

Cherry's Story

My name is Cherry. I am 46, wife of a farmer (we have our own farm) and mother of 19 year old twins - Jonathan and Melissa. Due to prematurity, Jonathan has severe Cerebral Palsy, but Melissa is fine.

As a child I was always a 'tom-boy' and I suppose I still am really. I used to go for at least an hours fast , brisk walk every day and ride my horse 3 or 4 times a week. I just love the 'outdoors' and exercise.

Unfortunately, this is not me at the moment. My problems actually began when I was 13. Between the ages of 13 – 17, I had regular periods when I was ill with dizzy spells as well as my limbs being very 'strange'. The doctors at the time just told my parents that 'it was all in the mind'.

Thankfully once I was 17, these symptoms disappeared, with only the very rare day when I was affected, so I was able to have a normal, active life that an 18 – 30 year old would have.

A few years after my twins were born, I began to have similar problems to those that I had as a teenager, so I went to my GP (different one, due to now being married and in a new area). His first words when I entered the surgery were "I have been waiting for you to come since your twins were born. No-one can cope with your situation (twins, with one having Cerebral Palsy) – you are 'depressed'." I argued with him, telling him that yes, I was obviously tired due to having twins, and with one that needed extra care, but I WAS NOT DEPRESSED. He never did believe me, so I went for several years, just struggling on.

My condition was getting worse. My son was now boarding at a specialist school weekly, so he couldn't be to blame for this. So, I decided to go and see another GP. He then referred me to a ME/CFS specialist. I knew I didn't have ME/CFS as my niece has this and my problems were very different. Yes, my limbs do get weak, but I have never suffered from tiredness like that of an ME/CFS sufferer– there is a difference. Anyway, I went and because I could tick a certain amount of boxes, I was then labelled as having ME/CFS.

I knew this wasn't a correct diagnosis, as when we took my daughter skiing for the first time, I tried to have a go. If you have been skiing then you know the difference between a snowplough which a beginner does and parallel turns that you do once you are more experienced. Well we used to go skiing when we were first married, so I know I wouldn't need to do snowploughs, so I set off, after a warm up of snowplough on the nursery slope as it had been many years since we had skied. To my horror, I couldn't turn my right leg. I could turn (parallel turn) to the right, turning my left leg, but there was absolutely NO messages going to my right leg, to make it turn.

This was not only a confirmation that I didn't have ME/CFS, but what I had felt for a long time that the messages were not being transmitted to the relevant part of the body.

A visit back to the GP then sent me to a neurologist, who after MRI etc said that he didn't know what was wrong and discharged me.

A couple of years later I was an impatient as the doctors thought I had a TIA as the whole of my right hand side had gone numb. Now I know this isn't what happened.

I was then getting worse, and for some reason, as the day progressed, my body seemed to go on strike even more. So from the age of 39 I began to be a hermit from late afternoon and the evenings.

If it helps, this is what happens: my limbs have an odd sensation – it is like they are returning from being numb from pins and needles, but it doesn't recover and neither had it gone completely numb in the first place; there is a lot of stabbing pain, but this moves around, so you never know where it is going to hit next; co-ordination is 'fun' as the messages just don't seem to want to tell my legs to move (arms are also affected by co-ordination, but not as much as the legs); I have speech problems where I can't say what I mean to say – the wrong words come out; when I am very bad, my cognitive ability goes (for example, one time I couldn't work out which loos were the ladies and even got it wrong!); messages also don't get passed from body to brain and sex is affected by this, due to lack of feeling; I often get double vision; fine motor and writing/cutting with a knife are hard to co-ordinate etc. I could go on, but these are the main problems.

A few years later I tried yet another GP, who really did listen to me, who thought I had Multiple Sclerosis. This time I was sent to a different neurologist who has said that I have **Neurological Functional Disorder** (not MS thankfully) and gave me this website. The Neurologist explained that the messages were not being transmitted or received. The scans are clear, but this was her decision after her physical examination. With both her and this website, I finally after 30 years understand what is happening.

I am doing hydro once a week, physio at home every day (bought equipment of internet). I still can't walk more than a few yards (even with crutches), so the NHS are providing a wheelchair so that I can at least get out and about. After 6 years of being a hermit, I now view having the wheelchair as being 'enabled' not 'disabled'.

I am very eager to regain a life, even if that has to be with the aid of a wheelchair. We have 3 dogs and I have an off road mobility scooter, so I can enjoy them too, and get out to town etc. I never believed that I would be saying this, but it is SO nice to get out under my own steam again 😊

I now understand what happens when my body doesn't work, which has taken a whole weight of my mind and I just have to live with it and adapt. I don't know what the future holds, but I have every confidence that it will be better than the last 10 years, with the knowledge of the condition and equipment that now have to enable this.