

Interview: Emily Wilcox

At 14, Emily began a slow descent into severe ME. She talks to Theresa Coe about her eight-year struggle to get her life back, and offers advice to other people with the illness.



Photo by Danny Howell, courtesy of Solo syndications and the Daily Mail

Tell us about when you first got ill.

I got glandular fever in 1991 then was abnormally fatigued for a long time. It was only four years later that I began to deteriorate dramatically and walking became a real problem. That's when I was diagnosed with CFS by Prof Findlay at the National ME Support Centre in Romford. He put me on his programme of occupational therapy (a planned rest and activity programme) and I expected to be better within 18 months.

Why do you think you got worse despite learning to pace yourself so carefully?

I think it was just the natural progression of the illness. I was doing everything right, paying attention to my diet and yet my mobility and concentration deteriorated and I soon became dependent on my wheelchair. I tried to do fun things to distract myself from what I was feeling in the hope that I would just snap out of it, but one trip to the theatre would put me in bed for three days. It just wasn't working.

Why do you think you didn't get a diagnosis sooner?

Well, funnily enough, people around me at school assumed I had CFS long before I was diagnosed. And during those early years my GP believed I was having relapses of my glandular fever. I thought I was just depressed though, because I was still doing well academically; it's just that it was taking everything out of me and I was losing my social life – all that stuff. Which was depressing.

What was the attitude of your teachers at the time?

I was under pressure at school to get As, even when I wasn't well. That seemed more important than my health. I feel resentful about that. I'm pissed off that they didn't get more clued up about the illness, that my teachers never said to me: 'Emily, your work doesn't matter. You're going to make yourself more ill if you push yourself this hard'. I did have a bed to go and lie down on in the sickroom, but looking back, I should have left school a lot earlier than I did. I do feel that if I'd been dissuaded from working so hard once I got sick, I would never have become so chronically ill.

So, you're at this really bad stage in 1996 and you finally ended up in hospital?

That's right – for five weeks. I was unable to walk and extremely ill. Light gave me migraines so I was lying in the dark all the time, without even the strength to hold a book. People had to walk me to the loo and lift me in and out of the bath. My therapist came to see me at home and realized how bad I was. She arranged for me to go into Hartswood hospital under Prof Findlay's care, but this time as an in-patient. [Ed's note: this is a BUPA CFS clinic linked to the National ME Support Centre which offers a rehabilitation programme for CFS/ME.]

How did you find it?

Oh God, I was immensely relieved to be out of my house, out of my bedroom, out of the dark. I thought the staff were terrific. At this point, I had nowhere backwards to go. I was at rock bottom. In hospital, I was helped out of bed into a chair for ten minutes a day and the curtains were opened ten minutes at a time to gradually desensitise me to light. I started to write three words a day and read for just one minute at a time; to try and get myself to the loo and back. Just tiny things but I was getting back some independence.

So did you make friends in the hospital?

No – that's the bizarre thing. You know, I never left the room. I had zero energy so it was enough to have the nurses bustling in and out. I was kind of hibernating and daydreaming or sleeping. Eventually I came home and my recovery since then has been painfully slow. Prof. Findlay expected my body's own healing mechanism to 'kick in' so I would start getting better, but that didn't happen. It was just a case of gradually going on with the occupational therapy (OT) and trying to slowly increase what I could do.

And you've also found the Alexander Technique helpful?

Yes. It's even gentler than yoga. It's about finding your body's natural posture and balance. As I'd totally lost my mobility, I needed to relearn how to stand, how to walk, how to climb steps. I also felt very negative about my body, very betrayed. To do gentle exercises that encouraged a sense of well-being within myself was excellent. I started by lying on floor and having my arms and legs moved by the therapist to open up my joints and relax the muscles, so it was entirely passive. The most strenuous thing I did for the first six months was stand up and sit down on my own.

Did you try any other therapies?

Aromatherapy and reflexology were both lovely as a form of touch, but I can't say they made any difference to my physical energy. I tried nutritional supplements but couldn't see any difference so I don't bother anymore. I have kept an eye on my diet though.

Did your friends stand by you when you were at your worst?

The girls did, but the blokes I'd known had all bugged off. For about three years I just followed the rest and activity [OT] programme at home. I was very very lonely though because my friends had all gone off to uni and I was too ill to go out. The drill was that a friend would

come and sit with me for an hour a week. We couldn't watch a video together – I didn't have the energy. I would just lie on the sofa, they'd sit with me and we'd talk.

I've also had penpals with ME, but I wasn't really interested in having friendships based on the fact that I had ME. I don't want to base my life around the illness. I hate it so much that I want to be around people who don't know or care about it.



Emily in her wheelchair days with mum Esther Rantzen and other young people with ME, Luke and Sarah

I know that you then hit a real low two years ago.

Well not exactly. What happened was that in the three years since my diagnosis, I'd improved enough to try and go back to sixth form college. My cognitive function was better but I was still in a wheelchair. I'd be driven to college for two hours and then have to sit in one place in the classroom. I loved the work, but didn't have the energy left for any kind of social contact. I thought: 'Why am I here when I'm not able to do any of the fun stuff?' That's why I got so low. It wasn't clinical depression, more a sadness at everything I was missing out on. I was in fact improving physically but it was masked by my feeling so miserable. Okay, when I read a fantastic book, I could transport myself to another place, a better place, but eventually I reacted against that and wanted to start having a life of my own, in the real world. So I got Prof. Findlay to refer me to a private psychiatric hospital, to a psychiatrist that he knows and trusts and who understands ME.

How would you advise other severely affected sufferers thinking about going into hospital?

When I was in the psychiatric ward, they were very sensitive, but then it was a private hospital and thank God I had my own room. But I always think there's a suspicion lurking in their minds that this illness might be partly psychosomatic. So I'd say you have to be incredibly careful with psychiatric wards. It's crucial that the doctor you're under understands about the physical limitations of the illness, otherwise they're going to push you too hard. I'm always terrified of hearing: 'It's your fault.' If someone tells me, 'Well, I think you're worse today because you're in a state emotionally,' that really upsets me.

What would you say to people who suggested that your illness was psychosomatic, given that you've benefited from time spent in a psychiatric ward?

I'd say – 'Try living with it. Try not being able to get out of a chair.' I used to throw crockery about because I was so furious at not being able to get up and walk. I was incredibly frustrated and just longed to move about – to go to the pub like anyone else. I want to be clear about this: it wasn't the psychiatric hospital itself that helped me to turn a corner; it was meeting new friends there and finding other people to talk to. For the first time in years I could chat about what I'd been through. I did art and drama therapy and realised again what a sociable person I am.

'I was lonely because my friends had all gone off to uni and I was too ill to go out.'

So you rethought everything in hospital?

I had a really good doctor, who listened to me and thought about my life. It became clear to me that I didn't want to go back home, to that house where I'd been so ill and so lonely. Don't get me wrong – my parents have been fantastic, but I needed to get my independence. It was devastating for my whole family to see me so ill. We did have family therapy and Mum and Dad got very upset. They had been protecting me from how they felt. In a way it was a relief for me to see them allowing themselves to let it out and have a good cry. When I left the hospital I moved into a YMCA hostel and did some courses. It wasn't great and when I realised I wanted to go to secretarial college, I found a better hostel in Kensington, where I now live.

Wasn't it scary to be without the support of your family around you?

No, I was euphoric! I would say living in a hostel for me has been a big help – although since my dad died I'm coming home at the weekends to be with my mum. I'm right near the college – I couldn't go if it meant commuting. There's also a canteen, so I get two meals provided a day, and there's a laundry room there. I've got my own room which is important 'cause I'm sleeping so much now I'm at college. There are always people around so I'm not lonely. That said, I couldn't have made the leap from being so well cared for at home straight out into the world, so going into the hospital first helped me make the break.

What advice would you give, having come through such a bad phase, to others who are stuck there still?

Do as many things you enjoy as possible (without overdoing it!). Don't waste energy with anything you feel you 'ought' to do. Also, reach out to people and try and get them into your home: friends, siblings, anyone – just so you've got company.

Things are looking a lot better for you now aren't they?

Yes – I'm about 75% better, I think. I've just spent four weeks studying in France. I still rely on medication to help me sleep – I take trimipramine [a sedating antidepressant]. On college days I'm asleep by 8pm – and it's quite a struggle to get downstairs to eat at 6pm. It's still difficult to move at all when I get very tired and a sore throat and headache are my warning signs to rest. But at least I'm now getting some social life at the weekends and I've made heaps of friends.

Do you have any fears for the future?

I'm scared of never getting completely better, of never being able to do a normal nine to five day and then go out in the evening. I'm scared of the prospect of having to sacrifice either working or social life – to have to choose between them.