

Charmaine's story

Whilst it is still not wholly clear why I suddenly began experiencing symptoms of FMD, your site has enabled me to reflect on my lifestyle and experiences to try and understand this better. A process of tuning in to my body I believe has also enabled me to manage my symptoms to a fairly good degree.

On paper, it may seem easy to attribute my having FMD to experiences of traumatic events in early adolescence, being a single mother to two children, having what would be considered a stressful job in child protection, and being driven and ambitious by nature.

Whilst I personally feel that I have always managed stress and difficult events well, and would consider myself quite a resilient person, in that I have sought support from appropriate sources when necessary, being an open individual, and maintained physical fitness through regular exercise, I now realise on reflection, that the pace of my life and demands placed on myself may have been a contributory factor in becoming unwell. My life has constantly revolved around activity whether it be in respect of work, family life or leisure (my idea of relaxation has been to run or attend gym classes). Rest and relaxation in its truest form has not really been a feature of my life for many years. Sleeping problems have also been a feature - I find it difficult to shut my brain down, constantly processing information. When I complete one task or challenge, I take on another. Whilst I have felt significant periods of fatigue and stomach problems over the years, I have not taken the time to properly rest and recuperate.

Since becoming so unwell I have had no option but to rest. This has not come easy, and felt almost unnatural to me. However, as I have learned to tune in to my body, I have realised the importance of it in the healing process.

Whilst I realise that everyone experiencing FMD will be different, I recognise that too much physical exertion is one of the triggers to me becoming unwell. When I was initially discharged from hospital I found even cleaning the house a chore. For someone so physically fit this was difficult to accept. I have gradually built up my stamina over the past number of months through regular gentle walking, but am still not able to run or return to gym classes. If I exert myself I first notice that I get a weakness and general feeling of being unwell. I then get an internal feeling throughout my body, almost like an electrical charge. In the early stages my speech would become slurred and I would black out, have a seizure and aggressive convulsions. Over time I have learned to sit or lay down when I get this feeling. I concentrate on my breathing and try to relax by blocking my mind from everything else going on around me. I believe that this strategy has been effective, in combination with the medication I am taking. Whilst I tend to get after feelings of nausea, I have not had a seizure or black out since the beginning of January, the intensity of the convulsions has decreased and spasms last a shorter period of time. My speech is no longer affected, and because the severity and duration of the convulsions / spasms has decreased, I find that I am no longer really feeling fatigued following an episode.

Sleep has become important. Whereas I would have been lucky to get 5 hours unbroken sleep previously a night, I now make a conscious effort to get at least ten. My brain has begun to shut down and I have little difficulty switching off for the night.

I have found the facial and body spasms and contortions one of the most embarrassing aspects of this illness. Whilst I have understanding family and friends who give reassurance and support when this happens, it is more difficult to deal with when it occurs in public. I do query whether anxiety about this results in the spasms worsening as they occur. But again, sitting down and resting, and concentrating on breathing seems to reduce the duration of this. Clasp my hands together or attempting to fold my arms also seems to reduce the effect of the shakes in my hands.

In comparison to the beginning of me being unwell, I have made tremendous progress. I have been symptom free for periods of up to two weeks. The intensity and duration of my symptoms has decreased significantly, and my consciousness and cognition no longer seems to be impaired in any way.

I hope that the small things I have done may be of use to others, and hope that I can learn from others