

Dear Sirs,

My main issue with the current draft report is that it needs to be further stressed that physical activity leads to permanent worsened health for ME/CFS patients. I enclose my own story as an example, see below.

Best regards,  
Anonymous #8, Licensed Nurse

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### My experience with GET

For three weeks in May 2007 I was assessed by the Swedish Social Insurance Agency. During the first five days, which were all-day sessions, I had to walk two long walks to car park and back; in the mornings under time pressure as I had major difficulties getting out of bed and getting there in time.

At lunch hour we had to take another brisk walk to a restaurant, which also was a major strain for me. Weeks two and three I had to perform a "working test" by working two hours a day at a grocery store. This led to a bad, typical ME/CFS crash. Still, there was doubts as to whether I even had fibromyalgia, a diagnosis I got as early as in 1986.

In September 2007 I was sent to psychiatric physiotherapy. It started slowly with several assessments of my function and health status. After that I was supposed to exercise at a gym.

The exercise program was supposed to be customized for me. It consisted of five to ten minutes of workout on an exercise bike, followed by floor exercises and various workout machines using very light weights and a set number of repetitions. All in all it was around 45 to 60 minutes, after which I was exhausted each time.

After a few guided session with the physiotherapist I was left to my own devices, and I continued until the end of January, a total of seven times over six weeks. However, I got sick with flu symptoms and exhaustion and had to take breaks occasionally.

After that it was decided I was to join a group working according to Body Awareness Therapy; a much milder method with slow movements. I attended this group during three periods from January to September 2008. This worked out fairly well, since I could move at a pace that worked

for me, and I was very careful not to do too many repetitions.

Each session lasted one and a half hour, including optional rest between exercises. I was not able to attend each week, for which I was criticized by my physiotherapist. He didn't want to believe my accounts of flu symptoms, and that I had to sleep for two hours after each session. Also, it was hard not to keep up with the rest of the group instead of keeping my own tempo, even if this was allowed.

All in all I was forced into a long period of worsened symptoms, for which I mainly blame the gym exercising and having to get to exercise facilities under time pressure.

Still, the Social Insurance Agency demanded that I began work training. I tried for six months in 2008-2009. This, too, took its toll on me, since I had to get out of bed early and get ready for work several days each week, as well as keep appointments. The Social Insurance Agency counted the hours I spent working and exercising each week, in total ten hours a week. In addition to this were the time spent traveling to and from all the activities. I had no restful time other than during weekends.

I never managed to achieve more than ten hours per week (apart from a short period when I tried for fifteen, which backfired), and had to stay at home several times with a high temperature and pain. My health was continually deteriorating. More and more pain and respiratory infections, and in the end I only had energy for sleeping and just eating what I could find at home. I had to take medications that make me ill and would have preferred to avoid (such as cortisone spray and NSAID). After six months the experiment was aborted because I was too ill.

After this I have not again reached the level of health I had before 2008. The Swedish Social Insurance Agency and the physiotherapy made me permanently worse. I have had to quit many of my recreational activities. I strongly advice against physical exercise. Had I known more about GET (Graded Exercise Therapy) and PEM (Post-Exertional Malaise) at the time, I would surely have put up more resistance, but the physiotherapist assured me he knew what he was doing.

To summarize, my life today is much more confined and restrained than it was before these actions were forced upon me by the health care, the Social Insurance Agency, and the Public Employment Service.