Surviving ME/CFS by Russell Fleming

the ME association

Last year I was invited by the Cabinet Office Disability Unit to write about my experiences with ME/CFS. Unfortunately, because of the pandemic, it wasn't published. But we featured it in ME Essential – the member's magazine – last Christmas.

We are often asked to share stories from people that have improved and that offer realistic hope. From the reception my story received, I think it struck a chord with members and I hope it will with you too.

It took a long time for me to see any meaningful improvement that could be sustained. Everything I do now is relative to how I was before and I am always conscious of the possibility that I could relapse. Being able to work full-time from home, even with a lot of support around me, was a dream I never thought could be achieved – let alone maintained.

But I'm in my 5th year of employment with the ME Association – having started with some volunteering and then project work part-time – and despite the expected set-backs that affect my working ability at times, I am very pleased with the progress I have made.

Of course, if I had written my story 10 or 20 years ago it would have been quite different. But I hope my perspective now is as helpful as it would have been then.

If you do have a story you'd like to share, then please get in touch: Feedback@meassociation.org.uk. We are very happy to consider contributions and will maintain anonymity if you request it. Photographs are welcome but not always necessary, and your story could be featured in ME Essential and/or ME Medical magazine, and on this website blog.

Take good care

Russell

My name is Russell Fleming. I am 52 years old and recently began working full-time from home on a flexible basis as Communications Manager for the ME Association (MEA). I had previously volunteered for the charity and then worked part-time after being involved with them for over ten years.

The MEA is a relatively small medical charity but one that always manages to punch above its weight, providing information and vital support to people with myalgic encephalomyelitis (ME/CFS) in the UK. It also campaigns, conducts medical education initiatives, and invests in biomedical research.

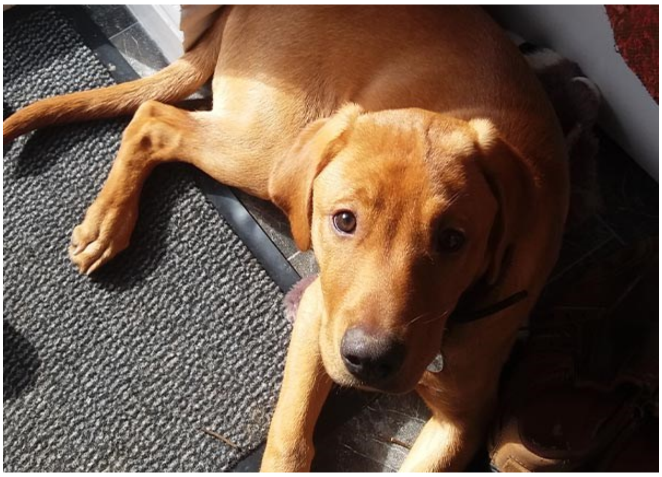
IMPROVEMENTS

I am in a fortunate position despite it taking me so long to reach this point. I have finally been able to accept, adapt, and accommodate ME/CFS, but it took 22 years, a lot of heartache, and many false-dawns, before my symptoms began to stabilise and then slowly improve and I could once again feel more confident in my abilities.

Last year I moved into my first real home (albeit a rented one) and have benefitted greatly from having a garden. The lift to my spirits has been both welcome and unexpected. I had always wanted to own a dog and be able to care for him myself. It's still a work in progress, but 'Buster' is proving to be a good companion and has made me realise just how alone I had become. He is now four months old and has brought a lot of joy back into my life.

In terms of symptoms, it is my cognitive function that has improved the most. I have learned to use prompts, reminders, and alarms to aid memory. I still can't read for long and I have to limit the time spent on certain tasks – like when and how I attend virtual meetings – but for the most part I have learnt to manage it well and it is this improvement that has allowed a return to work.

I find that listening and remaining focused to still be challenging and I take more time to write well, spell correctly, or to speak clearly, but working online for the most part and using a computer is helpful.



RESTRICTIONS

I am still restricted in what I can accomplish, how long I can work without a rest, and the kind of work I can do, but I feel very lucky to have gotten this far and to have an employer who understands.

Mobility remains a problem and I can't walk very far or climb the stairs without support. Taking a shower or washing my hair is a challenge and I average a shower a fortnight, relying on 'bed-bath wipes' (which can be heated in a microwave) for bodywashes in between.

I still experience disturbed sleep with night-terrors, vivid dreams, fevered sweats, and I wake feeling unrefreshed – usually after only a few hours. I went through a particularly bad few years more recently when I was frequently urinating while asleep – that led to a big increase in laundry – and while this is a part of my life now, it has also improved.

I need to rest and sleep several times a day when the exhaustion or other symptoms become too much. I tend to start work early in the morning, when sleep has evaded me, and if my head is clear, then finish before lunchtime or when I can't do anymore.

Pain is widespread and constant particularly in my muscles and head. I am easily exhausted and fatigue is ever present. I can't regulate temperature properly and feel very hot or very cold particularly in the arms and legs. It has always felt like I have the Flu but without a runny-nose and I find myself having to judge if, when, and how I can do things with the limited amount of energy available.

MENTAL HEALTH

After about 10 years, there were improvements in other symptoms. The vertigo, dizziness, palpitations, nausea, diarrhoea, and poor appetite stabilised. I still can't do many household chores for myself and am unable to engage fully in social activities or go on holiday, but I have a very good support system now in place.

I had a lot of problems with mental health – depression, suicidal thoughts, attempted suicide, anxiety, panic attacks, feelings of low self-worth and inadequacy. But these improved as my physical abilities improved. I still have issues but I am coping a lot better.

There will always be the spectre of relapse hanging over me, but I know what to do if things get worse for me again. I choose to work because it gives me purpose and is rewarding. It can be very demanding, but without support I wouldn't be able to accomplish what I can or be able to help others with ME/CFS and the families who care for them.

I choose to put my energy into my work and I depend on others to help me around the house with cooking, cleaning, laundry, taking me to appointments and walking Buster when I cannot. I can only look back in this way because I have reached a position of relative stability and improvement. Many people with ME/CFS do not.

In the last two decades I have struggled a great deal, not only with crushing physical limitations, but with the mental anguish of loss, of guilt, and the frustration of having a diagnosis that has been unfairly stigmatised and for which there is no effective treatment – let alone a cure.

HOW IT ALL BEGAN

Like many, my story began with an acute viral infection. I was 30 years old and living in Jersey – having been transferred from the UK several years before. I worked for Lloyds Private Banking and was recruited from college. I was an investment manager and independent financial adviser but had also enjoyed several other roles including in marketing where I led a team on the Bank's merger with TSB.

I loved my career and was on the fast-track. I had a lot of friends, a good social life, and was physically very active. My life was a good balance and my mental health was excellent. My dreams were to continue with my travels abroad and to settle down and start a family. I believed I had a bright future.

I was conditioned to believe that viruses can be fought, that recovery might take a couple of weeks at most, but that I would always return to full-health. Chronic illness was never on my radar. I had had glandular fever at the age of 21, which meant three weeks off work, and had experienced full-blown Flu. I was sick a lot as a child. But each time I would bounce back – full of energy – to carry on with life without looking back.

In 1999 I went on holiday with friends, picked up an infection, brought it back home, spent time in hospital, and felt like I had been poleaxed. The suddenness with which my life changed and the extent to which the illness left me physically impaired, hit my mental health especially hard.

A year later and my functional ability had not improved, I hadn't been able to return to work, and the diagnosis of a post-viral fatigue syndrome (PVFS) had become myalgic encephalomyelitis (ME/ CFS).

I was traumatised. I was terribly ill and for long periods of time I couldn't leave my bed. I didn't know what was happening; I was confused, distressed, and had lost a lot of weight. It often felt like I was dying. My family didn't know how to care for me and we received very little help from the NHS.

Even when my ability to cope was at its worst and my family felt out of its depth, there was nobody around to provide practical assistance or to tell us that I might have been eligible for welfare support or care from social services.

STRUGGLING

Symptom relieving drugs and antidepressants to help with pain, sleep, and mood had to be introduced slowly because they either had no effect or I was sensitive to them and the side effects.

It took a long time to find something that seemed to help even if it only did for a limited time. But such drugs only ever 'took the edge off' and did nothing to resolve the underlying disease process that I believe was causing most of the functional impairment.

Dealing with loss was incredibly hard. More so because I had a diagnosis that was still questioned. We also found it hard to get mental health support from the NHS but reached out to various counsellors and psychologists over the years because I had deteriorated so much.

At no time was it suggested that my mental health or attitude was causing or perpetuating ME/CFS. Unfortunately, this isn't true for everyone. I had good and bad experiences with therapists but on the whole and when I was able, it was good to talk and get things off my chest with a professional.

When I was physically at my worst, so was my mental health; and I have found the reverse to be true as well. The possibility of becoming disabled was not something I had ever considered – who does? The shock of it was profound. My body no longer produced sufficient energy to allow me to function normally. I came to rely on others for my basic needs. It was degrading, and there was a lot of guilt and shame.

I didn't know who I was anymore or what my purpose was in life. I often prayed for a different diagnosis – one that was more accepted and visible. If I had been diagnosed with multiple sclerosis for example, I think I would have coped better. I might have received more acceptance from friends, work colleagues, and certain healthcare professionals. The doubt about ME/CFS only served to make my ability to cope that much harder.

Because of ME/CFS:

- I lost my career – but received an early pension on the grounds of ill-health.
- I lost my fiancé – who stuck with me as long as she could but couldn't handle my deteriorating ability to cope (I didn't blame her).
- I attempted suicide.
- I spent a fortune chasing bogus treatments.
- I got into debt when my income dried up and had to go bankrupt.
- I returned to education as a disabled student but suffered several relapses and couldn't complete my degree.
- I made various attempts to return to work in jobs I thought I could reasonably manage but couldn't.
- I became reliant on welfare benefits to survive.

I had to give up my dreams of marriage, children, and owning my own home...

MANAGEMENT

MYALGIC ENCEPHALOPATHY/ ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

ME/CFS affects a person's ability to function – the way they think, remember, speak, stand, walk, sleep, initiate and complete daily tasks, and generate energy. It impacts their quality of life and that of their family.

Research has suggested the effects on quality of life are worse than they are for people with multiple sclerosis, cancer, diabetes, and other serious medical conditions, although in general, there appears to be a similar impact on mental health.

It robs a person of the vitality I think we all take for granted which makes it especially hard to manage. It can occur suddenly, and the trigger for the majority of people is an infection that is often acute.

Trying to do too much will often result in an increase in symptom severity, even a relapse, that is typically delayed by 24 hours. One of the difficulties that doctors have with ME/CFS is that the 'great panacea' for other illnesses, namely exercise – especially aerobic exercise – can cause harm.

Research has supported this phenomenon and the new NICE clinical guideline is alerting doctors against recommending exercise. Hopefully, over time symptoms will stabilise – it can be months, years, or decades – and people can show signs of relative improvement, which is when new activities – or an increase in the time and/or intensity spent doing an activity – might be attempted and maintained. Sometimes, these periods of stability might be fleeting, at others they can last longer and be built upon. Full recovery is rare and even a period of stability can prove false.

Self-management techniques such as pacing – where you learn what you can do within your limitations, what tasks you can delegate or spread out across several time periods, and where you attempt to stay within your ‘energy envelope’ – is the safest and most effective approach at this time. It isn’t an easy thing to learn. It will take time. But it is worth trying and returning to.

ME/CFS causes fluctuating symptoms, symptom severities, and functional abilities – for most it will adopt a relapsing-remitting course over many years. Symptoms can vary in intensity from hour-to-hour, day-to-day, and week-to-week etc. Relative recovery, if it occurs, is not in a straight line, there will be many ‘peaks and troughs’ along the way, and some people experience an illness that progressively gets worse or shows no sign of improvement at all. It can be quite individual and very unpredictable.

People who are very severely affected are wholly bedbound and require 24-hour care. They can’t walk or feed themselves and often can’t communicate. They can lose a lot of weight and can be extremely sensitive to light, noise, touch, and smell. They are the most neglected when they should receive the most care and support.

Around 25% of people with ME/CFS are severely affected at any one time – meaning they are confined to bed by the severity of their symptoms – and perhaps 5% are very severely affected, but there is a lack of research in this area which is shameful. Unfortunately, people have died from this condition or it has contributed to death as a result of complications and people ‘wasting away’.

If symptoms do stabilise, then a person can slowly learn to accept, adapt, and accommodate their disability. It is of course much easier said than done and can take an awfully long time, especially without good healthcare, social care, welfare, and family support.

Some people are better at acceptance and adapting than others. I resisted full acceptance for 10 years because it felt like I was giving up. I was very stubborn and didn’t want to surrender my dreams but, in the end, I realised they were holding me back.

ACCEPTANCE

Had I recovered, and I hoped I would after my time at university, then I would have returned to the Bank who had given me that option. But the relapses I experienced at university finally led to me seeing sense. My old life was over and I needed to make the best of the life I had.

Ultimately, I have been lucky, even after these two decades. If the physical symptoms hadn’t stablished and improved, if I hadn’t been able to give it time and be more certain of my abilities, I wouldn’t have been able to return to work, move into a new home, and find a new companion in Buster.

When this illness becomes chronic it may be unreasonable to think about returning to a previous life and career. But that doesn’t mean life lacks value and neither do people with ME/CFS. They are the bravest and most resilient people I have ever known and I hope they all get to experience the relative stability and improvement that I have achieved in recent years.

- Long-Term Conditions (of which ME/CFS is one example) are illnesses that cannot yet be cured but can be managed through medication and/or therapy.
- It has been estimated that over 26 million people in the UK live with a Long-Term Condition (around 40% of the population), and over 10 million live with two or more such conditions.
- People with Long Term Conditions account for over 50% of GP appointments, 64% of all outpatient appointments, and occupy 70% of hospital beds.
- Long Term Conditions represent a significant problem for the Government, NHS, and social care services. Research is lacking, and the solutions are inadequate (the above statistics are over five years old!).

ME/CFS is a neurological disease. It can affect anyone at any time of life and often becomes chronic or long-term. It is believed to be more prevalent in ethnic minority groups. Up to 75% of those affected are women. It is the biggest cause of long-term sickness absence from school. The number of people with ME/CFS has been estimated at 265,000 in the UK (0.4% of the population). It is likely that the majority remain undiagnosed or mislabelled and receive inadequate or inappropriate care and support.

A new NICE clinical guideline about ME/CFS has been published. It provides a framework of recommendations to the NHS and social care services and should lead to better understanding, support, and management options for people with the condition. It should also help increase early and accurate diagnosis. We recommend that anyone affected by ME/CFS should familiarise themselves with its content and discuss with their GP. A network of secondary care referral (outpatient) services exists across England and with the new guideline these should be improved and extended, with similar networks established for people who live in Northern Ireland, Scotland, and Wales.

The ME Association provides a large range of literature about ME/CFS (incl. Long Covid) written by Dr Charles Shepherd (Hon. Medical Adviser) and its other expert advisers. You can view all the booklets and leaflets by visiting the website shop where they can be purchased for a small fee (or are free) and downloaded. The ME Association website provides a lot of information for free and features regular blogs on relevant news and research developments, and its social media pages (e.g., Facebook) are a great place to visit and join in discussion about life with the condition.