

Fiona's Personal Story – May 2005

Fiona, who is a student at Sheffield University, writes:

I never thought that it would be relief that swept over me when I was diagnosed with a life-altering illness – but that's exactly what happened when doctors finally decided that the cause of my energy drain was the illness known as M.E. Relief that I wasn't going slowly mad, that I wasn't subconsciously preventing myself from getting up in the morning (or afternoon or evening for that matter), relief that friends and family could stop worrying that I was being bullied at school, and relief that I could finally, possibly, set at ease all of the other factors that had contributed to my feelings of complete uselessness and self-doubt.

As a healthy, extremely sporting young teenager it came completely out of the blue when I could no longer go swimming every day or play at the Hockey match on Saturday. I had always been very active but at aged about 12 my energy simply seemed to have disappeared. To be honest, at least the following 3 years of my life is a bit of a blurr. The main feeling I remember is of complete and utter frustration. Although it felt like it all hit suddenly, looking back, it probably crept up over the space of a couple of months. I was taking more and more days off school sick and going to more and more doctors' appointments. Initially diagnosed with a cold, then flu and then told I was skipping school deliberately and was simply lazy. To add insult to injury, my local G.P. then suggested psychiatric help for depression (to be honest if this had gone on much longer I would have needed it – as would the rest of my family who had to put up with an ill-tempered, frustrated, sister/daughter). By this point my Mum had had enough. As a trained psychotherapist herself, she knew that there was something seriously wrong and it didn't involve my grey matter! It was at this point that she marched into the doctors surgery and demanded that be referred to the Hospital (now you have to bear in mind that this lady is not a woman to be reckoned with at the best of times and she had just spent the last 6 months helping me get to the toilet – not exactly an enjoyable task!). Her persuasive powers (plus the fact that my grandparents had pre-retirement actually worked as doctors at the surgery) finally managed to get me a place on a ward at the Borders General Hospital. It was a long drive and, upon arrival – guess what – I was an overnight emergency! Not only did I have such a severe case of Glandular Fever that they feared I may have Leukaemia near the brain but I also had an extreme case of pneumonia and a form of hepatitis (my mum didn't actually tell me about the Leukaemia scare until years later – I guess she figured I had enough on my plate). Now don't ask why on earth the surgery didn't spot these – I don't know and I doubt I ever will!

Two weeks later I was sent home to recover but it just didn't seem to happen. Whenever I started feeling better I would go to do something and then end up feeling even worse than I did in the first place the next day. My hospital appointments continued (primarily to continue checking for signs of

Leukaemia) and I was appointed a specialist who, spurred on by a tip given to my Mum from a family friend, diagnosed me with M.E. It's not certain as to whether the M.E. was caused by the various ailments or whether they were caused by my M.E. There has been talk of my Polio vaccination possibly being the source. To be honest, I personally didn't care – they knew what I had and now I could rest in the knowledge that I was actually ill and not making it up and could work on doing something about it. A lot easier said than done!

It took months and months of trial and error to discover that my body doesn't conform to what you would see as a normal method of recovery. Instead of doing something and then resting afterwards, I had to build up stores of energy. Kind of like charging my batteries before I used them. I don't know how many times I would start to feel better, go out – even just for a walk along the beach which was 2 minutes from the house – and then end up at square one again, not able to move from the couch. Slowly however, I started to get the hang of it. It's amazing how in tune with your body you can get when you have to. It would start by resting for a week then going out for, say an hour, and then coming back, resting for another week and so on.... Although this was super frustrating, it was working. I won't lie and say that it was some magical cure. It's very difficult finding the balance between activity and rest and I got it wrong on plenty of occasions. Over time however I found that I was able to do more and rest less. After over 6 months off school I was able to go back for half days, and then full ones and eventually I was properly back and catching up on all of the work I had missed out on. I'm very grateful that the core of the illness was then and not a few years later as I think it would have been much harder to catch up had I been sitting my Highers at the time. Clearly being a teenager with M.E. wasn't great. It meant missing out on a lot of stuff that I certainly didn't want to be missing out on. I think my maturity helped a great deal in that respect. I knew that if I wanted to do fun stuff then I had to accept the fact that I would have to be patient. I suppose, to look on the up side, when I did get to do things I enjoyed them all the more! I do feel sorry for my family though – I'm not proud to look back at the tantrums I used to have at my Mum for not letting me go out when she knew that I simply couldn't take it.

Today – well, it's been a long, hard and frustrating 9 years but I'm now on top form! I'm in my final year at University studying International Law and I just coordinated a Fashion show in aid of Comic Relief. I think I was about 17 when I realised that I was finally on top of it. I conquered the b*****d and it feels so good! Although I don't think I'll ever be rid of the M.E. I now know how to deal with it. I'd say I'm 99.9% cured. I know my body; I know what works and what doesn't. There's only been a couple of occasions where I've felt the pang of , 'oh better have a wee rest now' over the past few years (note we're not including the mornings after the nights before – hey, I'm a student!) and if that's not a leap of improvement then I don't know what is!

If I were to give advice to anyone out there with M.E. all I can say is 'hang on in there kid!'. I know it's frustrating but you can get through it. It's a case of getting to know your body and know what works for you. Unfortunately it all

involves trial and error. In the long run though it's better to fail lots and eventually get the result sought than not try at all and end up frustrated, miserable and probably stark raving bonkers!

Oh, final tip – Echinacea! It's a supplement you can now get from most Supermarkets (you lucky things, I used to have to pay a fortune to get it from posh health food shops). You can get it in tablet, liquid and even tea form (the tea's nicer if you get the one with raspberries in it too!). Basically it gives your immune system a little boost every day. It really helped me – but again, no miracles promised, you gotta see how your body feels about it!

Well, that's me so far. Hope this wasn't too long winded for you. And if you are battling with the bugger that is ME, good luck.

Disclaimer: Resting and pacing are essential strategies for people with M.E./CFS but Sheffield M.E. Group is only too aware that many of our members have not been so fortunate as Fiona. We send Fiona our best wishes and our thanks for writing this for us. Echinacea has been recommended by other members too but it shouldn't be taken continually and it's not suitable for e.g. asthmatics – read the label!