

How Hannah Finally, Finally Learned How to Pace – and How it Helped

[Hannah Clark](#)

I came down with chronic fatigue syndrome (ME/CFS) very gradually after contracting something called labyrinthitis – a balance disorder caused by an inner ear infection. I caught the virus around Easter 2010. I recovered, but relapsed, recovered again, but then relapsed again, etc. This continued for about two years until eventually the symptoms became permanent. Following the usual negative blood tests, I was diagnosed with ME/CFS.

During the obligatory 6 months' wait from GP to ME specialist referral in the UK, not realizing how the illness works, I continued to push myself and got worse. I was then given general pacing instructions by the specialists I saw.

They don't really tell you how strict you have to be, though, (probably because they don't



Hannah knew she had to pace....but how much?

know) so even though I was pacing, I wasn't doing it enough, and still was getting worse. I was going into work on Mondays and Tuesdays but getting so ill I could barely walk by Thursday. I cut my hours for a few months, but it still wasn't enough, and eventually I went on a 6-month sick leave.

CBT/GET

Throughout this time, I was also accessing Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) via the NHS, as per the NICE guidelines. The CBT was as a supportive treatment, meaning they don't expect it to cure the ME, just support you emotionally whilst you come to terms with having the illness and the life changes you have to make. It was delivered via telephone by one of the psychologists on the team, and it was actually quite helpful in dealing with my new limitations at work.

The same psychologist also helped me with GET and pacing as you could only access one of the treatments offered (I'd only picked CBT as it had the shortest waiting list!). She wasn't that prescriptive with the GET, so it wasn't awful, but because the premise of GET is still to push yourself, albeit it in tiny amounts, it still made me worse over time.

Heart Rate Monitoring

I came across pacing using a heart rate monitor (HRM) via

one of the Facebook groups for ME that I belong to. I liked the look of it, because it offered a more scientific way of pacing the physical activity I was doing (counting steps and avoiding activity) – so I joined a great heart rate pacing group and learnt the basics of just staying below your estimated AT (anaerobic threshold) (109 bpm for me).

It definitely helped me prevent crashes, but I was shocked at how easily my HR got above my AT, and my lack of discipline meant I found it very difficult to stop what I was doing when that happened and rest.



Monitoring her heart rate helped her move forward.

I tried to go back to work on a very gentle, phased return, but I still couldn't even manage 2 hours on a laptop at home, so I was eventually let go. I'd basically gone from mild to moderate thanks to the GET, and work was just too much for me cognitively, regardless of any HRM pacing I was doing for physical activity.

I was very sad to leave my job as a business analyst. I loved it and felt great pride and achievement in what I did,

but I hoped it would mean I could concentrate on pacing and recovering. They discharged me from the ME/CFS specialist service shortly afterwards (despite the fact that I'd got worse), and back into the care of the GP who knew nothing about ME.

Rolling PEM

With a bit more research via the HRM Facebook groups, I learnt about rolling PEM (post-exertional malaise) (and PENE) (post-exertional neuroimmune exhaustion), and knew that it very much applied to me, and is just one of the (many!) reasons that GET doesn't work.

Rolling PEM is when you don't recover fully after each day or crash, and the PEM accumulates gradually over time. This accumulation of PEM means you get progressively worse over months or years as you fail to recover completely from each incidence of overactivity. This was the key for me and made me hopeful that perhaps I could get back to mild severity if I stepped up my HR pacing game.

As per the advice of the Workwell Foundation, I started resting every 2 minutes when my heart rate was in its 'exertion' zone (85-109 bpm) and was much more disciplined about not going over my AT.

But I was still folding those last few t-shirts despite my arms starting to ache and my heart rate alarm jumping,

still taking the stairs in one go and resting at the top to circumvent the 2-minute rule, when it would have been better if I'd climbed up slowly and rested halfway.

I was doing very easy recumbent stretches to ease the hypermobility, but instead of watching my monitor, I was still waiting for the first signs of 'the burn' or the alarm to go off telling me I was in the danger zone. I was doing significantly less than when I was healthy, but it still wasn't enough.

Heart Rate Variability Monitoring

Then I started monitoring my morning heart rate variability (HRV) readings. Your HRV tells you whether your nervous system is in balance or whether you're swinging into either parasympathetic or sympathetic dominance, i.e. whether we're crashing, so our very own PEM detector.

Now let me say that I only did GCSE (General Certificate of Secondary Education) biology, and I have forgotten it all, so I don't really understand the science, but after 3 months of HRV monitoring, I knew exactly what the parasympathetic or sympathetic states feel like, and I understood my crashes much better.

For instance, you know that family gathering you went to where you were fairly disciplined, and the next day you feel good, energetic even, so you think you got away with it?



Heart rate variability monitoring helped Hannah to pick up the subtle signs that her system was swinging into fight/flight

Probably not. The app often showed my autonomic nervous system swinging into sympathetic dominance – the fight or flight response – the next day. That’s the first stage of a crash for most, and is characterized, oddly enough, by feeling hyper, and happy, with your internal dialogue yabbering like an excited 5-year-old coming home from school.

I had subtle physical signs too, like trembling or vibrating in my veins, and a lump in my throat, and finding it hard to sleep/rest. Those more subtle signs are hard to recognize at first, especially in the morning because we I felt (relatively) so good.

If I rested and gave the SNS side a chance to quiet down the parasympathetic swing side – the rest and digest side – it was actually a bit of a relief for me. As someone prone to insomnia, the lethargy I experienced during that time helped me to sleep as much as possible. It was a sign that

I'd started recovering from a crash.

If I'm swinging either way (periods of being hyped up, and and lethargy), then I cut my activity in half, put the phone away (because in my sympathetic hyped-up swing I'm scrolling through social media like an addict thanks to the fake energy) and rested as much as possible.

So, it was only with HRV monitoring that I truly learnt my limits. I learnt that I cannot chat to new people for longer than 10 minutes or watch anything particularly scary on TV for very long (no more Walking Dead binge-watching!). No reading or Audible for any longer than 30 minutes.

If I'm doing anything physical, I've learnt that I can't feel any burn, ache or any type of effort expenditure without paying for it later. I learnt that you have to listen to your pain and body as well as your heart rate alarm to avoid crashing from physical exercise.



Recognizing how fragile her system was she began to pull back more

But it was all very much trial and error at first. For instance, to work out what physical stuff I could do safely, I collected some recumbent exercise ideas from YouTube, picked the ones I thought I could do, and experimented very gently and gradually, e.g. arm swings.

With each exercise, I did repetitions until my HR got to 95, or my limbs started to feel an almost imperceptible ache and noted down to do a few less. During any period of experimentation, I'd keep the rest of my day as similar as possible, so that I would be able to tell it was my experiment that caused any crash and not something else.

I experimented for a few weeks until I got a couple of exercise/stretching routines (with rest breaks after 2/3rds of the exercises built into the routine) that were designed to either loosen me up or strengthen my core, in the hopes that this would help some of the hypermobility aches and pains.

Once the routine was set, I then worked on other aspects of activity, seeing how much I could cope with, and doing a lot less.

I stuck to all the limits I'd set, pacing very strictly for another three months. I was just concentrating on getting a stable morning HRV and trying to eliminate the rolling PEM I'd accumulated over the past few years.

The Process Finally Works!

As I did this, an amazing thing happened. By month three, my heart rate became less reactive. An activity that would've put me over my estimated anaerobic threshold AT (109bpm) and into the danger zone previously was now only just getting me into my exertion zone (85bpm).



Three months of strict pacing worked – her energy envelope began to expand.

So, I started increasing my activity, very slowly, very carefully. I went from only being able to walk 100 yards with walking sticks to being able to walk 0.5 miles with sticks! I was also doing easy recumbent exercises daily (still with no burn allowed!), I discovered my **energy envelope had in fact grown** as a result of me doing significantly less – the opposite of GET theory!

Don't get me wrong; there were mini crashes as I

experimented with activity, but because I was monitoring HRV, I could tell that I'd overdone it, and when I'd recovered.

Life Interferes

I had great plans for my pacing, but then got pregnant (yeah!), which was great, but it raises your BPM and basically made it impossible to pace properly. Now, nearly 2 years on, I'm still unable to take accurate morning HRV readings due to the various mum responsibilities, but I'm still so grateful for HRM pacing, because I learnt so much about what crashing feels like, and what overdoing it feels like for me, that I've been able to pace fairly successfully without all the data.

I would recommend this approach to anyone with ME/CFS. It's truly a scientific and objective method of pacing and has really taken the guesswork out of my day.

It's also been a struggle to stay below my AT as I can't just put the baby down and rest when I need to. However, I know that any effort I make is better than zero effort. Just reducing the amount of times I go above my AT and the amount of time I spend in that zone will reduce the severity and amount of crashes I have.

Resources

- Workwell's Worksheet on [Activity Management with a](#)

[Heart Rate Monitor](#)

- Check out how one person improved their cardiovascular functioning using a heart rate based monitoring program

[Heart Rate Monitor Based Exercise Program Improves Heart Functioning in Chronic Fatigue Syndrome \(ME/CFS\)](#)

Check out how Karmin used HRV monitoring to improve her ME/CFS:

- [Your Crash in a Graph? How Heart Rate Variability Testing Could Help You Improve Your Health](#)
- [Heart Rate Variability \(HRV\) An Underused ME/CFS/FM Management Tool: PT II – Surveying the Landscape](#)

Check out more pacing and exercise resources

- [\(140\) Pacing, Exercise and Management | Health Rising's Chronic Fatigue Syndrome \(ME/CFS\) and Fibromyalgia Forums](#)

Hannah's Approach

Measuring Maximum Heart Rate

There are 2 ways to estimate your predicted heart rate at anaerobic threshold (HR at AT) (the point at which you rely more on anaerobic energy production). The standard

method is by using the calculation: $(220 - \text{your age}) \times 0.6 =$

From what I gather, the 0.6 represents the percentage that your severity impacts your functionality. So, mild ME patients might choose 80%, moderate 70 or 60%, Severe 50%+. It's quite an individual thing, but err on the side of caution. I used 60% but arguably when I became housebound, I should've changed it to 50%. You will be able to tell over time. So, back then I calculated mine to be: $(220 - 39) \times 0.6 = 108.6$ bpm

The only way to get a true reading, though, is to have a 2-day CPET. If you decide to go down that road, make sure you read all the info on the [Workwell website](#), and ensure whoever performs the test is aware of all the information too.

The [Workwell Foundation's findings](#) suggests that most people with ME/CFS met their anaerobic threshold at about 15 beats per minute above their resting heart rate. (Watches can provide average resting heart rates.) Workwell recommends charting your resting heart rate while remaining flat in bed after wakening.

There are two types of wearable devices that continuously measure your heart rate, a wrist-watch or a chest strap. The chest straps are more accurate, but as I have fibromyalgia, I can't wear a chest strap 24/7, so I chose a wrist-watch. (The most popular brands for heart rate

devices are (watch or chest strap) Polar, Mio, Fitbit and Garmin, as well as the Oura ring.) I used a FitBit Ionic.

Measuring Heart Rate Variability

Since my watch can't measure HRV, I bought a chest strap – a £30 chest strap paired with the EliteHRV app on my phone, for the HRV readings. I chose my particular chest strap simply because it was inexpensive, accurate and compatible with my phone and the app I wanted to use.

There are 4 popular apps for this, HRV4Training, Elite HRV, Welltory and SweetBeat. I used Elite HRV when I did it, though I would probably change to HRV4Training now, if I would do it all over again, based on the experiences of others who do HR Pacing.

The measurements themselves are taken in the morning when you first wake up, (after I put the chest strap on). They only take 3 – 5 minutes, depending on your app and chosen settings.

- Coming up – Workwell deciphers PEM symptoms