

Journey through the fog

Clare Elderkin shares the strategies she has found helpful on her way to recovery from severe M.E.

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 extremely sensitive to noise, smell and different foods and began receiving daily care through the Direct Payments Scheme. I was in this sorry state for around 10 months.

Arch nemesis

At my worst, my arch nemesis was worrying about what might happen. For example, would trying something new cause a relapse? This was a particular a problem when I spent all those months in bed with nothing to occupy my brain. Now I can see that all that worrying was using precious energy and probably was the cause of my perpetual state of ill-health. At that time, all day-to-day problems were taken out of my hands as I was far too ill to contemplate taking part in the running of my life. Since I have been able to do more, I have tried to think of strategies to prevent the worry. For example, writing things down that I need to do takes the weight off my mind, especially since a goldfish rivals my current memory capacity! Generally, there seems to be little point in using energy to worry, as it will not solve any problem you may have. Why not use that energy to devise a plan to deal with the problem instead?

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. 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 completely unable to walk. If only I had taken just a few steps I might not have had to 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.

Rest means quality rest

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; that way I know how much energy I have used. 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!

I attempt to do roughly the same each day, using a routine if necessary. This helps me to avoid the harmful 'boom and bust cycle' since I have a better idea of how much energy I have used. Also, by not using all of my available energy, I believe that my body



will be able to use the extra energy to help heal itself. I regularly experiment with trying different things, but I only change one thing at once in case I do have an adverse reaction. I am then able to gauge the level at which I should try next time. Sometimes, however, I seem to have a bad day for no apparent reason; I am assured that this is completely normal!

I used to keep a diary of what I did each day, but now my health is a little more stable, I make entries when something different to my daily routine happens. I find this useful because I am able to look back and see what progress I have made (sometimes more than I anticipated!). It is so easy to forget what I did in the not so distant past. On those times when I have done too much, I have used the diary to identify events that trigger my symptoms. However, a small increase in symptoms seems to be normal after doing a little bit more than I had previously. The discomfort usually subsides after a relatively short period of time while my body is adjusting. If it doesn't, I question whether I am doing a little too much.

Energy-saving equipment has proven to be useful, if a little 'untrendy'. When I was bed-bound I had to use a commode as I found that even being 'wheeled' to the bathroom in a wheelchair was too exhausting. Since I was unable to get to the shower, my

carer washed my hair using a purposefully made blow-up 'sink' that is intended to enable someone to wash your hair for you while lying in bed. When I started to try to leave the house, my carer would push me in the wheelchair, which allowed me to go out for much longer than I would have without it. I also used the wheelchair around the house.

Hardly 'cool' but helpful

While I was learning to walk, I used a walking frame (an item which no woman in her 20s should be seen without!). After that, I progressed onto crutches and now I am able to walk unaided.

Other items that have helped me include a stool in the shower, a perching stool next to the kitchen worktops and an indoor trolley that I used to 'carry' things from room to room. There are many other wonderful gadgets also available from mobility shops and the NHS.

When I was in bed, I was very sensitive to noise, so I used foam or wax earplugs and ear defenders (available from DIY shops) to help block-out loud noises. Also at that time, I had great difficulty chewing food, so I was prescribed an energy drink called Fortisip. At slightly better times, I ate soft foods (mashed potato, soup etc), or pureed food in a food processor.

I made sure that I kept moving around in bed as much as possible to help to prevent my muscles from deteriorating too much. Also, I found that the pain was worse if I lay still for long periods of time.

After several months in bed I began to develop painful pressure points (which if left untreated, may have developed into bedsores). I was seen by a specialist nurse who issued me with what I could only describe as a blow-up lilo (the sort of thing you might take to the beach). It did the trick; my pressure points did not get any worse. Also, to my great amusement, I pretended that I really was on the beach!

Since I was unable to watch television or listen to music, I discovered several strategies to occupy my mind and act as a pleasant distraction. I immersed myself in a visualisation; for example, in my mind I created a beautiful garden. It began quite simple but ended up being

very detailed. I imagined which plants might be planted in what place and even pretended to smell the scents of the flowers. If you don't like gardening, why not design a house in your mind, or even pretend you are on a beach (back to the lilo again!). I often played the 'alphabet game'. This involves picking a subject area; food for example, and starting at the letter 'a', thinking of an item starting with each letter of the alphabet. Talking books are also a brilliant source of entertainment.

The subtlest change to my surroundings gave me something different and positive to concentrate on. For example, putting some fresh flowers next to my bed or burning some essential oils to create a different atmosphere (perhaps to help in a visualisation). Personally, I loved listening to a CD of the waves crashing on a beach. There are many more available, including birdsong, dolphins and thunder.

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 at 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.

Moving forward

At my worst, I felt that M.E. was taking over my life and that there was nothing beyond it. I found that friends no longer bothered to see me or took the time to understand. The only way I managed to cope with this was the realisation that they did not do this on purpose, but that they lead busy lives and do not understand the impact of serious illness.

After about 10 months, things started began to turn around. I started to notice tiny improvements, which have now added-up to 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!

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. She was seriously ill with M.E. for five years and

has now completely recovered and is studying for a PhD. I believe that if she can return to good health, I can too. Although I still have a considerable way to go, I am making slow but steady progress. My ultimate dream is to return to work one day and be able to enjoy the finer points of life like going on holiday and having some fun!

I believe that the key to managing (and hopefully my eventual recovery from) M.E. is looking after myself in the best possible way. The accumulation of many small changes seem to have enabled my body to repair, even if an immediate effect is not seen. Also, I found that it was necessary to accept my situation and capabilities before I was able to move forward.

I have tried not to lose sight of the fact that recovery is possible and that I will make new friends that do understand. I am forever grateful to my family as their love and support saw me through some of the toughest parts of this journey. I look forward to sharing experiences with them that during my darkest hours I thought would be forever beyond my abilities. During all of the time I was housebound, I didn't think I would ever get to meet other members of Action for M.E. or my local 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!

About the author

Clare lives with her unusual pets (a snake and a spider) in a flat in Sheffield. She is currently studying Computing through the Open University and hopes to become a committee member of her local M.E. group later this year.

