

Managing ME/CFS/SEID: Learning to Pace

Dr. Charles Lapp, Hunter-Hopkins Center

[Very brief introduction by Dana Brimmer or Bruce Campbell. Slide #1.]

Bruce Campbell has just provided several vignettes that illustrate the Push/Crash Cycle, and he has suggested strategies to deal with this problem by limiting activity. As usual he presented several excellent cases that illustrate his points, and he ended his talk by making general recommendations for identifying those limits and adapting to them.

I cannot emphasize enough how important pacing or limit setting is to the person with CFS/ME. Pacing is *more important* than any medication, more than any supplement, more than Valcyte, or rituximab, or even Ampligen! Supplements only optimize one's health ... medications only treat the symptoms ... and there is no cure for CFS/ME at this time, so years of experience have taught me that pacing and limit setting are key to improvement and recovery.

So one of the *first* and major goals at Hunter-Hopkins Center is to teach new patients how to *pace* effectively.

Research confirms that regular activity improves the symptoms of ME/CFS, and if one stays within proscribed limits the severity of symptoms decreases over time. So we teach every new patient that it is important to “stay active but not too active ...”

[Slide #2]

PWCs quickly learn that if they exert too much then they get sick (feel badly), and if they *really overexert* then they can end up in bed for days or weeks afterward. Too much activity will predictably result in a flare or relapse.

[Slide #3]

On the other hand, some individuals who experience severe fatigue believe that they should crawl onto a sofa or into a bed and stay there until they feel better. Unfortunately, that doesn't work. Such “couch potatoes” end up getting stiff and sore (a condition we call delayed onset muscle soreness) and they get deconditioned. By “deconditioned” I mean that you feel weak ... the heart rate gets elevated and so you feel like you are running a race after even minimal activity ... and you may even experience dizziness or faintness on sitting up or standing up (postural hypotension). I have never seen anybody get better from CFS/ME by just lying around all the time ... you have to be pro-active, even if you are proactive 30 seconds at a time!

Soon after we began researching CFS/ME (1980's) we realized that exertional intolerance is a major part of this illness. In other words, persons with CFS/ME (PWCs) would try to accomplish their routine daily tasks but would relapse for days afterward. We called this phenomenon "pushing and crashing," but it is now also called "post-exertional malaise." It was clear that a cardinal finding in CFS/ME was a lack of energy or stamina. Once a person is struck down by CFS/ME, their energy is markedly depleted. How do you explain this concept to someone?

Well, Charlotte is a banking and finance community, so I began explaining this phenomenon in terms of "energy dollars." I explained that you used to have a nice large bank account with lots of money to spend -- disposable cash even! But now times have changed and there are many fewer energy dollars in your energy account. In fact, you have to budget by spending only a small amount of energy dollars each day. So when you get up in the morning and brush your teeth, that may cost one energy dollar; and if you try to take a shower, then it will cost you another couple of bucks. All day long you have to parse out those energy dollars.

Now, if your energy account is a little short you may find yourself overspending for the day. In that case, your energy account is just like the money account you have at the bank: when you overspend one day, then you have to pay it back the next day. How? By resting and allowing your energy dollars to re-accumulate. But just like at the money bank, when you overspend your energy dollars, you not only have to pay them back but you have to pay interest and penalties as well! So when you overspend or overexert you set yourself back, and if you continue to overspend day after day, then you become energy bankrupt and can't get better.

My dear friend Malinda Malott prefers to think of her energy in terms of marbles in a jar. (She gave me a big jar of marbles that I keep on my desk to remind me.) Malinda imagines starting her day with a jar full of marbles and every time she does an activity she removes a marble or two from the jar. When the marbles are all gone, then Malinda stops what she is doing and rests. She has even written a booklet about it for children, "How Many Marbles Do You Have?" (I suggested the title, "What, have you lost ALL your marbles?!")

When we recognized this problems of "pushing and crashing," or overspending the energy dollars, we asked the same question that is probably on your mind right now: "how do I know when I have over-exerted?"

[Slide #4]

To answer this question, we used actimeters (a fancy pedometer or step meter) and exercise testing. We would have patients ride a stationary bicycle while sophisticated medical equipment measured their energy levels.

These techniques produced several interesting results.

First, patients would be riding the bike and suddenly we'd see their energy drop – like “hitting a brick wall” – and we discovered that this “brick wall” occurred when they reached and exceeded their Anaerobic Threshold or AT. The AT is the point where your heart and lungs cannot supply enough oxygen to muscles and tissue. So it was not surprising that this AT was the stopping point, because without oxygen, muscles may tense up and hurt, and then they have to rely on sugar (glucose) for energy; but sugar metabolism produces toxins that your body doesn't like.

What *was most surprising* was that the majority of patients reached their AT as early as 3-5 minutes. So in the late 80's and early 1990's we taught patients “interval activity”: exert for 3-5 minutes, but then rest for 5 minutes (which is how long it takes for the oxygen level to recover). Then do as many repetitions as feels comfortable. With time, PWCs could build up their intervals to 6/5, then 8/5, 10/5 and then more and more.

[Slide #5]

The second thing that we learned was that the stopping point comes on rather quickly, and by the time our subjects felt symptoms it was *already too late*. So they would pedal the stationary bike for 3, 4, perhaps 5 minutes and then start feeling a bit tired. Then within seconds they would overexert and trigger a flare that could last for days. So we learned that as soon as a PWC feels symptoms he or she is already in the “danger zone” and has to rest immediately, or risk a flare or relapse.

[Slide #6]

The third thing that we learned was from the actimeters or pedometers. Empirically, if a PWC is taking less than 1000 steps-per-day he/she is too inactive – a “couch potato” -- and would end up getting deconditioned, That is, weaker and weaker over time. On the other hand, exceeding 5000 steps-per-day would frequently push our PWCs into crash mode.

[Slide #7]

So now we had at least 3 ways to fairly objectively monitor activity to prevent pushing and crashing or post-exertional malaise.

First way was interval activity: exert for short periods of time (sometimes as little as 30 seconds) and then take a prolonged rest break. Over time this exertion time can be cautiously expanded to minutes or even a couple hours without triggering a flare.

Second, ask yourself how you feel after exertion. If you feel tired or ill afterward, then you have exceeded your “danger zone” and you need to cut back .

Third, consider monitoring activity with a pedometer or step meter. You can get inexpensive ones at Wal-Mart, Target and sporting good stores, or get one of the fancy wristband types (FitBit or Jawbone). Experiment to determine how many steps per day

you take, on average, on good days, then try not to exceed that. A majority of our patients find that 2500 steps-per-day is comfortable and safe, so if they exceed that level then they know to slow down or stop their activity for the day. Another way to look at it is this: if you feel comfortable and safe at 2500 steps-per-day, then when you get to 2000 say to yourself, “I’ve got 500 steps to go. How am I going to use those steps?”

As Bruce Campbell taught me years ago, these concepts are “easy to say, but hard to put into action.” There are many reasons why PWCs push and crash: Some just lose track. Others still try to do what they used to do before CFS/ME. An occasional one will overdo just to prove that he or she can do it! For some it’s a matter of self esteem, and others feel guilty if they don’t push. Whatever the excuse, our experience has been that you just cannot improve if you are frequently pushing and crashing. You must learn to pace.

[Slide #8]

So what are some of the objections that we hear?

One of the most common excuses is, “I felt good, so I decided to catch up on what I couldn’t accomplish the day before.”

When you push hard one day however, then you can do less the next; if you push again, then you accomplish even less; over time it takes less and less to overexert and longer to recover. So don’t try to overdo it on a “good day.”

Here’s another one: “I push until I feel symptoms.”

As we discussed earlier, by the time you feel symptoms you are already in “the danger zone” and risk a flare or relapse. Try breaking up activities a bit with rest periods; and when you feel *any* symptoms, stop and rest.

Sometimes I hear, “Mornings are good for me, so I do all my tasks in the morning and rest all afternoon.”

But wearing yourself out in the morning just perpetuates the push/crash cycle. Try working in intervals; or rest at the first hint of symptoms; or monitor your steps-per-day.

Or, “I would never get anything accomplished using brief intervals and then resting all the time!”

Actually research has shown that PWCs who practice interval activity get *more done!* (By stopping before fatigue and pain occur you need to rest for briefer periods of time.)

And the classic lament is, “Sometimes I just *have to* push myself beyond limits, even though I pay a price for it.”

Yes, that’s a choice that you make, but why would you sacrifice your health and wellbeing just to get something done?. We know that triggering flares and relapses inhibits improvement and perpetuates illness. There are many sources in books and

online, including our self help site at TreatCFSFM.org that can teach you how to pace, delegate, and defer activities and still have a good quality of life.

[Slide #9]