

Am I Getting Better? – March 2005

Frances writes about her 'M.E. journey'.

I've decided to write an article about how far I've come since getting M.E./CFS, but also how confusing it is being somewhere in between an ill and a well person.

Over three years ago I came down with what I later discovered was M.E./CFS with symptoms of fatigue, brain fog, dizziness and muscle weakness. I'd just spent a year teaching abroad and travelling after finishing school and was in my first term at University. I doubt I'll ever know for sure what the initial cause was. A bad flu virus I had in Sydney? A parasite I picked up in Nepal or India? The vaccinations? I'm sure there was a combination of factors that included my busy and achievement orientated nature, and perhaps an emotional/ psychological element.

I quickly set on the task of trying to get rid of these horrible symptoms preventing me from getting on with my life. I did lots of reading on the subject and convinced myself of different causes as the weeks went on 'it's a parasite', 'it's Candida', 'it's glandular fever'... I gradually changed my diet. I began doing relaxation tapes, practiced more meditation and started yoga.

After two years I suddenly felt considerably better and had lots of energy. I think this was a combination of my healthy lifestyle, meditation and falling in love (with another M.E. sufferer, but that's a whole different story). Gradually this diminished and then suddenly I crashed down to an incredibly low level of health - worse than I had been before. I had naively thought 'I'm cured, I'm invincible' and done far too much for someone who should have been in a long period of convalescence.

At this time I struggled to make it up the stairs never mind out the house and ended up having to drop out of University for the second time. This relapse lasted for about 2 months before I started to get much better again. I spent the next four months in a cycle of boom and bust - roughly a week feeling really quite well, and a week really very ill.

With the help of learning reiki, which I have since practiced on myself every day, I pretty much stabilised at a relatively good level of health, which is where I've been for the last 6 months. Although during that time I've had many mini relapses of just a few days, not as bad as they were by far, but still very limiting and confusing.

One moment I think how great it would be to start running and to train for a marathon, the next I'm feeling dizzy walking to make a cup of tea. One minute I think I'm cured and feel excited about getting on with my life the next I realise my health is not consistent enough.

I'm now in China! Yes, I've actually made it to China. I've come to see my mum and her partner Jez who are teaching here. I've been off on my own for a week to a

beautiful spot in China where I cycled and learnt T'ai Chi for two hours a day. I've also been to Vietnam with mum and Jez for three weeks. I've managed walking up a mountain (albeit small!), continuing T'ai Chi practice, doing some cycling and many more things. But still in between all that there's been days when leaving the hotel room has been a struggle.

I'm writing all this down because I want to somehow express how confusing it is recovering from M.E. Days of feeling wonderful and elated about how much better I am, but then times of feeling frustrated and confused when yet again the old symptoms come back.

What's it all about anyway, this M.E.? I just don't get it! It makes one have all these weird symptoms, which can be very severe, but are invisible to other people. It's difficult, if not impossible, to understand oneself what is going on never mind to explain it to others and help them understand.

My main remaining symptom, which often is only subtly there, is the brain fog. It's the way my head and the area at the back of my neck feels. It's fine when it's only subtly there, I can still express myself and get on with things. But under certain circumstances- e.g. having a virus, walking, and lots of people in a conversation - it can really come back. It kind of feels like half my brain's just stopped functioning and the back of my neck and shoulders feels numb and achy. It's like my body's present but I am not present mentally. I feel drugged. It can be very surreal and scary and distances me from others. It makes me want to escape whatever situation I am in as soon as possible and can be very upsetting.

But anyway, like I said, I am a million times better than I have been so overall I am positive I am going in the right direction. I think I am writing this down to gauge where I am with it all at the moment. To remind myself I am not there yet and am still vulnerable. Hopefully to have a resonance with other's on their own journeys through this mysterious illness.

I have to accept I haven't yet healed myself through my lifestyle, which is something I like myself and others to believe. I've managed it and I've improved energy through various natural means such as my meditation, reiki and yoga practice. Who knows how long it'll be before I can say 'I'm fully recovered', but I feel confident that day will come.

I just really hope I will soon be able to share what I have learnt through my healing process and help other's do the same. I hope I will be well enough to work in a healing context - using reiki, and the Bowen Technique that I am learning at present.

To those of you that are more ill than me I hope this article inspires some hope that you can get a lot better. I hope it doesn't sound like I'm moaning about being semi-recovered, because I'm not. I'm really happy to be where I am now. I'm also grateful in a sense to the illness for teaching me many things and for changing me so completely. I am overall so much more content, peaceful and relaxed now than I was. I feel I am living more in the present and in a much more healthy and natural way.