



Pain: I Get It - Tracey's Story



## Tracey from Lincolnshire lives with Fibromyalgia. She tells us how it was hard for her to trust good healthcare advice after her pain had previously been disbelieved.

### **My life with pain started officially in 2014.**

Although, I think things had actually begun to change about 10 years earlier and I'd just learned to push through the exhaustion.

### **I started collapsing and we didn't know why, despite all the MRIs and tests.**

I'd been on a motorbike tour with my husband and while we were there I was feeling so ill that I'd go to bed at 8pm and get up at 10am. I got home and went to get out of bed the next morning for work and I literally couldn't move. I thought I'd been paralysed. **Even now I can recall how frightening it was not even being able to lift my head.** We got the doctor out and she checked various things and then said "I think you've got Fibromyalgia", a diagnosis later confirmed by a lovely rheumatologist.

Fibromyalgia can arise from trauma and it's such an all-encompassing condition that it can affect your joints, your muscles and your brain. **I was off work for nearly 3 months and I only left the house in that time to go to appointments.**

### **Having a diagnosis made me feel like I wasn't going mad, and someone was finally listening to me.**

**I had mixed emotions after my diagnosis.** In one way it was a relief because I felt believed; these symptoms I hadn't understood made sense and I had the best night's sleep I'd had in a long time.

I also experienced elation, fear, apprehension, even depression about the future. There's a huge amount of uncertainty.

I felt a failure. I used to work in a management role in retail, training staff and running shops. Now sometimes I struggle to remember how to turn a computer on – it can be soul destroying. I've also been a weight trainer and a gym instructor in the past and so not being able to do that anymore hurt very deeply. I couldn't understand why I wasn't able to grip, or why the inside of my head felt like the static fuzz that used to come on after television programmes stopped for the night. **Just putting my hands on my thighs felt like being touched with a soldering iron. It was so unbearably painful.**

After the diagnosis I had to search for my identity again and look at things differently. For example, I now drive to work the distance I used to be able to easily walk. When I think about how things are now compared to what they were before, it feels degrading. There's nothing I can't do – but every time I do it, it hurts – both physically and mentally. There's bereavement of the person you used to be. **Fibromyalgia won't take my life, but it has taken a big part of me.**

### **I have a lot of faith in me and I'm not going to give up.**

When I'm having a good day, I think nothing in the world can stop me but on my bad days (and there are many), there's nothing in the world that can get me going.

My husband is amazing and helps me with things like getting in and out of the bath and washing my back. When my 73-year-old boss tells me to sit down, it's hard to hear. I will do everything for people not to see my pain but even fighting that feeling can make my pain worse. So instead I say, ok I can do this but I have to do it slower.

I once had an appointment with Citizens' Advice for advice on applying for PIP and I broke down. I was having a very bad physical and mental day. The woman there saw my pain and said to me "isn't it about time you loved yourself now?".

I know I need that help but accepting it is really hard. I'm suffering with the pain day-to-day and I know there are thousands more. No one should be made to feel they're not worth it. But it's about knowing you can put your hand up and say "I am struggling today" or "I am struggling in general", "I need some help" or "I'd love a cuddle".

**“ Now I want to say to people that it's ok to accept help. Give yourself time and learn to pace. You're still you, you're just different and now you have different needs. And hey, isn't it about time you loved yourself now? ”**

On the days you feel useless, you're not useless, you've got a pain condition. **I am not a victim; I'm a survivor because I'm learning to live with it.** Some days I say I've been rained off! Whilst other days I have to just put my wellies on. It's a process and it takes as long as it takes.

**The realities of Fibromyalgia are the ups and downs and how quickly moments can change from a tear to a smile -** like this conversation today. I can do something one day but not the next. I go through the mental torture of it, arguing with myself which stresses me out.

It's quite common within the realms of Fibromyalgia to get problems elsewhere in the body. It affects brain, body and soul! You have to keep the faith - not in God necessarily, but in yourself. For the people who think Fibro isn't real, there's a million more like me who deserve to be heard and deserve that pat on the back for being here one more day.

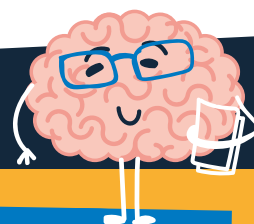
Depression is real. You've got to realise that you can get on top of it. I use medication to help - don't give up. Try, but don't try too hard on your own if you're struggling - **direct some compassion to yourself and ask for help.**

**“ All the pain management tools are soothing and informative, but you've got to want to let them help. It's not about simply letting them help, you've got to WANT to let them help. It's a big difference! ”**

**When I first heard someone say that pain doesn't always equal damage I was quite affronted.**

I thought how can you say that?! And it's not until I actually heard them out that I understood. **I was so protective of myself because of my experiences of not being believed in the past.** Listening to them, I realised it's ok to feel the pain and ok to react to the pain and also that it's not going to do any damage. Sometimes I try and work through pain because it might just make me feel better for doing it, which puts me on the route to a good day.

The role of pain and our nervous system in protecting us is a powerful thing. If you use that power to your advantage you'll get more out of your day, your week, your life. But you've got to hear the message out! Hear the end of the sentence with your ears and your mind open. **Education is worth the listen because it might just help you understand this amazing brain we have.**



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