

Minimizing Relapses: Pacing Yourself Through the Holidays

Bruce Campbell, Ph.D.
CFIDS & Fibromyalgia Self-Help Program
Palo Alto, California

www.cfidselfhelp.org

www.treatCFSFM.org

I'd like to thank the CFIDS Association for asking me to give this presentation. Like an earlier speaker, Dr. Lapp, I am including my remarks in the Notes section of the slides, which the CAA will make available on their website.

Speaking of Dr. Lapp, he announced during his webinar last spring that he and I were working together to create a website combining his Stepwise Approach with our emphasis on self-management strategies. That site is now available. It's called Treating CFS and FM: An Integrated Approach.

The Cost of Post-Exertional Malaise

Healthy person	\$100/day
Average PWC	\$ 25/day
If spend \$30,	\$ -5
Plus “Overdraft Fee” more)	<u>\$ -30</u> (or
Result	\$ -35

One way to understand pacing is by looking at what happens when you don't pace. Jenny Spotila drew our attention to this in her articles for the CFIDS Association on Post-Exertional Malaise (PEM), especially in the last article. PEM is the intensification of symptoms that results from overdoing, from being active beyond the body's limits.

I agree with Jenny that the key fact about PEM is that it is out of proportion to the overdoing. Let me explain using an idea from Dr. Lapp and also by giving you some examples.

Dr. Lapp talks about limits by saying PWCs get a certain number of "energy dollars" every day to spend on various activities. While a healthy person might get \$100 a day, the average PWC (functioning at 25% of normal) gets \$25. If the PWC overdoes it a little and spends \$30, they are in the hole by \$5, but in addition get charged a \$30 PEM "overdraft fee," putting them \$35 in the hole. They have to deposit \$35 to get back to zero.

Here are some examples:

John: One hour of extra gardening => rest of day in bed & 10-day relapse

Jane: One hour past limits => 1 day in bed

Several days over limit => 2-3 weeks in bed & loss of 6-7 months gains

Rose: Family visit => relapse lasting several months.

Key idea: Post-exertional malaise is very expensive, the penalty is out of proportion to the infraction.

Spending Energy Dollars

- Physical activity
- Mental activity
- Social activity
- Sensory limits
- Emotions
- Stress

So where do your energy dollars go? The first area that comes to mind is physical activity, things like bathing and dressing, cooking, cleaning and other housework, shopping, driving, standing, exercise and work, for those who are able.

But you also spend energy in other ways. For example, activities that require concentration, such as reading and working on the computer, use energy. The same is true of social activities, the time you spend interacting with other people, in person, on the phone or via email.

And then there are three other kinds of limits. One is vulnerability to sensory overload, which includes sensitivity to food and other substances (including medications!), vulnerability to noise and light, and sensitivity to weather and the seasons.

Experiencing emotions takes energy. For example, if you feel frustrated at how few energy dollars you have, that frustration will take some of your energy dollars. Finally, you can spend a large number of energy dollars on stress.

Special Events

- Non-routine times: holidays, travel, etc.
- Smaller envelope + pressure to do more
- Challenge: enjoy event & avoid relapse

Pacing is always a challenge but can be especially challenging during special times, such as the holidays. The end of year holidays are one example of something we call special events. These are out of the ordinary, non-routine times that challenge our ability to pace. Others include other family events, travel, moving and remodeling, and houseguests. For some people, going to a doctor's appointment or out to dinner could be a special event.

There are two key characteristics of special events: they shrink your envelope at the same time that you may feel pressured (by yourself, others or both) to do more.

Challenge: how can you enjoy the event without triggering a relapse?

Strategies for Special Events

- Rest, rest, rest
- Detailed planning
- Involve others

We have found that three strategies are helpful in meeting the challenge of special events and you can use them for all special events, not just coping with the holidays:

- Taking extra rest before, during and after the event
- Doing detailed planning for the event
- Discussing your plans with others

An example: Rose, the bedbound PWC for whom family visits had triggered relapses lasting several months, used these ideas to structure a visit from her step-daughter and seven year old step-granddaughter.

She prepared for the visit by reducing usual activities prior to the visit and using the time for extra rest.

Also, she created a plan to alternate days of socializing with days of quiet rest, and explained her plan to her step-daughter, who accepted it. She spent time with her step-granddaughter every other day, but in a quiet way that did not overwhelm her.

After her visitors left, she spent most of two days resting, then returned to her normal activities.

The result: no setback. Instead of a family visit leading to a several month relapse, it was an experience of control through pacing.

The message: Just as the punishment of PEM is out of proportion, the rewards of pacing can be out of proportion, too, in the other direction!

Rest

- Recuperative rest vs. pre-emptive rest
- Rest: lying down, eyes closed in quiet place

If you have experienced the push-crash cycle and PEM, you are familiar with one use for rest: to recover from relapses. But there is another way you can use rest: to prevent problems. Taking planned rests on a daily basis can help you reduce your symptoms, gain stability and, ironically, reduce your total rest time. We call this practice pre-emptive rest (PER).

"Rest" means lying down with your eyes closed in a quiet place. The optimal length of the rest period and the number of rests per day vary from person to person. Many people take one or two rest breaks a day of 15 minutes to half an hour each. To quiet their minds, some people use a relaxation procedure or listen to music while resting.

Rest can also be effective if it is taken as soon as symptoms appear. (The chili story.) One day a person in our program was cooking a big pot of chili and became very weak and tired. He was close to finishing and his first thought was "Finish the job; it will only take another 10 minutes." Then he remembered similar episodes when he ignored the signal and ended up needing to rest for two or three hours. So he turned off the heat under the chili, lay down for 15 minutes. When he got up, he felt fine and needed no more rest that day.

Fifteen minutes of rest taken in response to listening to his body enabled him to avoid two or three hours of rest later.

Planning

- List possible activities
- Prioritize
- Define limits
- Delegate, simplify, substitute, eliminate
- Plan B

The second strategy for mastering special events is detailed planning. Applying this to the holidays in five steps, first list everything special you would like to do between Thanksgiving and New Year's: shopping, decorating, cooking/baking, writing and mailing cards, attending parties and services, entertaining.

Include an estimate of how long each will take. For example, you might estimate that it will take 10 hours to send out holiday cards, including buying the cards and stamps, writing notes in some or all of the cards, stamping and addressing the envelopes, and mailing. Breaking each task into sub-tasks can help you to be more accurate in your time estimates and also suggests a strategy for minimizing the cost: divide a job into a series of small steps.

Once you have the list, prioritize the items from those that are most important to you to those that are least important.

Third, make an estimate of how much of your list is reasonable by defining your limits. (See the rating scale on our website: www.cfidselfhelp.org/files/rating_scale.pdf.) For example, if your energy envelope is about three hours a day, then you can be active about 20 hours a week. (That means all activities, not just holiday-related items.)

Fourth, if your wish list is larger than your envelope, reduce your activity level through delegating, simplifying, substituting and eliminating.

Delegating means finding someone else to do a task. For example, maybe a spouse, child or friend can do some of the shopping. Perhaps the family can put up decorations while you "supervise." Or you can change holiday meals by having someone else prepare them, having a potluck or going out to eat?

More Strategies

- Mental adjustments
 - Expectations
 - Self-Talk
- Educating & assertiveness
- Devices

Mental adjustments: Pacing means changing what we do, but also how we think.

• Changing expectations: Remembering energy dollars and imitating a koala.

• Changing self-talk: One person replaced “work until done” with “I rest when tired.” Another used to tell herself she was weak if she needed to take a rest. Now she says “rest gives me quality time with my husband and grandchildren.”

Educating & assertiveness:

• Teaching others about CFS: Colin gives repeated, specific reminders. Sunny educated her family using “For Those Who Care” brochure.

• Setting limits with others: Nancy: if say disabled but always respond “yes” to requests, people will keep making requests

Devices: computer (shop online), scooter (shop sitting down), stools & chairs, canes & wheelchairs, handicap parking tag, etc.

1% solution: gradual change, multi-year approach to holidays

Benefits of Pacing

- Less suffering (less PEM)
- Greater productivity
- More predictability
- Lower symptoms
- Sense of control
- Higher activity level (possible)
- Cost: Free

We've focused on one benefit of pacing: avoiding suffering because of less post-exertional malaise. In conclusion, I'd like to discuss other benefits that come from pacing.

First, you get more done. Some people think that because pacing means staying within limits, it means you get less done. But, if you don't spend lots of time out of commission because of PEM, you can be more productive.

Second, pacing produces greater stability and therefore predictability. Feel confident about accepting invitations!

Also, lower level of symptoms, control, possibly a higher activity level

Last: free!

Resources

www.cfidsselfhelp.org/library

Energy Envelope & Pacing

Managing Your Energy Envelope

(Summary of pacing in one article)

Pacing: What It Is & How to Do It

(Eight-part series)

Success Stories

Logs, Forms & Worksheets

Rating scale & many forms

Online Books

Managing CFS & FM: A Seven-Part Plan

If you would like to follow up on the ideas from the webinar, you can find many resources in the Library section of our website, including more than two dozen articles on pacing in the Energy Envelope and Pacing section. For an overview of pacing, see the article “Managing Your Energy Envelope.” For a more extensive discussion, see the eight-part series titled “Pacing.”

If you want to see how others have used pacing to improve, see the Success Stories section. For record keeping forms and a scale you can use to rate yourself, see the Logs, Forms & Worksheets section.

Lastly, for a comprehensive set of strategies, see our book “Managing CFS & FM,” which you can read online or purchase.