Rest, Pacing and Stress: What Every ME Patient Should Know

If you have Myalgic Encephalomyelitis, you are probably acquainted with the experience of push and crash. People who use this way of living with M.E. find themselves caught in a frustrating loop, swinging between over activity and forced rest. Push and crash leads to lack of control, unpredictability, discouragement and Post Exertional Neuroimmune Exhaustion.

Pacing as an Alternative

The contrast of push and crash vs. pacing suggests that our symptoms are not random, but rather due in large part to variations in our activity level. If we do more than our bodies can tolerate, the result is an intensification of symptoms.

On the other hand, if we stay within our limits, which we call the Energy Envelope, we can gain some control over our symptoms. Pacing offers the possibility of a more stable and predictable life. Using pacing, you can live your life according to a plan, rather than in response to symptoms, giving you a sense of managing your illness, rather than illness controlling you. The benefits of pacing include:

- Lower symptoms
- Less suffering
- More stable and predictable life
- Sense of control
- Less time spent resting (because less PENE)
- More productive use of time (because less PENE)
- Chance for improvement

The Three Parts of Pacing

Pacing has three parts:

1) Finding Your Envelope

ME imposes limitations. There are limits on physical activities and also limits in other areas, such as mental activity and socializing.

2) Adapting to Your Envelope

The second part of pacing is adjusting your life so you live within your Envelope. This is a gradual process, usually involving the use of multiple strategies.

3) Expanding the Envelope

You may be able to expand your envelope if you pace consistently but the trick is in finding and implanting keys to expanding the envelope without over exertion which will exacerbate your symptoms.

The single biggest factor determining recovery and remission from Myalgic Encephalomyelitis at this point is appropriate rest in the early and or severe stages of the illness. The importance of avoiding overexertion cannot be overestimated.

The Energy Bank Account

A second way to think about limits is to imagine your energy as money stored in a bank account. Because of ME, your account has a very low balance. While healthy people are able to store up energy for a day's activity with seven to eight hours of rest at night, people with either condition may get only a few hours of energy from a night's rest.

The small amount of energy available makes it easy to spend more energy than you have and overdraw your account. There is often a big service charge (intense symptoms) if you overdraw your account. Once you're overdrawn, you have to deposit more to your account in the form of rest.

The Bowl of Marbles

The bowl of marbles approach offers a similar idea with a different image. In this approach, you imagine your available energy as marbles in a bowl. Each marble represents a small amount of energy.

You estimate your energy level each morning and put an appropriate number of marbles in the bowl. (Some people in our program have taken this idea literally, using marbles, coins or poker chips.)

With every activity, you take one or more marbles out of the bowl: one for showering, one for dressing, etc. Some projects take more marbles than others. Also, the same task may require more marbles on bad days than on good days. Physical activity uses up your supply, but mental and emotional activity consume marbles as well.

For example, if you feel frustrated about how few marbles you have, your frustration will use up some of your marbles. Stress, tension and fear are all big marble-users. Whatever you can do to lessen them will preserve your supply of marbles for other uses. One person who uses this concept says that if she is overactive, she tells people "I've lost my marbles."

The Fifty Percent Solution

Rather than challenging your limits, you keep your activity to a safe level. The unexpended energy is a gift of healing that you give your body. This is a clever way of addressing our tendency to overestimate what we can accomplish. Another benefit is that it gives you permission to take care of yourself, something discussed in the chapter on mental adjustments.

The Spoon Theory

The Spoon Theory, which is described in an article by that title written by Christine Miserandino, a woman with Lupus. People with chronic illness sometimes use it to explain the idea of limits to family and friends. "When other people can simply do things,…I have to make a plan…Once people understand the spoon theory; they seem to understand me better."

To use any of these: **First, think of your situation as having three elements. The first is your available energy. This is the energy you have to accomplish things. It is limited and is replenished by rest and food. The second is your expended energy, the energy you lose through physical, mental and emotional exertion. The third is your symptoms, fatigue, brain fog, pain, and so on. In this view, if you expend more energy than you have available, you will intensify your symptoms. This is called living outside the energy envelope. An alternative is living inside the energy envelope.**

If you keep your expended energy within the limits of your available energy, you have a chance to reduce symptoms, and over time may be able to expand your limits. Many have found it helpful to think of their life using the idea of the energy envelope in this way. To explain higher than usual symptoms, they may say "I was outside my envelope this week." This statement may sound like an admission of defeat, but it implies the possibility of control: if you can live differently, you may be able to gain greater control of your symptoms

Everyone's Situation is Different: Each person's limits are different, because each person's situation is unique. The first, which you can think of as the medical aspect of your situation, is your *illness or illnesses*.

The most common pattern is people who have ME, but frequently people who have one or more other medical issues, such as arthritis, back and spinal problems, depression, food and chemical allergies, irritable bowel syndrome (IBS), myofascial pain, sleep disorders like apnea and restless legs syndrome, and thyroid problems. Long-term illness is much more than a medical condition. The second factor that defines your unique situation is your general *life circumstances*. Illness will have a different impact depending on such things as your stage in life and family situation. In this context, finances and support are particularly crucial.

Some patients find their financial situation to be similar to what it was before they became ill. They may be supported by a spouse or receive disability payments that replace their previous income. For others, however, financial pressures can be great, even overwhelming. Some may live alone, trying to get by on little or no income. Others may feel forced to work when their bodies are asking for rest.

Patients' levels of support can vary greatly, also. The term "support" applies to both practical and emotional help. Practical support may mean assistance with tasks such as grocery shopping, cooking and cleaning. Emotional support means feeling that someone understands and cares.

The third factor is coping skills. Your ability to live well with chronic illness depends in part on your own resourcefulness. We have seen many people respond to adversity with flexibility and resilience. Luckily coping skills, like other skills, can be learned and improved through practice.

In summary, each person's situation is different. Your limits will be shaped by your particular combination of illness, financial and family circumstances, and coping skills. While some factors are fixed, support and coping skills can be improved over time.

Pacing involves first finding your limits and then adapting to them.

Finding your limits is a challenge! I haven't found them all yet, but I am making progress and monitoring my heart rate has been a big help.

Note: An elevated heart rate triggers an intensification of symptoms.

Learn to monitor your heart rate. If it goes over your threshold, it’s time to stop. This prevents many crashes. Also learn it feels when my heart rate is too high, which was very useful for those who don’t use a monitor. Find your resting heart rate is very useful. If your resting heart rate goes up by 2 or 3 points above normal, I label the graph with what I did that caused it.

Some find that after a big overdoing, their resting heart rate goes up by a few points each day for 3 days, then it slowly comes down, one point every day or two. It takes a lot longer to come back down than it does to go up. By watching your resting heart rate, you can rest a lot before the worst crash day, and avoid a really bad relapse.

Logging, Experimentation and Rules

Along with all this tracking and graphing, some log the big items for the day. This gives them the information needed to figure out where they went wrong! So logging is another strategy that can be used to monitor activity and symptoms. You can use your heart rate to figure out your limits, except for the mental limits. You know when your brain is tired, because you can no longer think straight

Finding Your Limits One Area at a Time: It’s helpful to understand your energy profile and limits in more detail. Just as activities come in many forms-from walking to reading to phone conversations-so, too, do our tolerance limits for each. By zeroing in on each type of activity and asking yourself a few questions, you can begin to build a detailed profile of your energy envelope.

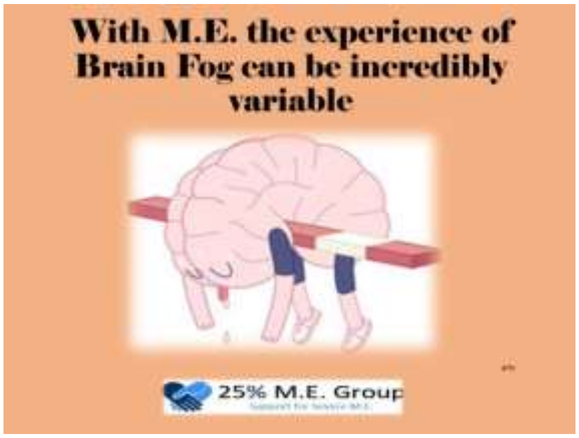
Physical activity: We all have limits for various activities, such as housework, shopping, driving, standing and exercise. You can determine your envelope for each by focusing on one activity at a time.

For example, if you think your envelope for housework is 10 minutes, try that much and then ask yourself how you are feeling. If you feel OK, you may be able to do more (but increase slowly!). If worse, try less. Soon you'll get picture of how much of your primary physical activities you can do without exacerbating your M.E. Keep in mind that your limits will likely vary from activity to activity. One person might be able to sit up for hours but the next person tires after a few minutes.

Brain activity and Involuntary Organs: Activities requiring concentration, like reading, working on the computer or balancing a checkbook also make demands on our energy. Your heart, kidneys, bladder, liver and others are involuntary organs that use energy so we must learn to factor our movements accordingly. If you overexert – it’s not just your capability of walking or sitting up that comes into question. You need energy for your organs to work properly.

Social activity: Consider the time you spend interacting with other people, either in person, social media or on the phone and assess that energy toll. Ask yourself: How much time can I spend with people without making my symptoms worse? Is the amount of time dependent on the specific people involved? You may tolerate only a short time with some people, but can spend more time with others. How long can I talk on the phone without making my symptoms worse? For in-person meetings, you might also ask yourself whether the setting makes a difference. Meeting in a public place or with a large group may intensify your symptoms, but meeting privately or with a small group may be OK.

Physical sensitivities: It also helps to determine if you have sensitivity to food and other substances, vulnerability to noise and light, and sensitivity to weather and the seasons. Questions in this area are: Do I have allergic reactions to food? Am I chemically sensitive? Am I susceptible to sensory overload: noise, light, or stimulation coming from several sources at the same time (for example, trying to have a conversation with music playing in the background)? Am I affected by the seasons or changes in the weather? A deeper understanding of these environmental elements can help you make better decisions about managing your energy.



Strategies to Manage the Energy You Have

Once you know your limits, your next challenge is to adapt to them. This is a gradual process, usually taking a period of years and involving the use of several strategies. Here are nine techniques often used by people in our classes.

Reduce Overall Activity Level: The primary strategy for adjusting to energy limits is to reduce your overall activity level, using some combination of delegating, simplifying and eliminating. Delegating means finding someone else to do a task that you used to be able to do. For example, hire a cleaning service or have family members do the grocery shopping. Simplifying means continuing to do something, but in a less elaborate way, such as cleaning house less often or cooking less complicated meals. Finally, you may decide to eliminate some activities altogether.

Take Scheduled Rests: Taking planned rests every day can help you reduce your symptoms, gain stability and reduce your total rest time. (Note: "Rest" means lying down with your eyes closed in a quiet place. Watching TV, reading or talking on the phone are low-level activities, not rest.) The optimal length of the rest period and the number of rests per day vary from person to person. Those who are bedbound may need to spend less time on social media.

Set Limits for Individual Activities: To translate activity limits into practice, many people set limits on particular activities. For example, they limit how long or how far they drive, how long they spend on the computer or the phone, the time they spend socializing or how long they spend doing housework. You can find your limits by experimenting, as described above. Some people enforce their limits by using a timer.

Use Short Activity Periods: Two short periods of work with a break in between can produce more and leave you feeling less symptomatic than the same amount of time expended in one block. For the people who can use this strategy, alternating periods of activity and rest seem to expand their functional capacity, allowing them to accomplish more of the tasks they set out to do.

Practice Activity Shifting: Another strategy for getting more done is to shift frequently from one activity to another, for example switching between physical, mental and social activities. For example, if you find yourself tired or confused after working on the computer for a while, you might stop and call a friend or do something physical like fixing a meal. Another way to use task switching is to divide your activities into different categories of difficulty (light, moderate and heavy), switch frequently among different types and schedule only a few of the most taxing activities each day.

Pay Attention to Time of Day: Most people with ME find they have better and worse times of the day. For some, mornings are good, while others perk up later in the day. It's likely you can get more done, without intensifying your symptoms, by changing *when* you do things, so that you use your best hours for the most important or most demanding tasks. For example; if you find that your best time of day for mental activity was in the afternoon then only use your mental activity in the afternoon as you may be able to extend your limit with a higher level of understanding.

Keep a Health Log: A few minutes a day of record keeping can give you get a clearer picture of your limits and reveal the connections between what you do and your symptoms. Also, a health log can help you hold yourself accountable for your actions by documenting their effects on your health and symptoms. A health log can motivate you by showing you that staying inside your limits pays off in lower symptoms and a more stable life.

Develop Personal Rules: Some people with ME have had success using very detailed and individualized rules to protect them from doing too much. For example; people with severe ME have to plan their challenges if they are in a position that they have to leave the house. This requires assistance and the stress can exacerbate your symptoms and severity. Other people develop rules for specific circumstances. For example, they might limit themselves to 15 minutes on the computer or two hours socializing.

Make Mental Adjustments: Pacing means adopting new habits, but it also requires making psychological adjustments rooted in an acceptance that life has changed. Acceptance is not resignation, but rather an acknowledgment of the need to live a different kind of life. This acknowledgment leads to a different relationship to the body, described by some as "a shift from trying to override your body's signals to paying attention when your body tells you to stop or slow down." One part of this shift is changing our internal dialogue or self-talk, so that it supports our efforts to live well with illness rather than generating guilt. For example, some patients have been accused of being lazy when they took a nap. Now, you can tell yourself, "I am helping myself to be healthy. I am saving energy to spend time with my husband or to visit with my grandchildren."

In Conclusion: Pacing is not a quick fix or a panacea. It requires many small adjustments in how we live our daily life. It is not a single action or strategy, but rather a way of living with ME... But the rewards of pacing, used consistently, are greater control, lower symptoms and, for some, expansion of the energy envelope

M.E. patients that are newly diagnosed, or still in the acute stages especially must be given their best possible chance for recovery and be enabled to rest appropriately. Improvements in symptoms and stability of the illness can also be positively affected at every stage of the illness by appropriate activity management/reduction. Limiting activity levels to only as much as the patient is capable of dealing with may well be the single most important factor in the patient’ s ME improving over time.

It is vital that patients avoid physical over exertion and are never encouraged to exercise beyond their individual limits, particularly in the early and acute stages of the illness but also at any stage of the illness. There is nothing to be gained by people with M.E. pushing themselves to the limits as this can only cause unnecessary relapses. Permanent damage to the heart and disease progression may also be caused and the e have been reports of sudden deaths in ME patients following exercise.

The evidence which shows that some CFS patients are merely deconditioned and can be restored to health through GET & CBT is based on patients who do not have M.E. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular and other abnormalities present in ME sufferers which cause the high level of disability associated with M.E. It should go without saying that treatment of one disease cannot be determined by studying a completely different and unrelated patient group.

25% M.E. Group
Support for Severe M.E.