

The Migraine Trust with Steph Weatherley and Katy Brown

Speaker 1:

Welcome to the Sunflower Conversations where we explore the hidden disability sunflower and its role in supporting people with hidden disabilities.

Chantal Boyle:

Welcome to the Sunflower Conversations with me, Chantal. Joining me today is Steph Weatherley, who is the information and support adviser at the Migraine Trust. Steph also has lived experience of migraines. And we are also joined by Katy Brown. Katy is the CEO of her own company, Magic Mountain, and also lives with chronic migraines. So welcome to you both. Thank you for joining us today. How are you doing?

Steph Weatherley:

Yeah, I'm good, thank you.

Chantal Boyle:

So I think the first one we have to say is that a migraine isn't a headache. And this podcast, this conversation today is going to talk about what migraines is, how it affects people, and just maybe do some myth busting. So Steph, can I go to you first please? Can you explain what a migraine is and does it affect everyone the same way?

Steph Weatherley:

Yeah, absolutely. So migraine is a full body experience. You do have a headache with it, but it does affect other parts of the body as well. So all in all it's a neurological disease, it is a brain disease and the exact cause of it is not known, and it can be down to a number of different things and also a number of different triggers that can trigger it to happen.

Steph Weatherley:

So around one in seven people actually get migraine and it's estimated that 190,000 migraine attacks actually occur every day. And the symptoms for that can be things such as head pain. There's an aura as well, which some people do get. Not everybody gets the aura. And an aura is a visual disturbance. So you might get flashing lights, zigzags, blurred vision, for example. It can also be a body aura. So tingling in the hands, weakness, numbness like a pins and needle sensation can also be felt.

Steph Weatherley:

You can also have a sensitivity to light. Some people might find harsh lights very bright, not able to watch a TV, needs to go and sit in a dark room away from any light sources. There's sound sensitivity as well. And some people can also have an issue with smells, so they might find that certain smells are stronger during a migraine than when they're not having one.

Steph Weatherley:

There's an element of fatigue that comes with a migraine. It can be very tiring during a migraine when you're combating obviously the numerous symptoms that can happen. And another very common symptom is actually nausea and vomiting. So a lot of people find that they have to vomit, and vomiting can sometimes help the migraine, but not always. And the vomiting can go on from a couple of hours to sometimes a couple of days. So it can be quite a lengthy situation if you have those sort of symptoms.

Steph Weatherley:

So it's right that it's not just a headache, it is a number of other symptoms as well that when all put together can be very debilitating.

Chantal Boyle:

That sounds really debilitating. All of any one of those things that you've listed there. So the statistics, you said that's one in seven people in the UK are affected by it, who will live with it. How does that play out across male and female? Is there any statistics around that?

Steph Weatherley:

It affects approximately three times more women than it does men. There's not official statistics, but I imagine it's going to be around a 70% to 30% split roughly. So you do find that when we have contact from people on our helpline that the majority of them are female with migraine.

Chantal Boyle:

And is that a link to hormones or is there any research into why that might be what was causing that differentiation between the 70 to 30%?

Steph Weatherley:

Yeah, absolutely. There is a known link between migraine and hormonal changes throughout a woman's life, and that can be during the menstrual cycle, ovulation, perimenopause, and menopause. So a woman obviously has a lot of different hormonal changes, even from puberty, as obviously they get older. Men aren't as affected by that, and I think that's why we do see a majority of women coming to us. Although not all of them are solely impacted by hormones, hormones is one of the things that does make a difference and it can peak at certain times as well. So the perimenopause is quite a large peak for women, as is the menopause, and it takes a bit of time for hormones to settle down after the menopause as well, so it's quite a long timeframe for women having migraine if they are impacted by hormone. But there are a number of different triggers for migraine. So it can be hormonal, it can be due to stress or anxiety, for example. Even the weather can cause issues with migraine as well. So there's number.

Chantal Boyle:

I've heard of that. I've heard of somebody saying it was very much sort of... They knew when a storm was coming before it was even kind of forecast.

Steph Weatherley:

Yeah, absolutely. The storm and the atmospheric changes are normally the ones that we hear of the most, and the summer are as obviously a higher peak for people because it's more sunshine and that goes with the light triggers that can happen with migraine as well. So it's amazing really what can trigger migraine. And a lot of the time it's not just one thing, it can be a combination of things as well, which is why it can be hard to work out what is actually causing the migraine for you.

Chantal Boyle:

So Katy, when did your migraines first start and how do they physically affect you?

Katy Brown:

Yeah, so I've got chronic migraine and my story, I guess, or at least the part I'm here to talk to you about today started about 10 years ago now. I was living in London, just starting out in my career working in management consulting and financial services. It was a job that involved a cocktail of long hours, lots of travel and plenty of stress, it's fair to say. And a couple of years into that career, I started experiencing regular tension headaches. They gradually got worse and eventually over a number of years they became daily chronic migraine.

Katy Brown:

And it's the kind of pain that feels like screws are being tightened into my skull while a hammer pounds above my eyes. I've tried to explain it to people before that imagine waking up with the worst hangover you've ever had but you didn't have a great party the night before and you certainly haven't consumed any alcohol, and then do that seven days a week, and that's kind of how it feels. So my reality now is significant daily pain with flareups throughout the day as well. And sometimes I'm fortunate and that eases a little bit, but it has many, many triggers for me, so it is a daily reality.

Chantal Boyle:

Because it sounds like it's a combination of triggers for you. Is diet involved in any way for you?

Katy Brown:

So I have IBS and irritable bowel syndrome as well, and so there are definitely certain foods that I shouldn't eat or that I try to avoid. I typically find that there isn't or there aren't particular foods that trigger a migraine, largely because I always have one, so it's very hard to figure out what would. There are other triggers that I know will make things worse. So some of the things Steph was mentioning around light, the wind if it's really cold outside as well, those are all classics for me. And not getting enough sleep is another one. Similarly, getting upset about something or feeling quite a kind of extreme or strong emotion, that will be another trigger.

Katy Brown:

But when it comes to food, I think I've tried lots of different diets, I've tried a kind of low FODMAP diet, I've tried eliminating different food types. For me personally, it hasn't been something that I found helpful, but I know for others it definitely does help.

Chantal Boyle:

In a sense, I hope you don't mind me saying this, but it sounds like your daily life is walking a tight rope to not feel a strong emotion and to try and manage everything to keep your brain, I guess, in balance so that you don't trigger a migraine, but they seem to occur anyway.

Katy Brown:

You're absolutely right. I think you've put it really beautifully. It is a kind of tight rope walk and there are definitely days where, for example, if you're going to try and go out for dinner in the evening, you'll deliberately do less during the days so that you've got enough energy left to be able to go and do something in the evening. And that's a big, seeing that many people will, I think, empathize with for chronic illness sufferers is you don't have this never ending amount of energy where you can just go all through the day without having to worry.

Katy Brown:

I think the reality is if you that you want to do something, you've got to pace yourself. And I can certainly manage about one social occasion in a day. I certainly can't add any more in. And I probably go out for dinner once in a blue moon. And if I do, it's to a quiet restaurant and I ask for a corner table, and I never go on a Friday or a Saturday night because it's too noisy. So yes, it is a tight rope and it is a balance, and it can be tricky at times because, as you say, there's so many different factors that it can be quite difficult to plan for all of them.

Chantal Boyle:

And so that's kind of within leisure time. How do you manage your life in other senses? So with regards to work, exercise, how do you manage that?

Katy Brown:

Yeah. I read an article once that described chronic migraine as a life sentence. And I think that while it sometimes does feel like that, it's also taught me a lot about how to best respond. And I think one of the biggest things when it comes to managing my day to day life is that sense of acceptance and adaptation and kind of patience and perseverance as well. I've really focused or learned to focus much more on what I can do rather than what I can't.

Katy Brown:

And I think the most important thing for me has been that recognition that our greatest freedom is in how we respond to things. So for me, accepting the cards I've been dealt was incredibly helpful. It doesn't mean I've got no hope for treatment or a breakthrough, but it means that I'm not living my life in a holding pattern where I'm waiting for something that may never arrive or I'm constantly angry or frustrated about the fact that I'm in pain. I think acceptance means I can make the most of the here and now. And so that is probably, when I

look across all of my life, the most helpful thing that I could do, was get to a place of acceptance and then be able to work from there.

Chantal Boyle:

That's really good advice. And I'm guessing it is your own advice and that's what you would suggest to anybody else who was looking for way to balance their own life between their employment and health.

Katy Brown:

Yeah, I guess when it comes to work, there's probably a couple of things because it's incredibly hard. It's incredibly hard to balance your work and your wellbeing, and I think I've certainly been there for the last 10 years where I've been finding that balance difficult. Some days I've got it right, other days I haven't, and I couldn't figure out for the life of me why that was the case. I think for me, for people, or for anyone who is struggling to find that balance, one of the things that I think is very helpful is, if you're comfortable doing so, is talk about it with your employer, with your colleagues. Help them to understand how they can support you, how they can create an environment where you can bring your whole self to work, you can manage whatever chronic health condition you may have while still doing great work. I would say to people, you deserve that support. Battling chronic illness, it makes us resilient, it makes us determined and incredibly adaptable and strong. It doesn't make us less capable at doing our jobs and I think that's really, really important.

Katy Brown:

And the other thing I would probably say for people in that situation around kind of balancing work and wellbeing is set healthy boundaries. So for me, I try to avoid working late into the evening, working at weekends. I do my best to switch off properly where on holiday. I block out time to move every day as well. And those boundaries are non-negotiable. I think I realized quite early on that I'm the one who has to hold the line on these things because at some point somebody will ask you to compromise, and you've got to hold firm and say that, "Look, I'm really sorry but this is what I need in order to do a great job," and maintain that somewhat fragile sense of balance.

Katy Brown:

So I'm a firm believer that no one should have to choose between meaningful work and their health. I think unfortunately there are times when we do have to choose. That's life, and in those times you've always got to choose your health. As people have said to me before, you have one health, you'll have many careers.

Chantal Boyle:

That's absolutely right, and I commend how you've set out these sort of healthy boundaries. And as you say, you are answerable to you, aren't you? Your health is very important that takes priority so that the rest of everything can function and flow.

Katy Brown:

You're so right.

Chantal Boyle:

It's how we approach it, isn't it? Rather than say, "Oh, is it okay if I have?" or "Would you mind if I did?" Well, you've got the talent otherwise you wouldn't have been employed to do the job in the first place, you've got the skills, it's saying what you need to get the support in order for that employer to get the best out of you. And that's what all employers should be doing, whether you have a disability or not, putting structure in place to get the best out of their employees and to support them and help them thrive.

Chantal Boyle:

You are listening to the Sunflower conversations with Chantal. To find out more about the topics discussed in this podcast, details are in the show notes.

Chantal Boyle:

What are some of the common questions that come through to the Migraine Trust?

Steph Weatherley:

We do get a mixed number of questions actually. I would say most of the inquiries usually are around people seeking emotional support. That's one of the biggest things, and they're very unclear about what their treatment options are. So we do get quite a lot of questions about what their doctor can do for them, what treatment options are available to them, and also what they can do for themselves when they're finding the information doctor's given or the treatments they've been given aren't quite working for them. So a number of self-help strategies and things are normally asked for.

Steph Weatherley:

We do have a number of parents that contact us about their children and migraine in schools and support with schools as well. And we get quite a few questions actually around employment where people are struggling with their migraine at work and they're finding that their employers aren't supporting them enough.

Chantal Boyle:

So in your experience, so businesses are maybe not quite set up to support employees. It's one of the most common used excuse for not going into work, isn't it? "I've got a migraine." And I think that that term is clearly banded around too freely, incorrectly and that's actually damaging for anybody who does have chronic migraines.

Steph Weatherley:

Yeah. There does seem to be a bit of a stigma around migraine where people, or employers and people don't understand the symptoms that come with it and the impact that it actually has on a person's quality of life. And you're quite right that a number of people, they do ring in, they say, "I've got a migraine, I can't come in today," and that gives a bad impression of it for someone that actually does have a migraine condition. And as I said before, it's not just the headache, it is a full body experience that that person goes through that can last anywhere from a couple of hours to a few days. So it's not just something that they're going

to have one day and then be able to go to work the next day because they could well be impacted for a longer period than that.

Steph Weatherley:

I think when you asked about employers and understanding of migraine, we find that some employers can be quite good and others have no knowledge of migraine whatsoever and they don't have the right support mechanisms or network in place to support any employees that do have a migraine condition. So in order to help those that have migraine within work, we do actually have a toolkit on our website that can be downloaded and it gives the guide basically about what migraine is, the explanation of migraine as a disability, information that can be provided to the employer and things that the employer can actually do to support a person with migraine as well.

Steph Weatherley:

And it just helps if we find that people tend to download it and forward it onto their managers, for example, their HR department, and it actually just gives them an idea of what migraine is and the awareness of it. And many times people have come back to and said, "Oh, do you know what? That's actually really helped me because I feel they actually have an understanding of what I'm going through now." But in some cases people do still struggle, and that can sometimes be down to the resources that the employer has available to them and the adjustments that they can actually make because not every employer is large. Some are only small and they may not have the facilities to be able to make the right workplace adjustments that a particular person might need.

Steph Weatherley:

But we also do migraine awareness raising sessions for employers. So that's normally an hour long Zoom meeting where we will discuss migraine, the impact of it, what an employer can do. And we've actually done quite a few recently and they seem to go down quite well. So it's doing our best to raise the awareness of it within the employment sector, but it just takes time unfortunately.

Chantal Boyle:

So Katy, I think that would've helped you when you were in financial services for your employers to have been able to take that training.

Katy Brown:

Yeah, definitely. I think there's definitely that stigma, as Steph said, around chronic migraine. It's a very popular excuse for a sick day, as you say, Chantal. And one of the reasons I think I kind of hid behind a mask for so many years and didn't really talk about migraine for so many years was, one, because it's an invisible illness and I look perfectly healthy. And two, is the stigma attached to those health conditions. People do think it's just a headache and the number of times I get asked, in a very kind way, but, "Do you just need some paracetamol? Can I get you some paracetamol?" And I think no one has an idea or very few people understand how debilitating migraine can be.

Katy Brown:

The World Health Organization categorized it as the same level of disability as dementia and quadriplegia, and chronic migraine is more disabling than blindness and rheumatoid arthritis. And it can even be, when it's really frequent and severe and impactful, it's a disability under the Equality Act, and I think very few people know that and have that awareness of the real impact that it can have, and I think, as you say, kind of pragmatically what we can all do to try and support workplaces and support employees to feel like they're working in an environment where they can thrive.

Chantal Boyle:

And you wrote an interesting article, didn't you? About your condition and about the fact that you kept it hidden for many years. And I'm assuming the reason that you wrote that is for the things we've just been talking about.

Katy Brown:

Yeah, I think I got to a point where I didn't feel I was being authentic because I was presenting a version of myself to the world that didn't include something that was this huge part of my life and had been a huge part of my life throughout the time, eight years, now kind of almost 10. And actually I kind of thought, you know what? I need to own this. I need to stand in my story and own my experience, and I need to do that in order to try and help get rid of some of the stigma, help raise awareness of something that is an incredibly debilitating condition, and perhaps just help one or two other people who also have chronic migraine, who perhaps also feel alone or anxious or depressed because of the amount of pain they're in to know that there are other people out there. So yeah, it was actually incredibly liberating to start talking about it so openly after so many years of not ever mentioning it at all.

Chantal Boyle:

Did you get much feedback?

Katy Brown:

Incredible support and an incredible also level of disbelief. Not in terms of disbelief, "I don't believe you," but disbelief of, "This is invisible. You look incredibly healthy and you do a very kind of, I guess, stressful pressured job, and how on earth do you manage to do all of that when you are in so much pain?" And it was incredibly supportive to have people come and say such really kind things. I think also, you've got people who said, "You know what? I feel empowered to talk about this thing that I'm carrying around with me that I never thought I was going to have to." And whether that was a physical condition or whether it was a mental health condition, that was brilliant to see as well because quite a few people then felt that they could start talking about their challenges and I think that was one of the best outcomes really.

Chantal Boyle:

That's brilliant. I think that's where we all need to start the conversation.

Katy Brown:

Absolutely.

Chantal Boyle:

And back yourself. So have you tried different treatments, Katy, or any that you can share with us?

Katy Brown:

Yeah, I've been very fortunate to see numerous neurologists and specialists over the years and I seem to be almost impossible to treat. And so I'm sure that I'm an absolute nightmare for any neurologist who has to see me, and I turn up with a large almost book of treatment notes that they end up having to read, and I think probably they just put their head in their hands. So yeah, I've tried almost every treatment available from the conventional prescription medications, I think I'm at about 12 or 13 at last count, through to Botox, occipital nerve blocks, Aimovig and Ajovy, which are the new, the kind first drugs that have been developed specifically to treat migraine.

Katy Brown:

I've also been down the alternative route, so I've tried things like acupuncture, craniosacral therapy, homeopathy. I spent a small fortune on Chinese medicine and some of these things I couldn't even tell you how they're meant to help, but when you are in severe pain you'll try with anything.

Chantal Boyle:

Yeah.

Katy Brown:

I even have a daith piercing in my ear because apparently it relieves migraine for some people, and I got so desperate about five years ago that I thought that was worth a try. So.

Chantal Boyle:

That's a piercing in your ear? What type of piercing is that, sorry?

Katy Brown:

It's a daith piercing, which is in a... This is literally an old wives' tale. This is myth. This is not science I should-

Chantal Boyle:

Don't do this at home, folks.

Katy Brown:

Yeah, do not do this at home. It's very painful. And yeah, it was again something that, an act of desperation because I had a couple of friends who had migraines and it's a kind of acupressure point, and they found that it helped relieve their migraines. And I've kind of had got to a point where I thought, well, what have I got to lose? I've tried everything. I was eight years into treatments at that point and when it's a very long journey. That's the thing I

think people often don't fully understand with migraine treatment, you are on a three to six month trial of a drug, and then it takes you a long time to get onto that drug anyway because there's a waiting list or you've got to jump through a load of hoops to qualify for the drug in the first place. So you can be trialing maximum two to three drugs a year, and if they don't work, then you're waiting for the next thing and then you're onto trialing the next thing. And that kind of treatment cycle of hope and disappointment can be a really exhausting one.

Chantal Boyle:

Yeah, you've got to protect your mental health through that process I would've thought.

Katy Brown:

Definitely. Definitely. I think depression and anxiety are close friends of chronic pain. And as Steph was mentioning at the beginning, living with daily pain is exhausting, and it's emotionally draining as well. So I think there is a lot to be done around how we best support our mental health while going through that kind of challenge.

Chantal Boyle:

Steph, Katy listed out a lot of different treatments that she has tried. I don't know if you caught them all, but do you have any other examples of treatments that are available?

Steph Weatherley:

Yeah, absolutely. There are a number of treatments, as Katy listed I think. And also with every treatment, and they're normally available from the GP or neurologist, is they are about three months each, so you can only do so many within a year. And as Katy quite rightly said, you do get that air of desperation when something's not working but you have to keep doing it and you do look at trying other things.

Steph Weatherley:

So many people do also look at non-drug treatment options. So you've got your supplements there, which are things like the magnesium that can be used. There's vitamin B2, riboflavin as well, which some people try. And you've got your Coenzyme Q10, which can also be used, and they act as like a natural preventive. But even for those, they still take a good 12 weeks to actually start working properly and reach their full efficiency level, so they're not a quick fix either unfortunately.

Steph Weatherley:

And there are some nerve stimulation devices now which are available. We've got more information about those on their websites. Some can be purchased and they're not available in the NHS. There's different ones and different cost levels, but some people, they find they work, some people find they don't, and it really is a trial and error process. But when you are in that desperation and that situation where every day is so difficult, you're waking up with that head pain, you've got those symptoms, it's not easy, you do find that you do end up trying as much as possible to try and alleviate it.

Chantal Boyle:

Yeah. Is there a lot of funding that goes into migraines? That sounds like quite a lot of things that you've both been able to try or recommend. Is there a lot of funding or is it all sort through charitable donations?

Steph Weatherley:

There is funding there. So with the newer medications, I think Katy mentioned Aimovig is one of them, the CGRP medications which are available now. They became available in 2020, but to be honest, it's probably taken the two years for people to actually start being able to access it on prescription. But even then they're still struggling, and a lot of that is down to funding and the clinical commissioning groups not being able to access it. So I think there are struggles in terms of migraine treatment and that's the first treatment really that's been solely designed for migraine, whereas everything else, you have preventive medications, Botox and things for example, are used for other conditions but shown to be a benefit for migraine. But as Katy said, even if you get passed for a treatment, you could still be waiting a good three to six months to actually start it before you can actually begin it. And it is a really lengthy process in terms of treating migraine unfortunately.

Chantal Boyle:

So have you got any advice for someone who is experiencing migraines? Should they do in the first instance to seek support?

Steph Weatherley:

If obviously it's undiagnosed, then your first steps normally are to go to your GP. The GP is the first point of call in terms of migraine treatment. They can prescribe the preventive medications, which they will use if you normally have four or more migraines in a month or if they're having an impact on your quality of life. They can also provide what we call acute treatments, so effectively your pain relief medications that you take at the time of the migraine. And the NHS pathway actually requires you to have tried at least three different preventive medications that are available from a GP before they can refer you to see a neurologist. So that's normally the first point of call.

Steph Weatherley:

And Katy mentioned earlier about how important it is to actually talk to your friends and your family. And I think a lot of support does come from your friends and family network, your employer, if you make them aware of their condition and things as well. So it's not just about the treatment, it's about being able to tell other people what you are going through, where you can get that support.

Steph Weatherley:

And we have a very helpful helpline that anyone can contact. It's open Monday to Friday. The phones are open from 10:00 AM until 4:00 PM, and we also have live chat services as well, or you can send an email. So we provide as much support as we can to people as well, and guidance in terms of steps to take if they are having migraine and don't quite know what to do first.

Chantal Boyle:

Well, I'd definitely like to put a link to the Migraine Trust website in the show notes. What's the website?

Steph Weatherley:

Yeah. So it's migrainetrust.org, O-R-G, organization.

Chantal Boyle:

That's great because there's been some really helpful things that you've spoken about throughout the podcast. So we're doing this podcast because it's a non-visible disability, very disabling it can be at times. I'd like to know what you both think of the Hidden Disability Sunflower, what your thoughts about it are.

Katy Brown:

I think it's a great way to help raise awareness of invisible illness and hopefully foster a culture that has greater understanding and more compassion and support. I think, as we've said, one of the biggest challenges with all invisible conditions is that you simply can't see them, and so it's very hard for people to empathize. It's very hard for people to know that you may need additional support without the person who's experiencing that particular condition having to always be responsible for communicating their needs. And I think having something like this where you are able to really help raise that awareness is really, really important.

Steph Weatherley:

Yeah, absolutely. I fully, fully agree with that as well. I think it is a really good way to highlight and give a voice to those with hidden disabilities that find it difficult to speak out. Not every disability is visible, and the cards and the sunflower itself, it's easy to show, it's easily recognized, and it does show that assistance or support may be needed, although a person may not physically look like they need that help and support.

Chantal Boyle:

Everything that you've described to me, Katy, today about your experiences over the last 10 years and just how invisible what you've been going through has been, where the reaction would've been so different had it been a visible disability, the reaction and support that you would've got from people would've been I'm sure phenomenally different.

Katy Brown:

Yeah, absolutely. I'm sure it would.

Chantal Boyle:

Well, listen, I just want to thank you both for shining the light on the migraine condition. I hope that everybody listens to this podcast and educates themselves. It truly is a chronic, painful, and debilitating condition. And Katy, I wish you all the best with your next round of trials. Please don't pierce any more of your body.

Katy Brown:

Thank you. I won't. Yeah, I will most likely not be going down more speculative alternative therapy routes.

Chantal Boyle:

And Steph, you've been so knowledgeable and informative. It really has been really wonderful. And thank you both very much.

Steph Weatherley:

Right, lovely. Thank you so much.

Katy Brown:

Thank you, Chantal.

Chantal Boyle:

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

Speaker 1:

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