

Returning to work with chronic fatigue syndrome

It's long, hard, and painfully slow, but it can be done, says Margery Morgan

Nearly three years on, living with chronic fatigue feels absolutely fine to me—if I didn't have to do anything. Add on living, running a house, looking after children, and trying to go back to work, and my energy stores soon run out. Life for me now is balancing limited activity with rest, in the hope of regaining a normal life.

Chronic fatigue is a syndrome of unknown aetiology, possibly caused by disordered immunity. For me it was triggered unusually by thyrotoxicosis in July 2001. The next year was spent with short bursts of activity, inevitably followed by lengthy periods of recuperation.

Getting started

By December 2002 I began to think that working again might be a possibility. With the approval of my occupational health consultant and general practitioner, I started back (unpaid) by visiting my office and loyal secretary. This was just once a week, on a Friday afternoon.

I chose the afternoon because this gave me time to recover from getting up and dressing slowly. I chose Friday because parking was easier and also fewer people seemed to be around, stopping me kindly to ask after my health (prolonged standing is quite difficult).

There were times that the whole process was too much, and I just sat in a chair in my office for a couple of hours. But, as time passed, it became easier. There were fewer "corridor inquiries," and I felt that coming back was a reality. But could I cope with patients, would it just be too exhausting, and would I let my colleagues down?

The next step

The next step was to join a kind colleague's antenatal clinic as an extra. Getting clothes ready the night before, resisting the temptation to do any housework before leaving home, and easy parking preserved valuable energy for the clinic.

There was no pressure to do anything, and if I felt exhausted, I could sit and read journals in the coffee room until the clinic finished.

I was not prepared for the sheer pleasure of being with patients again—and I had been quite close to giving all this up.

What worked for me

It took a while to realise that I was quite hypotensive in the morning. Armed with the confirmation of this from a 24 hour recording I started to work with it. The sessions I do, now increased to four independent ones, are mainly in the afternoon. Getting up slowly, support tights, a corset, and caffeine all help me feel reasonably normal in my morning clinic. I sit down whenever I can.

Small clinics with half the usual number of patients were sensible to break me in. At first I found talking remarkably tiring, and having drinking water available was essential to get through consultations in the first few months.

It really was important to ration what energy I had, so extra meetings were missed, however interesting. Much as I love teaching, medical students turning up just as the clinic started were a dilemma: my solution was to restrict them to an hour of my time and then send them off to spend the remainder talking to patients.

The next seemingly enormous step is to work a full day. This may well mean I will be resting on the floor of my office at lunchtime—with "Do not disturb" on the door.

What didn't work—"not lazy, not crazy"

There is undoubtedly scepticism about the validity of chronic fatigue among medical colleagues and friends. I'm ashamed to say that before I was ill, I shared it. I remember smiling with my anaesthetist about a young patient of mine who had told me that swimming with dolphins was the most effective of all the treatments she had tried. Thinking back, I too would try anything to have my life

Tips for people with chronic fatigue

- Pace yourself carefully, particularly when feeling well
- Resist extra commitments
- Never make long term decisions about work when unwell
- Keep an intermittent diary—record the slow improvement
- Streamline your home life
- Readjust your timescales—six months is not long

Tips for colleagues

- Be sympathetic—your colleague may look well but is probably feeling ghastly
- Try to understand the isolation of an illness with no diagnostic tests and no known cure
- Be encouraging of progress, however small

back. Antidepressants, fludrocortisone, cognitive behaviour therapy, Chinese medicine, and the rest haven't helped me.

My sympathetic occupational health consultant said with regret that the NHS was unlikely to view chronic fatigue as acceptable for retirement on ill health grounds—that certainly made me feel a fraud.

Discussions with human resources often left me feeling unappreciated, unloved, and ready to pack it all in. Maybe that was the idea. Despite this, with support from my BMA representative, and perhaps because my illness has been classed within the Disabilities and Discrimination Act, I was allowed to build up my sessions (taking on one more about every three months) and I am grateful to the trust for this.

The future

"Many people would have abandoned the struggle long ago," was a chance remark from occupational health. I initially took this as a tribute to my dogged persistence and personal motivation. On reflection, I wondered if I was being told the struggle was actually too much and should be abandoned regardless.

My thoughts do wander in this direction especially when I've become overwhelmingly tired. Progress is slow but sure. Milestones are tiny but can be reached (for example, the first time I didn't need to go back to bed after dressing in the morning or attendance at my first divisional meeting after work). So far I have not had any sick leave since returning and have progressed to running the labour ward for an afternoon a week. Returning to independent surgery will take much longer.

I heard of a headmistress with chronic fatigue who gave up the struggle, retired, recovered, and is now back as a headmistress five years later. I'm not sure medicine is so easy to return to after such a long gap so I'm hanging on for the time being.

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