

Pacing – the next steps

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Pacing is the practice of matching actual energy levels with activity levels throughout the day, so that at no point do we use up all our energy and cause an increase in our symptoms i.e. Crash, Blip. Pacing primarily is about learning to save more energy than you are using.

When it comes to creating your paced routine it's important to be very aware of your body and how you operate, BUT we need to keep in mind some basics about the human body.

- Humans are designed to sleep at night-time.
- Humans are designed to be more active and outside in the daytime.
- Humans are social creatures.

So if we are sleeping all day are awake all night, no matter how much pacing we do, we will not feel a whole lot better, as we are out of the normal sleep/awake cycle (circadian rhythm) we are not also able to get outside in the sun/light and natural environment enough to help restart the rhythm.

Sleep can have an elusive nature for those of us with ME/CFS/FM, the majority of us have a sleep disorder, many sleep but do not feel refreshed, and this can make pacing complex. When we are sleep deprived, we find it hard to think clearly and rationally which adds to the Brain or Fibro fog.

We may have moved on from cave man like days, but our basic operating system has not, artificial light especially blue light at night tells our bodies it is the day and to stay awake.

- Reducing the amount of blue light from midday onwards can help to encourage a natural sleepy state in the evening.
- Check the light bulbs in your home, if they are white or bright, try changing them to warmer tones.
- Change phones and computer to night tones with more yellow/red light.
- Get at least 10-15 minutes of sunlight directly on your eyes/face/skin without sunglasses each day when possible.
- Try getting some morning light on your face/eyes if you feel groggy and need to wake up.
- Make your bedroom as dark and cool as possible, we need our bodies to drop several degrees to help us start the sleep process.
- Routine is very important before sleep, if you don't have one, create one, a unwinding, relaxing, breathing, reading, shower or bath etc maybe part of this.

Now let's consider the **different types of activity** that we do daily that use our energy and that we need to investigate for pacing. What are to different types of activity?

Physical: housework, walking, breathing, sex, shopping, cooking, having a shower, driving, working etc.

Mental: reading, watching TV, online computer activities, working, writing, studying, talking, planning, etc.

Social: meeting people, talking to people, online or in messenger groups, texting, having visitors, living with other people who are not cats.

When you think about activity, ask yourself:

- How long I SUSTAIN doing a **physical** activity WITHOUT my symptoms worsening?
- How long can I ENJOY **social** activity WITHOUT my symptoms worsening?
- How long can I spend doing **mental** activities WITHOUT my symptoms worsening?
- Are sometimes better than others for doing activities?
- Are some people or tasks more draining than others?
- Does the location, numbers or setting make a difference?
- How much physical, mental and social activity do I NEED to do in order to survive in this world?

Now ask, what task or roles can I **delegate**, **simplify** or **eliminate** in order to have more energy in my body for healing?

It can be very helpful to break down what we do, and think about why we do these things and ask "are they are helpful to my recovery?"

Finding your **energy baseline** about working out how much "actual" energy you have in your system on average.

Do you have 10% battery, 7 spoons a day, \$40.00 credit in the account?

It is not an easy thing to try to find how much energy your body has on average when this changes day to day, week to week or even hour to hour. Change is the only constant.

The best way to find out is by using an **ENERGY DIARY**. In it you can note your activity, what you eat, when you sleep, nap, the quality of that rest, how you feel, what symptoms etc for at least 2 weeks or longer.

After a few weeks, you will be able to see how your energy fluctuates: over the day; over the week, at different times of the month, after a variety of foods, after differing types of sleep and after tasks. From this you will see what taxes your energy, what causes PEM and how much rest etc is required to improve energy

This information should give you a rough idea of where your baseline is i.e. are you at 40% of average energy levels etc.

Here's a rough guild to understanding energy levels:

- If you feel **very** fatigued most of time, then it shows that you are chronically overdoing it. You are operating outside your energy envelope and need to do less activity on average over the days, weeks etc.
- If you notice that your body seems rested but that your mind is racing or overactive then perhaps you are not doing enough physically. You may be operating below your energy baseline and leaving too much undirected energy in your system which creates anxiety and over thinking.
- If you notice that you feel a lot better after a rest etc, this shows that regular resting will help you, and that you may be slightly overdoing it as well. See what activities you can stop/reduce/change doing to help you feel better?
- If you see that you seem to have good periods when you feel well and achieve a lot, then you crash/blip for several days, this shows you maybe overdoing it. You could look at what you are doing when you are feeling well, and instigate more "checking in" or body assessments or more compulsory rests.
- You may notice that your body experiences more fatigue than your brain, or vice versa, your brain is more fatigued than your body. You can build this into your pacing by doing more or less mental or physical activity.
- If you feel ok most of the time, then you are probably at your energy baseline.

The baseline is when we are **not spending more energy than we are producing**.

It is in theory our new energy average level. The baseline means that like any person we will feel tired after a day, but that that day's activities will not create PEM and make us worse for the next day/s.

Once we have this baseline we can then pace, and over time if we notice change we can shift the pacing to suit.

There are two types of pacing, Body based, and Head based.

How to listen to the body: Body Based Pacing

Learning to LISTEN to your body, learning to FEEL how your body is in each moment, the pain, fatigue etc, will help you to be responsive to your symptoms and moderate your pacing accordingly. When you can sense your body's symptoms levels you will be able to recognise, after time, how your body and mind is each day and then alter your pacing/activity to suit.

But how do we do this, especially when your feet are speaking French, your head is speaking Mandarin, and your tummy German?

For most of us we live our lives in our heads and not our bodies, and that is even more the case when you have ME/CFS/FM as your whole-body hurts and is in a heightened stress response. Moving into your body, into the discomfort, moving towards acceptance of how you really feel; gets us much closer to your own true energy and a better more honest way of being in our own skin.

So how do we inhabit our bodies again?

- Some people meditate each morning and/ or use a body scan to see how the body is feeling.
- Use "Check in" techniques; pause take a moment ask yourself "How do I feel right now?", then listen to the answers "Sore... where investigate? Tired... how investigate? etc", then ask, "What I can do right now to feel better?" and do it.
- Use gentle movement, slow stretching, grounding, Yoga, Tai Chi or Qigong etc to communicate with the body through movement.
- Keep a diary and write down how they are feeling every day.
- Draw or use numbers to rate how they are feeling on a daily basis.
- Be curious, experiment...

Now we are listening, we can start to create a **PLAN, Head Based Pacing**, of how we manage these symptoms in relation to how much energy we have.

The aim is to have a **daily plan** which you can manage to do on your WORST DAY as the norm, with the tasks you need to do each day in order to stay well.

- A good idea is to classify how much energy each task takes – High, Medium, Low. Each of us will find different tasks taxing, so work out your levels. For example, computer work is High energy, cooking Medium and reading Low.
- You may find shifting between the different tasks helpful. You could do something high energy for a period of time then something low energy.
- Another concept is to cap activity to 5-10-minute units and see how the body responds. This would look like; vacuum 7 minutes, rest then see how you feel and either stop there or do another 7 minutes.
- Or combine the two and do a high activity for 7 minutes, rest 10 minutes, Low energy activity, Medium energy 7 min, rest etc.
- We can also alter tasks to make them easier and less fatiguing, i.e. cook seated, shop online, ask others to do tasks for you, eliminate unnecessary tasks etc.

The aim is to do some of the task you need to do, like feed yourself, wash yourself or even work, and not use all your energy each day: **Be and energy SAVER.**

List of tips:

- Be aware of your active and inactive times of day
- Take scheduled rest **regardless** of how you feel
- Use short activity periods
- Practice task switching
- Keep a health diary
- Develop personal boundaries or rules
- Simplify your environment and life
- Identify stressors
- Prioritise the things that nourish you
- Loving kindness – it takes time to adjust

Please Note:

- It is not helpful to push while fatigued and using pushing will not help to find your baseline. It can take time, even months +, to find this.
- It is not just Fatigue that means you are overdoing it, Pain, Brain Fog, Nausea, Insomnia, Tired & Wired etc are all symptoms of overdoing it.
- When in a crash it is not appropriate to find your baseline or pace, just work on calming your stress response.
- Most PWCFS/ME/FM are chronically overdoing it, please don't blame self for this, use loving kindness.
- Be interested and curious.
- You see that sometimes you can be very active and create no PEM or additional symptoms but then at another time the same activity causes symptoms, it's often how we are doing things that matter, i.e. stressed and rushing.
- Being in a calm Healing State is helpful.
- And sometimes we just don't know what causes our symptoms, it's ok not to have all the answers.
- We need to create our own plan that suits us as we are all unique.
- We have different levels of physical and mental endurance, please do not compare yourself with others.
- Pacing is a lifelong ever-changing process which keeps us moving forward and hopeful of recovery and change.
- Pacing only works if you do the work, and sometimes it is not easy.

Diary 1 examples

Sleep	8.30pm – 7.30am Broken, add details – busy head, pain etc What did you do? Radio, breathe etc
Daily action	Work 9-12pm Rest 3pm- 4pm etc
Toolkit	Meditation Qui Gong 25mins etc
Symptoms	Muscle pain etc
Heart rate	Resting max low steps.
Menstrual	Day 12 etc
Breakfast	Toast etc
Lunch	
Dinner	
Snacks	

Diary 2

Date: Day:

TIME	ACTIVITY
Resting Pulse AM	70
Breakfast am	Level of fatigue: 1-10
Morning tea am	
Lunch pm	Level of fatigue:1-10
Afternoon tea pm	Exercise 3min X 3 ratio 1X3.
Dinner pm	Level of fatigue: 1-10
Bedtime pm	Level of fatigue: 1-10
Max Rate	