

Clare's M.E. Journey – August 2006

My name is Clare, I am 27 years old and I have suffered from M.E. for 2 1/2 years.

I originally became ill following a virus which left me feeling very unwell and drained of energy. After six months and many visits to my GP, I was diagnosed with M.E. My health steadily declined over a period of about a year, to a point where I was completely bed-bound, too weak to sit up, unable to talk or be spoken to. I couldn't feed myself or attend to even my most basic needs alone. I was in this sorry state for around 10 months before things began to turn around. I now have a level of wellbeing that allows me to study with the Open University for eight hours per week, volunteer with the Sheffield M.E. Group and even enjoy a very modest social life! What follows are details about all the things that have helped me in this journey. I was fortunate in that I have been under the care of an excellent healthcare professional. Most of the rest of this article is based on information given to me by her and by the Sheffield M.E. Group.

Throughout my illness, a close friend of mine was the source of my strength and determination to once again lead a healthy and normal life. I also believe that the key to managing (and hopefully the eventual recovery from) my M.E. seems to be to have looked after myself in the best possible way. The accumulation of many small changes seems to have enabled my body to repair, even if an immediate effect was not seen. Also, I found that it was necessary to accept my situation and capabilities before I was able to move forward. Although the information that follows may help you, each person should find what works for them. Remember: never give up!

As my health declined, I found myself becoming afraid to do things that I struggled with or to try new things. I suppose that was completely understandable after having bad experiences with some activities; however, I found myself in a position where I was unable to do things because of deconditioning, and not necessarily due to tiredness alone. The less I did, the less I felt able to do. I don't think for a moment that pushing myself was the solution as this can be equally dangerous. Looking back, I think the key would have been to find a balance whereby I did an activity only once a week or once a month if that was all I could manage; but at least I would have been keeping my muscles in a condition that would allow me to do it! For example, I once collapsed while trying to walk to the bathroom. Instead of trying again the next day, I was too frightened and after a while, I found myself in a position where I was completely unable to walk. If only I had taken just a few steps I might not have had to completely learn how to walk again (a very strange experience!). Just because you have had a bad experience doing something once, does not mean that it will happen again. If you don't try, you'll never know

Pacing

I believe that pacing has played an important part in the improvement of my health. For me, the key to this is to find a baseline of activity that is achievable on both a good and a bad day. This strategy brings security in that I know that I

should be able to sustain that level of activity. I also alternate between mental and physical activity (no-matter how small) with regular rest breaks. Rest means quality rest; not watching TV etc!

Energy-saving equipment has proven to be useful, if a little 'untrendy'!

In order to maintain my sanity and motivation, I try to celebrate what I *have* managed to do, rather than what I cannot. It sounds silly I know, but I congratulate myself the end of each day for all the tasks I have done, no matter how small. Keeping positive about my situation has really helped, no-matter how depressed I have been at times.

Diet and Chemicals

Bottled spring water is best (it contains the fewest impurities which can hamper in the recovery of M.E.), however it may be substituted with filtered water, and tap water will do if the other two are not a possibility. I have been advised to opt for organic wheat and carrots since the 'inorganic' ones absorb greater levels of pesticides from the ground than all other crops. Again, this can affect M.E. by leading to a build-up of toxins. Generally, I eat a well-balanced diet, avoiding processed foods as they often contain flavourings, preservatives, high levels of salt etc. I have cut out most of the sugar in my diet; although it provides an instant 'hit' of energy, I experience a trough afterwards. Instead, I opt for slow-release energy in the form of carbohydrates. I try to avoid caffeine and alcohol as they are diuretic substances which inhibit the absorption of nutrients (from food), which are crucial if the body is to repair itself. Decaffeinated tea and coffee are apparently no better due to the unpleasant chemicals used to strip the caffeine away. Manuka honey has been shown to have healing properties when eaten in its natural state (do not heat it as the beneficial effects will be lost), plus it tastes wonderful!

I eliminated potentially harmful chemicals (harmful in terms of M.E.!) from my surroundings and from products that I use and food that I eat.

Supplements and Symptom Control

I was advised to take a range of tablets and supplements for symptom control and to aid the body to heal, including Prime Directive, a Biocare multivitamin and mineral, L-Glutamine, Ginko Biloba and Amitriptyline.

I used foam or wax earplugs and ear defenders (available from DIY shops) to help block out loud noises. I had great difficulty chewing food, so I was prescribed an energy drink called Fortisip.

During all of the time I was housebound, I didn't think I would ever get to meet other members of the M.E. Group. Now that I have, I have discovered that they are all wonderfully friendly and welcoming people. Most of all, I take comfort in the fact that there are people who understand and are willing to listen. We are not alone!