanks so much for joining us.

Sam: [25:53] Thanks, Leigh.

Leigh: [25:54] Alexis, it's been great. Thank you.

Dr Selby: [25:56] Thank you.

Leigh: [25:57] Thank you for joining us for our nerve podcast, Hope beyond brain disease. I'm Leigh Hatcher. Check out our website for a whole range of information and resources at www.sydcog.com.au.

[26:07] [music]

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