

I am number 17
Mel's experience

My diagnosis happened when I was 52 years old.

They thought I was okay at first, but by the time I was 6 months old I wasn't able to sit up. I would flop to one side, and however much someone tried they couldn't get me to sit up properly. My parents were trained by physios to pull me about to try to strengthen me, but they had no idea what was wrong with me. My earliest memory of pain was when I was three years old sitting on my grandmother's lap and I used to say, 'my knees are buzzing'.

I was forced to take part in sports at school; schoolteachers used to think I was being lazy. I remember being forced to do a backwards roll and being in agony afterwards because it really hurt my neck. Through school I always felt like I was the clumsy child; the one who couldn't run as fast as the others. With hindsight it's easy to know why, but at that stage it was frustrating because I wanted to be as good as the rest and do all those things the other kids were doing.

When I got to senior school, I used to get a lot of pain in my legs. I used to get severe shooting pains and terrible back ache. Sometimes the other kids used to put their arms together and carry me around the school yard, which was quite good fun in some ways, but made me feel a bit silly in others. Also, we moved to Wales from Nottinghamshire, so there was a language barrier initially and difficulties in that, as I didn't want to stand out.

At 13 years old my backache was horrendous, so I was taken to see a doctor. My parents' friends were specialists and expressed concern, so I went to Barnsley Hospital and had various X-rays. They initially thought I had cancer and performed an exploratory operation on my spine, however, thank goodness it wasn't cancer. At that age, this situation was very traumatic. The nurses and doctors at the hospital at the time weren't very focused on how I was, they would just say 'Get up! Get out of bed! Help serve the food on the ward'. It was assumed as a youngster that you could just get on with it. It also turned out that not only was the operation exploratory, but the whole process was a learning experience for the doctors too. I remember being put in a room full of doctors, whilst naked, at 14 years old, not able to speak because I was under sedation. I can just remember these windows behind me and all these doctors watching on whilst they moved me all about in funny positions.

As I got older, I just got worse and worse. I had two beautiful girls. But they were quite difficult births because the shape of my spine was different, so they lay against my spine, which meant giving birth to them was traumatic. I wasn't very well, but I got on with it. Mick, my husband, is a teacher and he used to run home at lunchtimes – 6 miles – to support. As soon as they were old enough, I taught them that due to my horrendous sciatica, they would have to be like little koalas and hang on to me, rather than picking them up. I was always told it was growing pains and a bit of 'wear and tear'. I used to take painkillers, slow release pain killers. Then basically those next ten years just went by.

I always liked to earn money, so I always wanted to work. I worked for the BBC before we had the girls, which was great fun. However, my career path was thwarted from a young age. I wanted to go to college and do art, but I had an accident at 16; I chopped off the end of my finger. So, I became a short-hand typist rather than going to art college. Although I had done alright at school, they wanted me to go back and sit the 6th form again, and I didn't want to do that. At this point I hated school. I hated being there; it was just so uncomfortable. Mick and I had already met each other by that stage as youngsters. Mick has been with me and this condition from a very early stage, so we've really looked after this together.

Whilst working for the BBC it was good and I didn't have any other commitments at the time, which worked well. Then we moved to North Wales and I worked for the council for a bit as a secretary. It was never very easy as you're sat at a chair and posture was uncomfortable, but you carry on regardless. Once I had the girls, because there was no one around to help out, we decided that I would just be at home. To make ends meet I used to type at home. We needed the money. As the girls have grown up, I've had to tailor by career. Most projects have been short term, as I couldn't really commit to anybody. I am capable, but sometimes my body is not capable of doing stuff.

You don't tend to tell people about your condition, because you don't want people constantly asking how you are or noticing that you're struggling. If you go to friend's houses you wouldn't say that you were uncomfortable, you would just suffer the next day. You grit your teeth and get through it and go home early. You don't want to be noticed. You don't want to stand out as being different you just want to fit in really.

I've done all sorts of things; I started out on a typewriter, and then went on to word processing on computers, and basically taught myself to do all of this stuff, and then went on to teach women returning to work how to use computers using databases and spreadsheets. Then went on to teach adults who had no idea how to use computers. I did that sort of stuff for a bit, as I didn't go to university and I felt a bit frustrated, because I felt like I could have achieved academically. It really ground on me that I had missed out and I hadn't proven myself, so I started doing NVQs for a couple of years. Then I went to go on to do the teacher training course for adults at night school. I taught in the local school on and off with adults for about three years. I also became a bursar for the school for a while. Later on, when the girls were getting older this then didn't fit in, because they were both fabulous musicians, so I was trying to take them here there and everywhere. We then moved to a new house. It was a rented accommodation, because we wanted to build our own home. At this stage I still didn't know I had the condition, I just carried on regardless. I was told I had fibromyalgia at this point.

However, the pain and workload took its toll and I ended up having a breakdown. I felt unsure of the diagnosis and was really struggling with pain and getting nowhere with doctors. I needed support and went on a course called 'The Expert Patients Programme'. This course was to help people manage their long-term health condition – whatever it was. So, I went on this course and straight away was asked if I wanted to be a trainer. I went on the trainer course, and within a few months – they asked me if I wanted to apply for the job as a coordinator for them. I got the job as a coordinator on the programme. The main job was based 40 miles from home, however due to my condition they agreed I could work from home some of the time. So, I would co-ordinate the meetings for that and teach. The board itself didn't understand what it meant to live with a long-term health condition. They expected me to move all the paraphernalia, all the books, flipcharts, and they would expect me to drive 2 hours to do a course and drive back. I managed it for three years before I had a breakdown. But I loved the job and I loved helping people. I could really empathise with them, and I was really good at it because I totally understood what people were going through.

I have been told that I have mental health problems and that 'its all in your head', I was told this by a gynecologist many years ago, as I had to have a hysterectomy in later life. I thought I was losing it, which was scary at the time, because I knew I wasn't and the pain was real.

I had a referral to a pain clinic, where they said they could not help me, but expressed I was a good self-manager already. I decided to leave The Expert Patient Programme, so could I focus on my artwork a bit more, which helped. In 2008 I lost my father very suddenly. He was away on holiday and died in his campervan, which was very distressing for me. He always used to say to me 'Mel, you should do more of your artwork, you're really good'. I had found this form of art which I really admired called encaustic - artwork created with beeswax - but I could never afford the stuff or had the time to do it. However, I had recently lost my dad, had left my job and needed to get stuck into something new, so it was perfect timing. Within the space of 12 months, I already had a big exhibition in the local gallery.

During this time the girls had left home and so we did B&B. I joined the Bala Tourism Association and I was asked to be the chair of the tourism board association for the town. I threw myself in to the role, along with a team of good people and we did a lot for the area. I did this for 6 years before it burnt me out again.

The secretary of the tourist association had been a specialist nurse; she used to come around and ask how I was, and she had really seen how I was because there was no hiding from her, so she used to say 'Mel! This isn't good enough. You need to go back to the doctors; they are not listening. I would be having cortisone injections in my shoulders, hips and elbows. They were so horrible because they were deep and absolute agony. I also had operations on my shoulders to remove inflamed tissue and calcium deposits.

A few years went by and I was frustrated. You see all different types of people, as it was all over my body; because it was in my feet you would see a foot person, somebody with my elbow, somebody with my hips, someone else with my shoulders and nobody would talk to each other! I collected evidence from each meeting with each specialist. I would make a note on the test results, on all the salient points of the meetings, and what the outcome was - whether it was shock wave therapy, whether it was cortisone. During an appointment at the hospital, I had met this nurse, and she was going through these results and said, 'your alkaline phosphatase is really low'. I went back to the GP and turns out it had been really low for 7 years and nobody had picked it up, or thought it was important. At that point I returned to my GP armed with my evidence and he began to look into it. He referred me to a metabolic specialist. I was 52 at this point. After about a year of tests and things he diagnosed me with hypophosphatasia.

Because I had worked with people on the expert patient programme who had fibromyalgia, I always knew I didn't have that. They had good days, I never had good days, I always felt rubbish.

I had seen a rheumatologist and had asked 'is it just fibromyalgia?' and he flew off the handle at me 'what do you mean just fibromyalgia!? It is a very serious condition', which just stopped me in my tracks, and I didn't say anymore. That was about 5 years before my diagnosis. I had been diagnosed with other things: polymyalgia, rheumatica, they had put me on steroids which I couldn't tolerate. So, the diagnosis was a revelation. However, he said there was nothing we could do, so I lived like that for a few years.

I try and keep myself as healthy as I can, but my biggest worry is losing my muscle tone and strength. The pain and weakness means that I can do less and less. So, when the weather is good, I get out on my recumbent electric trike. There is less strain on my feet on the trike, walking is a nightmare these days and it is fantastic to be out in the countryside again seeing the surroundings that inspire my artwork.

With the help of Metabolic Support UK, I have been trying to raise the profile of hypophosphatasia over the years because I think there are lot more people out there with the condition who have just not been diagnosed yet. It is a very simple test to get diagnosed, so if we could get the healthcare professionals to know what the test is – it's just testing your alkaline-phosphatase – and it's very simple. If people are turning up with bone pain, and fractures and calcification, if they could just do this little test. I have started a blog, and I have written various articles for metabolic support over the years just sharing my story in the hope that I can get it out there. It's called HPP and me.

I want to improve education within healthcare, and to be honest, within the workplace.

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