

Managing Your Energy Envelope

BY BRUCE CAMPBELL, PHD

How to identify and maximize the energy you have.

AT-A-GLANCE ►

- **By examining the activities you engage in and how they affect you, you can begin to understand your individual energy profile.**
- **9 strategies to help manage your available energy and use it to its greatest advantage.**

When I was first ill with CFS, I experienced frustrating cycles of push and crash. I was active when my symptoms were low and then retreated to bed when they became intense. Living in response to symptoms, I felt like my life was beyond my own control.

Eventually, however, I found a way to bring stability to my life by determining my energy profile and pacing myself accordingly. To me, pacing means understanding my limits and then adapting to them. By staying within my limits, I reduced my symptoms, gained stability and started a gradual upward spiral that led to recovery.

Over time I developed my understanding of pacing and eventually put together a self-help course that uses an approach similar to one I learned at the Stanford Medical School. In the process of conducting 250 self-help groups over the last decade, I've seen the difference pacing strategies can make for people with CFS, and some clear ideas have evolved about how to create a personalized pacing program. Here are some of the key concepts.

Assessing your limits one area at a time

There's a wide range of energy levels among people with CFS. I use the term "energy envelope" to refer to the limits imposed on an individual by illness. Other terms for the same thing include the "energy bank account," or a "limited set of spoons."

Seeing your energy as something in limited supply provides a motivation to set priorities and to make informed decisions about how to spend a precious resource. For example, one person in our program shares how every day she tackles the challenge of "how to spend my energy chits."

The average person in our self-help courses has an energy envelope of around three hours a day. To get an idea of your overall energy envelope, estimate how many hours a day you can be active without intensifying your symptoms.

But it's also 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're feeling. If you feel OK, you may be able to do more (but increase slowly!). If you're feeling poorly, try less. Soon you'll get a picture of how much of your primary physical activities you can do without worsening your CFS.

Keep in mind that your limits are likely to vary from activity to activity. For example, when I had recovered about 75 percent of my pre-CFS activity level overall, my exercise ability was still only about 30 percent of what it had been before I became ill.

Mental activity: Activities requiring concentration, like reading, working on the computer or balancing a checkbook also make demands on our energy. Questions to help define your mental energy envelope include: How many hours per day can I spend on mental activity without making my CFS symptoms worse? How long can I spend in a single session? What is my best time of day for mental work? Do I have different limits for different mental activities (reading vs. computer work)?

Social activity: Consider the time you spend interacting with other people, either in person or on the phone, and assess that energy toll. Ask yourself: How much time can I spend with people without making my symptoms worse? How long can I talk on the phone 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.

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 alright.

Physical sensitivities: It also helps to determine if you have sensitivities to food and other substances. Questions in this area are: Do I have allergic reactions to food? Does exposure to certain chemicals or their

fragrances affect me negatively? Am I susceptible to sensory overload from 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.

Finally, many people with CFS experience additional medical issues that impose further limits on their activities. Successful treatment of other problems often eases the symptoms of CFS, effectively expanding the envelope.

9 strategies to manage the energy you have

Once you know your limits, your next challenge is to adapt to them in a way that ultimately expands your capacity to function. 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.

1. Reduce overall activity levels: The primary strategy for adjusting to energy limits is to reduce your overall activity level, using some combination of delegating, simplifying and eliminating. *Delegating* tasks means finding someone else to do something you used to do. For example, hire a cleaning service or have other family members do the grocery

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shopping. *Simplifying* means continuing to do something, but in a less elaborate way, such as cleaning the house less often or cooking less complicated meals. Finally, you may decide to *eliminate* some activities altogether.

2. Take scheduled rests:

Taking planned rests every day can help you reduce your symptoms, gain stability and decrease your total rest time, freeing up more space for managed activity. But remember that 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 most productive number of rests per day can vary from person to person. Many people take one or two rest breaks a day, lasting from 15 to 30 minutes each. To quiet their minds, some people use a relaxation procedure or listen to soothing music while resting.

Scheduled rest is a popular energy management strategy because it's straightforward and brings immediate benefits. One person from our self-help course wrote, "I decided to incorporate two scheduled rests into my day, and the results have been incredible. My symptoms and pain have decreased and I feel more in control. My sleep has been more refreshing and even my mood has improved."

Planned rest periods can be useful even for people with severe CFS. One bedbound person with CFS wrote to

me that before she took our self-help course she thought she was nearly always resting because she spent most of her time lying down. Through the class, she realized that she was actually quite active—talking to people, working on the computer or watching TV. Now that she understands and practices rest periods of quiet with no activity, she's experienced a dramatic improvement in her symptoms.

3. Set limits for individual activities: To translate activity limits into practice, many people set specific 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. Some people enforce their limits by using a timer.

You can find your limits by experimenting and paying attention to your energy level and resulting CFS symptoms.

4. 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 energy expended in one block of time. For example, one person in our program does ten minutes of housecleaning, rests for five minutes, and then does another ten minutes of cleaning.

For the people who employ this pacing strategy, these 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.

5. Practice task switching: Another strategy for getting more done is to shift periodically from one activity to another; for example, switching between physical, mental and social activities. 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 effective way to use task switching is to divide your activities into different categories of difficulty (light, moderate and heavy), switching frequently among different types and scheduling only a few of the most taxing activities each day.

6. Pay attention to time of day: Most people with CFS find they have better and worse times of 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.

A woman in one of our self-help courses discovered that her best time of day for mental activity was in the afternoon. If she studied then, she could read for twice as long as in the morning, with a higher level of comprehension. Some people with CFS report that mornings are their best times, with their energy waning as the day draws on.

7. Keep a health log: A few minutes a day of record keeping can show a clearer picture of your energy

profile 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 the effects on your health and energy. Records can also show you the rewards of staying inside your limits: what better motivator than fewer symptoms and a more stable life?

8. Develop personal rules:

Some people with CFS have had success using very detailed and individualized rules to protect them from doing too much. For example, one person I met with severe CFS has three rules that keep his energy and symptoms in balance: no more than three trips outside the house per week, no driving beyond 12 miles from home and no phone conversations longer than 20 minutes.

Other people develop rules for specific circumstances. For example, they might limit themselves to 15 minutes on the computer or two hours

of socializing. If you develop specific rules for yourself, you can simplify your illness management program and counteract brain fog by asking yourself two rote questions: What situation am I in right now? What is my rule for this situation?

9. 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 one person in our program 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 your internal dialogue so that it supports your efforts to live well with illness. For example, one woman in

our program says that she used to think she was lazy when she took a nap. Now, when she rests she tells herself, “I am helping myself to be healthy. I am saving energy to spend time with my husband or to babysit my grandchildren.”

In conclusion

Pacing is not a quick fix or a panacea. It requires many small adjustments in how you live your daily life. It’s not a single action or strategy, but rather a way of living with CFS. But the rewards of pacing, used consistently, are greater control, lower symptoms and, for some, expansion of the energy envelope and even recovery. ■

Bruce Campbell, PhD, created and directs the CFIDS/Fibromyalgia Self-Help program. Campbell has worked professionally at Stanford University on self-help programs for chronic illness, including the Arthritis Self-Help course and the Chronic Disease Self-Management course.

ADVICE TO A NEW PATIENT

What are the most important things to remember in coping with CFS? When Bruce Campbell asked CFS patients in his self-help program to describe what things they find most helpful in coping with their illness, here’s the advice he got.

1. Accept your illness.

Your illness is real, physical and long-term. While you should accept that your illness is long-term, you should also be hopeful because there’s much you can do to improve your life. Rather than fighting your condition, be compassionate toward yourself as someone with a serious illness.

2. Live within the limits of the illness.

Adjusting your activity level to the limits imposed by the illness is one of the most helpful coping strategies

ONLINE BONUS!

For more information on assessing your energy profile, pacing strategies and other self help for CFS visit Bruce Campbell’s website at www.cfidsselfhelp.org.

you can use. You have less energy than before, and if you try to do too much, you can intensify your CFS symptoms. But you can gain some stability if you learn to live within your limits.

3. Get support.

Chronic illness can be isolating and demoralizing. Others may not always understand or sympathize. Seek out support from fellow patients. Stay connected to family and friends to the extent possible, but be realistic in your expectations. Some people may never understand.

Other themes included keeping a positive attitude, educating yourself about the illness and resting daily.