

Stockport

A Letter in support of an incremental approach to exercise and activity, in the recovery and treatment of C.F.S.

Background.

In the early part of 1994, I developed Bronchitis and was off work for four days. This absence was an unusual event for me, as I rarely took time off through sickness. I was prescribed antibiotics, which were very effective in clearing up the bronchitis.

My work load lightened a little in the summer of that year and although I felt quite tired, I found myself looking forward to our summer holidays.

When we arrived in North Wales for our August holiday, I remember feeling extremely tired and run down. I thought that this was due to the fresh sea air. As I was sleeping a lot, I had no cause to be concerned. However, as the holiday progressed and the children became more energetic, I found myself unable to keep up with them. On one occasion, after a walk around the castle walls at Conway, I remember feeling totally exhausted. I made a mental note to try and get fitter after the holiday.

Escalation of symptoms.

After the holidays I returned to work, but I did not feel refreshed and recharged; indeed quite the opposite! It seemed that rather than being beneficial, my holiday had drained my energy reserves and left me alarmingly short of stamina. I remember finding it a real struggle to get through the working day.

Although it may appear foolish now, at the time I did not perceive that there was anything wrong with me, just that I was simply unfit and in need of a bit more exercise! Things gradually got worse. I remember feeling as if I had 'flu', with muscle aches and pains but without the associated high temperature. Events finally came to a head one evening, after I had been swimming. Normally a swim boosted my energy levels. On this occasion, it resulted in the opposite effect. I felt absolutely worn-out and extremely fatigued. For the first time I suspected I needed medical attention.

Words cannot describe how ill I felt after this visit to the swimming baths, I had chest pains and muscle aches in unusual places and an overwhelming feeling of exhaustion.

I was unable to work the following day, yet I still thought that a few days off would cure this latest incapacity. This time I was very wrong. The G.P. suggested that I take more exercise in the form of walking, get out of the house more and get back to work as quickly as possible!

Being an obliging sort of individual, this is what I did. Four weeks later and feeling terrible, I returned to work. I managed two whole days but I felt so ill that on the third day, I was sent home from work.

Any exercise or activity that I did to try to do, resulted in a 'kick-back' a day or so later. I then had to rest to recover from what my body had experienced, which felt like ten rounds with Joe Bugner! Although some days I felt really tired and useless, I rarely went back to bed. Instead I tried to keep moving. This was very difficult on some days because I felt so drained and fatigued.

Motorway driving also had an unusual delayed effect. I always felt quite capable of driving at the time but there was always a price to pay for this wanton energy expenditure. It took me a long time to recognise that mental activity also triggered the dreaded 'kick-back'.

It is now well known that C.F.S. incapacitates in different ways and at different severity levels. For this reason I do not think it is helpful for others' if I catalogue all of my symptoms and complaints. Suffice it to say that if you have it, you certainly know you have it!

The Road to Recovery.

In January 1995 I was at my lowest point. I had made all the usual New Years Resolutions about getting fit, getting back to work etc. but I honestly had no idea how I was going to achieve this. I had some more blood tests and my G.P. signed a sick note for three months. I was going nowhere.

Then, I was introduced to Pauline Powell, in the Department of Medicine, at The University of Liverpool.

Pauline advised me to get an exercise bike, which I used initially for 10 seconds, twice a day, as instructed. I felt such a wimp! When Men get C.F.S. 'macho' elements surface and pride and ego take quite a battering.

Pauline also suggested that I keep a Log / Diary to chart my progress. This was literally, "painfully slow" at the beginning of the exercise programme.

By the end of February, I was up to 1 minute 20 seconds, twice a day and although I had many other problems associated with the illness I felt as if I was able to progress still further by gradually increasing my time on the exercise bike.

By the end of March, I was up to 3 minutes 45 seconds, twice each day and on Saturday April 8th I reached the 10 minute barrier. I felt like Roger Bannister! This was still at only 20 m.p.h. and with no tension on the machine.

In order to correct any wrong impressions, I must say that this regime was not at all easy to adhere to. There were days when it was very difficult indeed to get on the bike. And as all C.F.S. sufferers know by experience, there were many other background problems associated with my condition, which mitigated against regular exercise.

Progress accelerated during April. During this period I dispensed with the twice a day routine, favouring just one session, which I undertook in the morning. I also used relaxation tapes, which I found offered effective relief against my muscle pains and other personal problems. By the end of April I had reached 27 minutes and I felt fitter, physically, than I had done for quite a while. Of course, I had to reach 30 minutes and this was reached in May. By this time I was recovering from some of the other attendant problems of C.F.S. and was negotiating to go back to work on a part-time basis.

My log book entries became more sketchy in May, but I do recall that the exercise bike mileometer, showed a total of 500 miles before I went back to work.

My first day back at work was quite eventful. A familiar story repeated itself; I was fine at work with all the re-introductions and well wishes of friends and colleagues, after such a long time off work. The next day however, resulted in a very large "kick back". I felt quite depleted of energy and many negative thoughts surfaced about whether I would actually work again etc. Fortunately, I had negotiated with my employer to carry out some duties at home and so I was able to rest in between periods of work. This setback was only temporary and I worked part time for several weeks. By the time August arrived, I was able to work to full time.

Epilogue.

It is now over 2 years since I returned to work. There have been setbacks, but these have only been temporary. I believe that I am 100% fully recovered. My life is completely normal and I have a full-time demanding job which involves two and a half hours of Motorway driving each day. My life is much the same as it was before C.F.S. with the one exception that I no longer work 14 hour days! I take exercise, swim whenever I can and live as I did before.

My symptoms may not have been as severe as some with C.F.S. but my illness required almost 8 months off work. All I can say from my own experience is that without a focus in the treatment of this illness, recovery is likely to be a long term event. I really believe that a graded exercise plan is the way to recover from C.F.S. An exercise bike is ideal because it offers a lot of advantages over other means of exercise. The chief advantage is that progress does not depend on external events or anyone else; it puts the user in total control. It can also be used at any time of day and whatever the weather. Keeping a log might seem a waste of time but in my case it helped me to realise that I really was making progress.

It is possible to recover fully from C.F.S. if a graded exercise programme is undertaken. From experience I know that this can be very difficult to follow, particularly at the start, when progress is barely measurable. The dividend for me was that I got my life back.

I do hope that current research into C.F.S. results in a wider understanding and tolerance of this debilitating illness.

John M.

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