​Jenica Leah

You know, if you were to like hold an ice cube in your hand or put on a part of your body and it feels freezing cold and then you get to that point where it's so cold that you want to let go, like it's penetrating through your bones anything, if you were to still hold on for the ice cube for as long as possible -- that pain kind of multiplied, I don't know, by a hundred and then everywhere in your body, or wherever the site of the crisis is. Kind of like that, but then there’s, there's so many different types of pain you can have like muscle pain, you can have bony pain, which it literally feels like your bones are being crushed by something, like I don't know like being run over by a van. It's just -- I don't know burning… I just heard it's so painful, something that I wouldn't even wish on my worst enemy. Like it's just kind of indescribable... ​

I think the main barrier is that it mainly affects Black, Black people, African Caribbean. So I think already, we’re kind of, you know, we're at a disadvantage. And then there's also, I think I know with a lot of patients, because we've lived with this condition for our whole lives – we know what works for us, which may be different to what a healthcare professional may have learnt, and telling someone what you want, instead of waiting to see what they're going to give you, or how they're going to be treated. I think that then is another barrier. And then again, just a lack of empathy, understanding, even just listening. I think sometimes we're kind of just -- you know, if you're, if anyone is in pain, no matter what colour you are, no matter what race, religion -- if you're in pain you're going to act, you know, you're not going to be acting your usual self. You might be crying. You might be, you know a little bit angry. You're going to be hot, you're going to be flustered, and then automatically, like me just being in A&E, I felt like I was just straight away labelled as just kind of like an angry black person, when I was just, I'm just trying to explain -- if you ask the question, I'm answering the question. Maybe the way that I'm speaking, it's not like how I'm speaking to you now. It's going to be you know, a little bit disorientated, or maybe a bit slow. Or maybe I'm crying but I'm not being disrespectful or anything like that, but it's just completely perceived in the wrong way, and it just kind of again is another barrier. I just think there are many.”​

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