

Living with ME/CFS. Challenge for scientists?

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A GRADED EXERCISE THERAPY (GET) – MYALGIC ENCEPHALOMYELITIS (ME)/CHRONIC FATIGUE SYNDROME (CFS) RUNNING ANOMALY

Imagine you have been disabled with ME/CFS's cluster of symptoms for 19 years. Yet, this morning you just ran an easy 10K with no flare up of your exercise intolerance symptoms during the run or post-exertional malaise after the run. Then later in the day you go browsing for books and after 30 minutes or so your exercise intolerance and post-exertional malaise symptoms flare up. You experience a wave of exhaustion, achy muscles and additional cognitive fog, all of which carry into the next day. To me, this is a confusing anomaly that needs an explanation.

Exercise intolerance and post-exertional malaise are among the symptom array that functionally defines ME/CFS (Fukuda *et al.* 1994). From my 1992 ME/CFS onset, I could not walk a soccer field without a wave of exhaustion and persistent calf pain hitting me within 30-minutes or so along with increased cognitive fog. Each of these symptoms continued into the next day as post-exertional malaise.

In a 2007 Internet search, I found a 2004 University of Western Australia paper called *Randomised controlled trial of graded exercise in chronic fatigue syndrome* by Professor Karen E. Wallman, AR Mortan, C Goodman, R Grove and AM Guilfoyle (Wallman *et al.* 2004). Yet, according to University of Calgary's Dr. Eleanor Stein not all GET programs use valid ME/CFS criteria. Her 2005 GET analysis says Wallman *et al.* was one of "two stud-

ies using valid diagnostic criteria and both report improved fatigue by self report (Chalder Fatigue Scale) (Wallman *et al.* 2004; Moss-Morris *et al.* 2005)" (Stein 2005). Prof. Wallman writes "most subjects (91%) rated themselves as feeling better after the exercise intervention, and no subject felt that graded exercise worsened their [ME/CFS] symptoms (Wallman *et al.* 2004)."

I assessed the study. I chose treadmill walking. I started its graded-exercise protocols for persons-with-CFS. One protocol is a health-care practitioner is to supervise participants. A second uses the Borg Scale (Borg 1982), a self-assessment of physical exertion. The 12-week program insists no one go beyond what is perceived as "somewhat hard", which is Borg Scale 13/14. I decide my exertion limit. The third protocol is the exercise is done every other day. The fourth protocol monitors heart beeps-per-minute (bpm) as a double check to safeguard one is within an exertion-comfort zone. When do I know I am beyond my exertion-comfort zone or have reached Borg 13/14? My ME/CFS *exertion threshold* is that point-in-exercising where I develop a wave of exhaustion, achy calf muscles and increased cognitive fog with these symptoms carrying into the next day.

In early 2008, I started the Wallman *et al.* program. I chose a physiotherapist as my health-care practitioner to supervise me. She was a competitive roadrunner, which added exercise-training expertise to her credentials. The study's four graded-exercise protocols guided each step. My pace was somewhat faster than a browsing pace, so I distinguish a fast-paced walk from a browsing walk. On the treadmill, at the 2-minute mark

I experienced exhaustion, heavy breathing, and achy calves. I had reached Borg 14. I stopped. For 3 weeks wherein I reached 10-treadmill minutes heavy tiredness and achy calves told me I reached Borg 14. Of note, each time it took a little longer on the treadmill to reach Borg 14. My physiotherapist, from her running experience, adapted the protocols by adding slower maintenance walks every-other session instead of every session. This meant less exertion.

Accordingly, my distance and time at Borg 14 increased somewhat every-other session rather than every session. After 3 weeks I advanced in distance and time *without* heavy exhaustion or achy calves flare up unlike the first 3 weeks at Borg 14. I can't explain that. From that point on, a gentle fatigue, so to speak, told me when I reached Borg 14. My distance and time gradually got further and longer *without* ME/CFS symptoms surfacing as long as I stopped at Borg 14. With exercising every other day, I reached a 30-minute walk at Borg 14 in 12 weeks, which was the study's goal.

I then decided to walk beyond 30 minutes. My physiotherapist oversaw the same Wallman *et al.* 4 training protocols. Over many weeks, I incrementally fast-paced walked every other day to reach and maintain 55 minutes at Borg 14 (somewhat hard). My exercise intolerance and post-exertional malaise symptoms *never surfaced* during or after these 55-minute walks. Of interest, over time I noticed at the mid-point of my every-other-day walks my bpm had dropped from 129 to 114.

In spring 2009, I jogged 77 seconds before the Borg Scale said, "Stop". In a mere 77 seconds I reached Wallman *et al.*'s exertion threshold for jogging, which is Borg 16. The limit for walking is Borg 14. In jogging, I train between Borg 14 & 16. I gradually went from 77 seconds to where I now can run over 60 minutes at Borg 16 *without* enflaming my exercise intolerance or post-exertional malaise during or after each run. My physiotherapist as a competitive runner adapts my *Training Regimes* to Wallman *et al.*'s 4 graded-exercise training protocols. With medical setbacks unrelated to ME/CFS, it took 5 years to go from a 2-minute treadmill walk to a 10K run at Borg 16. I train for six 5K and one 10K road races at Borg 16 over 10 months. As you'd expect, my Borg 14 & 16 self-perceived exertion points get further and faster over time, though a limit exists.

SEVEN FACTS AS CONTEXT FOR MY GET-ME/CFS RUNNING ANOMALY

(i) At age 69, I am now conditioned. (ii) I've lowered my Resting Heart Rate (RHR) from 71 to 54 bpm measured by a 2007 polysomnography prior to my GET program and after 4 years of running another in Dec 2013. (iii) I was legitimately diagnosed with ME/CFS in 1995, as will shortly be seen. (iv) I run 5 & 10Ks at Borg 14 & 16 *without* triggering my ME/CFS's exercise intolerance or post-exertional malaise symptoms during or after each run. (v) Borg 16 is my exertion threshold. The Borg

Scale maximum is 20. (vi) In 19 years with ME/CFS, I have never had a remission. (vii) When I'm not running, my exercise intolerance and post-exertional malaise symptoms remain as they have since my 1992 onset. That is, if I browse walk for 30 minutes or stand for 30 minutes a wave of exhaustion, achy calf muscles and more cognitive fog ignite and carry into the next day.

STATING MY GET-ME/CFS RUNNING ANOMALY

As a person-disabled-with-ME/CFS since 1995, by following the Wallman *et al.* graded-exercise training protocols under a physiotherapist's supervision since 2008, over significant time, I gradually went from a 2-minute treadmill walk to running 7K on average every other day at Borg 14 & 16 *without* triggering exercise intolerance or post-exertional malaise. Yet, on any given day since my 1995 ME/CFS diagnosis, I cannot browse walk for 30 minutes or stand for 30 minutes without a delayed wave of exhaustion, persistent calf pain and more cognitive fog surfacing that carries into the next day as post-exertional malaise. To me, this doesn't make sense.

AN OVERVIEW OF MY 1995 ME/CFS DIAGNOSIS AND SYMPTOMS

In 1995 my presenting symptoms met the *Guidelines for the Evaluation and Study of CFS, 1994 Working Case Definition for CFS* by the Centers for Disease Control, Atlanta, Georgia (Fukuda *et al.* 1994), the standard then for a ME/CFS diagnosis-by-exclusion that took me 2½ years (1992–95). During this time I suffered from my symptoms. I had to push myself to work given a diagnosis-by-exclusion takes time. In assessing my symptoms, a psychiatrist ruled out affective disorders, a sleep clinic ruled out sleep disorders, an internal medicine specialist ruled out issues in his field, and a cardiologist found no heart issues. I met more than four of Fukuda *et al.* (1) polythetic criteria. In 1995, the psychiatrist, internal medicine specialist and my family doctor diagnosed ME/CFS.

After receiving the specialists' reports, my family doctor asked me to look at his calendar and pick a date. I picked April 28, 1995. He said, "That's your last day of work." I went on a 6-month sick leave. I hoped the rest would improve my symptoms. They didn't improve in the least. Though it may not seem as clinical evidence, a real test surfaced: prove my disability claim to my insurance carrier. Persons in the ME/CFS field know how strictly insurance carriers examine disability claims. They approved my claim in 3 weeks without a question. In Canada, the insurance carrier then has the claimant apply to our federal government's Canada Pension Plan (CPP) Disability to see if one qualifies for that allowance. If approved, the insurance carrier subtracts that amount from its payment. CPP approved my disability a month ahead of schedule without a question.

Other ME/CFS definitions exist besides Fukuda *et al.* (1994). A prominent one to surface since 1994 is the *Clinical Working Case Definition of ME/CFS* of the 2003 *Canadian Consensus Document* (Carruthers *et al.* 2003). I meet its symptom checklist in addition to the 1994 Fukuda *et al.* criteria when I was diagnosed.

Regarding chronic fatigue, if my body is a 10-cylinder engine, I have operated 24/7 on one cylinder since symptom onset. With 10% of the energy of what's normal for a person my age, since day one my energy ebbs and flows along a 1-to-10 continuum. One is bed ridden; 10 is the maximum energy my ME/CFS allows. Fluctuations relate to how well I rest and pace my daily exertion output.

Cognitive fogging is a central ME/CFS symptom. A telling example is writing these pages. I could focus for about 30 minutes a day. It took me close to 12 weeks to compose and revise this letter.

Sustained anaerobic household tasks like raking leaves or heavy lifting triggers heavy breathing, sweating, additional cognitive fog, achy calf muscles and exhaustion with post-exertional malaise.

An example of browse-walking leading to exercise intolerance and post-exertional malaise is shopping. If I go into a bookstore to browse books, about half hour later my calf muscles start to ache, I get foggier, and an exhaustion wave swirls in. These symptoms persist into the next day. Cognitively processing the bookstore's multi-stimuli no doubt contributes. So, I don't browse stores. I adapt. I go in for a specific item, get it and leave. If I bend this rule, I pay a symptom tax.

When my son worked in the Silicon Valley, I wanted to sightsee. It had to involve no major walking, rest every other day in his apartment and seeing most sights from the front seat of his car.

Since my ME/CFS onset, I wake up each morning unrefreshed. Sleep restores nothing. I've onset insomnia. In 2007, a sleep study found an obstructive sleep order. Since then I use CPAP nightly.

I am sensitive to hot and cold when others are not. I have never had a remission in 19 years. All my symptoms are not cited here. If you have questions about them or ME/CFS, please email me.

TWO QUESTIONS

What physiological mechanism enables me to run on average 7K every other day following Wallman *et al.*'s 4 graded-exercise training protocols and not enflame my ME/CFS's exercise intolerance and post-exertional malaise symptoms during or after these runs *while* at anytime a browse walk for 30-minutes or standing for 30 minutes triggers my exercise intolerance and post-exertional malaise symptoms? Might this physiological mechanism point to a clue to unravel a neuroendocrinology mitochondrial aspect of ME/CFS and cradle a breakthrough?

ONE HYPOTHESIS TO EXPLAIN MY GET-ME/CFS RUNNING ANOMALY

My hypothesis is a layperson's. It speaks to mitochondrial dysfunction in persons-with-ME/CFS. Mitochondrial mechanisms produce the adenosine triphosphate (ATP) energy currency we need for tasks. I refer to Doctors Sarah Myhill and Lucy Dechéne for insights into ME/CFS's mitochondrial dysfunctioning in end-notes (Dechéne *et al.* 2014; Myhill *et al.* 2009). They indicate other researchers in the same field.

Could ME/CFS malfunctioning mitochondria impede ATP production not to energize cells by poor oxygen supply? Does low ATP cause low energy, which in turn causes exercise intolerance and post-exertional malaise? Key question: how can I fast-pace walk and run 10Ks if mitochondria didn't produce ATP? I surmise Wallman *et al.*'s 4 basic graded-exercise training protocols: (i) the Borg Scale's self-perceived exertion not to exceed "somewhat hard" or "hard", (ii) resting every other day, (iii) monitoring exertion by heart beats-per-minute, and (iv) supervision by a health-care practitioner somehow generated conditions for ATP I needed to walk 5K and progress to run 10Ks *without* triggering exercise intolerance and post-exertional malaise during or after such exercise.

My hypothesis is the 4 Wallman *et al.* graded-exercise training protocols somehow in gradual increments gets oxygen into my mitochondria, which in turn enables them to produce the ATP I needed to progress *without* exerting myself from a 2-minute treadmill walk to a 10K run at Borg 16. But crucial to recognize is, when I do not fast-pace walk or run, my mitochondria may not be receiving oxygen to produce ATP for browse walking or prolonged standing. My mitochondria may be in a dysfunctional mode when I'm not running. Such mitochondria dysfunctioning could explain how browse walking for 30 minutes or standing for 30 minutes is enough exertion to trigger a wave of exhaustion, muscle achiness in my calves, and more cognitive fog with all three symptoms carrying into the next day as post-exertional malaise. If you have questions or comments, please email me. I hope someone can solve my GET-ME/CFS Running Anomaly.

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