

Walking on fire: living with chronic pain

Mother and daughter Janet and Lucy Mahar talk about the chronic pain that they live with, and **David Bennett**, Wellcome Clinical Scientist at King's College London and member of the London Pain Consortium, explains this condition and some of the ongoing research into it.

JM: Has anybody ever walked on the beach when it's been burning hot and you put your foot down and go "ouch"? Our feet are like that 24 hours a day, even if it's bitter cold.

DB: Acute pain, you can rationalise to yourself: "well I've cut myself but it's a cut, it will heal, it will go away". The great difficulty with chronic pain is that it often can be a lifelong condition and there's an element of lack of control as well.

JM: I've had pain in my feet since I was about 14 or 15, burning more than pain. If I tried to wear socks, tights, boots, trainers, they started burning, aching and you think "my health is just deteriorating, I can hardly work, something's got to be done", which is hence why I went to the doctor. I was quite surprised they didn't laugh and that they listened to me to be honest, they understood.

It hasn't been diagnosed yet that me and Lucy have got the same condition, it's only just been diagnosed with me and later today we're going up to King's to see Dr Bennett. We presume he's going to take the same tests with Lucy today that he did with me to either get it confirmed or not.

LM: It'd be nice to find out –

JM: To put a name to it, even if we don't know it and can't pronounce it.

LM: Yeah.

JM: That there is a word for it, that we've not just lost our marbles.

DB: The term is erythromelalgia, or some people use the term erythermalgia, and originally that term arose around a clinical syndrome, which was that people developed, usually starting in their feet, severe pain associated with reddening of the feet. And one of the key aspects is an increase in temperature, so things like being in a hot room or wearing shoes exacerbates that pain. So really the idea with her was to come back so I could discuss the genetic results with her, talk about treatment options and also to meet her daughter as well, who complained of similar symptoms.

JM: It's like first degree burns. Your feet are – not warm, not sweaty, not hot, they are on fire.

LM: It's really hard to live with, really, ain't it?

JM: Because you can't see it and people don't understand it, you're either a hypochondriac or you're lazy. That's the impression people give me.

DB: One of the difficulties for patients is that they're trying to explain to people the fact that they're living with this very severe chronic pain syndrome, but most of the general public would expect there to be a significant injury or some kind of very clear disease process causing that, and there's not an understanding of the fact that pain in itself arises from some dysfunction in sensory processing.

We took your DNA and we looked to see if there were any abnormalities in the DNA, and the results have come back and I think we need to do a few more confirmatory tests but it certainly looks like there's an abnormality in your gene for this particular sodium channel, so that explains why you've got this pain in the feet. When I spoke to your mother she was suggesting that you have a similar problem to her, do you just want to go through what symptoms you've been having, what problems you've been having so that we can assess that in your own right?

LM: Day-to-day pain, burning, the only way I can describe it is like walking across glass, it's really bad pain.

DB: When the pain's bad if you had to grade it with zero as no pain and ten as the worst pain you ever had, what would it rate on that scale?

LM: Ten onwards.

DB: In their case they have a mutation in the sodium channel Nav1.7 and that's causing hyperexcitability of their sensory neurons, their primary afferent sensory neurons that transmit information from their periphery, such as their skin, back up to the spinal cord, and that is driving their pain state.

I think the sensible thing is that we send the same genetic test that we did on your mother in your case as well.

JM: She's got a lot of years ahead of her and if what they've found in my feet over the next few years, they're going to develop it, could even be a cure, I mean we don't know do we? It's exciting. It's not nice for us getting it but for medical people it's got to be exciting, they've found something new. Would be us that's got it.

LM: There's not enough money in the world that I wouldn't give to not have this pain.

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