

CFS & Fibromyalgia Workbook:

Creating a Self-Management Plan

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Introduction

Living with CFS and/or fibromyalgia can feel overwhelming at times, but there are many things you can do to regain control. This workbook focuses on the area likely to produce the biggest gains: lifestyle change, which means adjusting your habits and how you live your daily life. This is a gradual process, changing one or two things at a time, but used consistently it can be transforming.

This class focuses on the two areas we believe are the heart of a self-management plan for CFS/FM: pacing and stress management. The next class (Self-Help III: Living Your Plan) offers support for integrating pacing and stress management into your life, and also focuses on other areas, such as treating symptoms, managing emotions, reworking relationships and creating a new life in response to loss.

Two disclaimers before we begin. First, this workbook will not make you better. Only you can do that. The workbook will give you the tools for feeling better and the class will offer you support, but you have to do the work.

Second, learning to live well with a long-term illness requires hard work, determination and patience. You will probably feel discouraged at times. When that happens, we hope you remember that many people before you have had similar feelings and have gone on to improve, one step at a time. The keys to improvement are a willingness to adapt and consistent use of the tools of self-management, especially pacing and stress management.

Chapter 1: Understanding Your Situation

When you develop a long-term condition like Chronic Fatigue Syndrome or fibromyalgia, you may feel like you have entered a new world in which all the rules of life have changed and there is no obvious way forward. This perplexing situation can make you feel helpless. But there are many things you can do to regain control and improve your well being. This workbook will show you how. Using the ideas you'll find here, you can create a plan for managing CFS and/or fibromyalgia.

When you first experienced CFS and/or fibromyalgia, you may have thought you had a short-term illness, but at some point, you were confronted by the fact that your problem was something quite different. Rather than a temporary problem, CFS and FM are conditions that persist. Instead of resuming your previous life after a brief interruption, you were faced with having to adjust to long-term symptoms and limitations.

CFS and fibromyalgia are different in a second way. Not only do they impose limits and bring symptoms that persist, they have comprehensive effects, touching many parts of life. They affect your ability to work, your relationships, your moods, your hopes and dreams for the future, and even your sense of who you are. Living with a long-term condition like CFS or fibromyalgia means much more than managing symptoms. A plan for managing them has to address all its effects.

Third (and perhaps most important), Chronic Fatigue Syndrome and fibromyalgia are affected by how you respond to them. There is so far no cure for either CFS or fibromyalgia, but how you respond to your situation has a big effect on symptoms and quality of life, often a larger effect than medical treatments. As Dr. Charles Lapp says, "There are limits to what your doctor can do." The key to recovery with these conditions, he says, "is acceptance of the illness and adaptation to it by means of lifestyle changes, for which medical treatment is no substitute."

Each person with CFS or FM is different, so your self-management plan should fit your unique situation. We begin with exercises to help you understand your individual circumstances.

Your CFS/FM (Severity)

The severity of CFS and FM varies greatly. Some people's lives are touched lightly, while others have their lives disrupted moderately and still others are housebound or even bedbound. To treat your illness effectively, you need to understand your version of CFS and/or FM.

You can get an overall idea of *your* CFS or FM by placing yourself on the Rating Scale on the next page. Place yourself on the scale by answering the question "What is the highest level of functioning I can sustain without intensifying my symptoms?"

Your rating gives you an idea of the severity of your illness and of the activity level your body can tolerate at present. For example, if you rate yourself at 30 (average for people in our program), your activity level would be about three hours a day.

My Self-Rating _____

CFS/Fibromyalgia Rating Scale	
100	Fully recovered. Normal activity level with no symptoms.
90	Normal activity level with mild symptoms at times.
80	Near normal activity level with some symptoms.
70	Able to work full time but with difficulty. Mostly mild symptoms.
60	Able to do about 6-7 hours of work a day. Mostly mild to moderate symptoms.
50	Able to do about 4-5 hours a day of work or similar activity at home. Daily rests required. Symptoms mostly moderate.
40	Able to leave house every day. Moderate symptoms on average. Able to do about 3-4 hours a day of work or activity like housework, shopping, using computer.
30	Able to leave house several times a week. Moderate to severe symptoms much of the time. Able to do about 2 hours a day of work at home or activity like housework, shopping, using computer.
20	Able to leave house once or twice a week. Moderate to severe symptoms. Able to concentrate for 1 hour or less per day.
10	Mostly bedridden. Severe symptoms.
0	Bedridden constantly. Unable to care for self.

Additional Medical Issues

Living with CFS or fibromyalgia is often complicated by the presence of additional medical problems. Many people have both CFS and FM. Also, CFS and FM are often accompanied by one or more other health issues. Other conditions often found together with CFS and FM include those listed alphabetically below. In addition, people with CFS and FM often experience conditions common to aging, such as arthritis, back and spinal problems, and high blood pressure.

- Chemical sensitivity
- Depression
- Food/digestive issues: Candida (yeast infection), Celiac disease, lactose intolerance
- Gastroesophageal reflux disease (GERD)
- Irritable bladder syndrome (interstitial cystitis)
- Irritable bowel syndrome (IBS)
- Migraine headaches
- Myofascial pain syndrome (MPS)
- Orthostatic problems such as neurally mediated hypotension (NMH) or postural orthostatic tachycardia syndrome (POTS)
- Prostatitis
- Restless legs syndrome (RLS)
- Sleep apnea
- Temporomandibular joint disorder (TMJ)
- Thyroid problems

Fill in your medical issues below, rating the severity of each from 1 (mild) to 10 (severe).

My Medical Issues	Severity	_____	Severity
CFS	_____	_____	_____
Fibromyalgia	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Your Life Situation

Just as people with CFS and fibromyalgia differ in the severity of their medical problems and in the number of illnesses they have, so do they come from many different life situations. Some people with CFS/FM are young; many are middle-aged; some are older. Some are married, while others are single. Some are raising children, while others are empty-nesters. Some are in supportive relationships; others in conflicted ones. Some are financially secure, while others are struggling.

Your challenges and the resources you have to deal with them will vary depending on your situation, especially your family circumstances (single or married and stage in life), your finances, your responsibilities (who is dependent on you: children, parents, spouse, grandchildren or others) and your sources of support (family, friends, church or other religious group, etc.).

Your situation includes two other significant factors: your coping skills and attitude. The good news: these factors can be changed. Research has shown that people can learn effective coping skills for managing long-term illness, either on their own or through self-help classes such as this one. Attitude is also important to living well with long-term illness. The attitude that seems to help is one that is both realistic and hopeful. We call it *acceptance with a fighting spirit*. People with this attitude combine recognition that life has changed with a conviction that they can find ways to improve.

For some examples of the effects of a constructive approach to CFS and FM, see the Success Stories on our website: <http://www.cfidsselfhelp.org/library/topic/Success+Stories>. For ideas on how to change your attitude, see the article [Optimism, Hope & Control](#).

Your Goals

What would you like to accomplish through using this workbook? People give different answers to this question. Here are some of the more common ones. The program is designed to help people achieve these goals.

1. **Reduce my symptoms.** One of the challenges of CFS and FM is living with symptoms that bring ongoing pain, discomfort and suffering. Reducing the intensity of symptoms and the extent of their interference with life is a goal for many people. The workbook will show you how to reduce symptoms by changing how you live. (For Dr. Lapp's recommendations on medications, see Treating Symptoms section at the website we developed jointly with him: www.treatcfsfm.org.)

2. **Regain control of my life.** Many people with CFS and FM experience repeated cycles of push and crash. They swing between periods of activity, which produce higher levels of symptoms, and times of forced rest. The cycle often leads to a feeling of helplessness. The workbook will show you how to get off this roller coaster and establish a more stable life.

3. **Learn how to avoid relapses.** Relapses are a frequent and often demoralizing experience for people with CFS and FM. In addition to creating additional pain and discomfort, they are often troubling, creating the worry that you will never gain control or make lasting improvement. The workbook will show you how to minimize relapses by being consistent in pacing.

4. **Have a more predictable life.** Many people with CFS and FM find it very difficult to plan and feel undependable because their symptoms vary greatly from day to day and they aren't able to predict how much energy they will have ahead of time. By adapting to the body's limits and living consistently within them, you can have a more predictable life.

5. **Do more without triggering a relapse.** For many with CFS and FM, the only way to get more done is to go outside their limits and pay for overdoing with a relapse. The workbook will show you another way. Pacing offers the possibility to increase activity level without triggering a relapse.

6. Accomplish and contribute more. People with CFS and FM often ask “how can I contribute when my old self is gone and I have such severe limits?” For ideas, see the “Your New Life” section on www.treatcfsfm.org.

We ask you to state your goals before you start, because they provide a reference point and motivation. The path with chronic illness has its ups and downs. When you feel discouraged, reminding yourself of your goals can re-motivate you and help you “stay the course.”

My Goals

Chapter 2: The Energy Envelope

Many people with CFS and FM find themselves caught in repeated cycles of push and crash, swinging between overactivity and forced rest. When their symptoms are low, they push to get as much done as they can. But doing too much intensifies their symptoms and they crash.

Pacing offers an alternative, a way to live a more stable and predictable life by finding and then adjusting to your current capabilities. With pacing, you can live your life according to a plan, rather than in response to symptoms, so you have 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
- More accomplished
- Chance for improvement

Pacing can help you reduce the suffering that results from overdoing. One hallmark of CFS/FM is post-exertional malaise (PEM), the intensification of symptoms that results from overdoing. The amount of rest needed to recover from PEM is out of proportion to the overactivity, a punitive price even for small mistakes. It is not uncommon for PEM to last days, weeks or even months. Keeping the price of overexertion in mind is one motivator for pacing.

One way to understand PEM is to think in terms of “energy dollars.” Each one of us gets a certain number of energy dollars to spend each day. A healthy person might get \$100, but the average person with CFS or FM is likely to get something like \$25. If a person with CFS/FM spends \$30, they are in the hole by \$5, but in addition get assessed a \$30 PEM penalty fee for overdrawing their account. They have to deposit \$35 to get back to zero.

The goal in pacing is to live consistently, doing a similar amount of activity each day and taking a similar amount of rest. The rest of this chapter and the next two chapters provide the tools you can use to move toward consistency.

The Big Envelope & the Little Envelopes

As mentioned, pacing involves discovering and adjusting to the limits imposed by CFS and FM. You can think of your limits in two ways:

1) The Energy Envelope

The overall activity level you can sustain without intensifying your symptoms, measured in hours per day. You got an idea of your overall envelope by placing yourself last week on our Rating Scale.

2) The Little Envelopes

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. We suggest you look at limits in six different areas.

Physical Activity: We have limits for activities such as bathing and dressing, chores, gardening, shopping, walking and driving. 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. If worse, try less.

You will likely find that the effects of activity may be delayed and are often cumulative over several days. It is often possible to reduce symptoms by having several short activity periods rather than one long one. Also, the amount of activity that can be done without intensifying symptoms may be dependent on time of day (some people do better in the morning, others in the afternoon or evening).

Mental Activity: Activities requiring concentration, like reading, working on the computer or balancing a checkbook also make demands on our energy. People have different limits on the total amount of mental activity they can do in a day without worsening symptoms and also limits on the amount in an individual session. Again, you can find your limits by experimenting.

Social Activity

Consider the time you spend interacting with other people, either in person or on the phone and assess that energy toll. People have limits on the total amount of social time they can tolerate. The amount of time may be depend on the specific people involved and the situation. You may tolerate only a short time with some people, but feel relaxed around others. Also, the setting may be important. Meeting in public or with a large group may be stressful, but meeting privately or with a small group may be OK. By noting your reactions to different situations, you can get a picture of this envelope.

Sleep and Rest

This factor refers to the quantity and quality of sleep at night and rest during the day. Questions to ask in this area include how many hours of sleep do you need? What is the best time to go to bed and to get up? Can I reduce symptoms by taking daytime rests? If so, how many rest periods and how long?

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.

Stress & Emotions

Stress is increased and emotions made stronger by long-term illness. Finances can be great sources of stress due to loss of income, worries about disability payments or feeling forced to work when symptoms are strong. Long-term illness changes relationships, creating new obligations and also new strains and frustrations. Family and friends may not understand. Strong feelings, such as sadness, worry, frustration and guilt, are common and understandable reactions to all the changes and uncertainties brought by illness.

Chapter 3: Pacing Strategies

Once you know your limits, your next challenge is to adapt to them. This is a gradual process, usually taking a period of months to years and involving the use of multiple strategies.

The master strategy for most people is to reduce their overall activity level so it fits within their body's limits. You can reduce your activity level using a combination of delegating, simplifying and eliminating. *Delegating* means finding someone else to do a task that you used to do. For example, have other family members do the grocery shopping or hire a cleaning service. *Simplifying* means continuing to do something, but in a less elaborate or complete way. For example, you might clean house less often or cook less complicated meals. Also, you will probably have to *eliminate* some activities.

Suggested Places to Start

There are many other pacing strategies as well. We recommend two as particularly important: scheduled rests and setting limits for individual activities. We suggest you start with them, but feel free to begin with another pacing strategy if it has greater appeal to you.

Scheduled Rests

Taking planned rest breaks every day gives you a way to control your symptoms, bring greater predictability to your life and reduce your total rest time. In contrast to rest taken as a way to recover from intense symptoms (*recuperative rest*), scheduled or *pre-emptive rest* is a strategy for avoiding flare-ups and escaping the cycle of push and crash.

Pre-emptive rest involves taking scheduled rest breaks every day. For people with light to moderate CFS/FM, this might mean one or two rests of 15 minutes to half an hour each. Those with severe CFS or FM may benefit from taking multiple brief rests a day, for example a 10 to 15 minute rest every hour or two.

Scheduled rest is a popular energy management strategy because it is straightforward and brings immediate benefits to most people who use it: greater stability, reduced symptoms and greater stamina. Scheduled resting often results in a reduction in total rest time, because of a reduction in crashes that require long rest periods for recovery.

If you want to try scheduled rest, we recommend you start with lying down in a quiet place with your eyes closed. If you find yourself distracted by your thoughts, try using a relaxation technique (see the discussion of relaxation in chapter 5) or listening to music or to a relaxation CD.

You may be tempted to skip your rests on days when you are feeling good. At such times, it may be helpful to remind yourself that by taking scheduled rests, you are avoiding symptoms, and more rest, in the future. Resting according to a fixed schedule, not just when you feel sick or tired, is part of a shift from living in response to symptoms to living a more stable life.

For more, see the article [Nurture Yourself with Pre-Emptive Rest](#).

Limits for Individual Activities

Another strategy is to set limits on particular activities. This can mean that you stop doing some things entirely or, more commonly, that you reduce the amount of time you spend doing something so that you stop before your symptoms intensify (“stop before you drop”).

For example, you may set limits on how long you stand, how long or how far you drive, how long you spend on the computer or the phone, the time you spend socializing, how far from home you will travel, and how long you will spend doing housework (or even which chores you will do).

A good starting point for people with moderate to severe CFS/FM is to set a limit on trips outside the house. For many people rating themselves from about 20 to 35 on our scale, a typical limit is two or three outings a week. For people who are lower, the limit might be one trip per week or less (with extra rest before and after).

You can find your limits by experimenting and then enforce your limits by using a timer and notes to yourself. For some further examples of limit setting, see the article “[25 Reasons Why I’ve Improved](#).”

If you have trouble falling asleep at night, consider establishing a wind down period, typically an hour or so before bedtime. Thus, if your bedtime is 10:30, your wind down would start at 9:30. The wind down may involve turning off the computer and television and may include a bath, reading or some other relaxing activity.

Other Pacing Strategies

Over time, you may also use some, or even all, of the following additional pacing strategies.

Short Activity Periods

In addition to controlling symptoms through limiting your overall activity level, you can affect your symptoms by adjusting *how* you are active. For example, 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 example, one person in our program does ten minutes of housecleaning, rests for five minutes, then does another ten minutes of cleaning.

The same principle can be applied over longer periods of time. You may find, for example, that your overall symptom level is lower if you spread activities through the week, rather than trying to do many things in one or two days.

Activity Shifting

Another strategy for getting more done is to shift frequently from among 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.

The Rule of Substitution (Pigs at a Trough)

It's easy to do "just one more thing," but this often leads to higher symptoms. The solution: think of substitution rather than addition. In order to add a new item to your schedule, drop one. For example, if your envelope allows you to leave the house three times a week and something new arises, find a way to postpone one of the usual outings in order to honor your "three times a week" limit. This approach is sometimes called "pigs at a trough." There is limited space beside a trough. The only way a new pig can get in is to squeeze another out.

Time of Day

Most people with CFS and FM 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 with less impact on your symptoms if you change *when* you do things, so that you use your best hours for the most important or most demanding tasks.

One person says, "I have a window between 8 and 11 in the morning that is best for most activity, both mental and physical." Another person reports that her best time of day for mental activity is in the afternoon. If she studies then, she can read for twice as long as in the morning, with a higher level of understanding.

Sensory Input

Many people with CFS and FM have an increased sensitivity to sensory information, especially light and sound. They find their concentration is affected by having too much sensory input. If this is true for you, you may be able to get more done and experience a lower symptom level if you focus on one thing and simplify your environment. For example, you may be able to understand what you read better if you turn off the TV while reading or move to a quiet place. If noisy restaurants bother you, try visiting during non-busy times. If you find large groups difficult, try getting together with only a few people. If media bother you, limit your exposure.

Devices

You may be able to get more done, avoid symptoms or both by using devices to help you. For example, you can use a pedometer (step counter) to find and then limit your physical activity. Similarly, you can use a heart rate monitor to keep your heart rate within safe limits. For specifics, see the articles [Pedometers: A Tool for Pacing](#) and [Pacing By Numbers: Using Your Heart Rate to Stay Inside the Energy Envelope](#).

If you tire quickly or feel faint while standing, consider sitting down whenever possible, for example to prepare meals and while showering (use a plastic stool or chair for the latter). Some people with CFS and FM, who can't stand for long, who are sensitive to sensory input or both find shopping easier if they use a scooter or motorized cart. Many large stores have such devices, which they make available for free.

Other devices include timers (to tell you when to do things or to stop), grab bars in the bath, grabbers, canes and wheelchairs, and handicap parking tags.

Pleasure

Living with a chronic condition means ongoing discomfort and frustration. Pleasurable activities reduce frustration and stress, distract you from your symptoms and give you things to look forward to. Planning to have some time daily to devote to enjoyable activities can make it easier to accept your limits.

Mental Adjustments

Pacing means adopting new habits, but it also requires making mental adjustments rooted in an acceptance that life has changed. 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 our internal dialogue (self-talk) and expectations, so that they support your efforts to live well with illness rather than generating guilt. For example, one person 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 baby sit my grandchildren.” Another person says, “I now accept the fact that I have a chronic illness and that this condition has, and will continue to, put great constraints on how I live. I now have a ‘half life’ but I am going to make it the best ‘half life’ that I can.”

Another technique supporting this shift is call the Fifty Percent Solution. Estimate how much you think you can accomplish, then divide that in two and aim to do the lesser amount. Another idea is to make a “[NOT TO DO List](#).” Having such a list gives you permission to eliminate activities without feeling guilty about it.

Daily and Weekly Schedules

The goal of pacing is to move gradually toward consistency, having similar amounts of activity each day. Planning can be an aid to consistency, beginning with creating a daily schedule and moving on later to making a weekly schedule. For more, see the discussion of planning in the next chapter and also [The Pacing Lifestyle](#), chapter 10 in the introductory course textbook.

Reduce Activity Level for Special Events

Anything out of the ordinary --a vacation, a holiday celebration, a wedding, move or remodeling, having houseguests or even perhaps having people over for dinner-- creates a challenge if you have CFS and/or FM. Non-routine events require more energy than you normally use and thus temporarily shrink your envelope, thus making you vulnerable to a relapse. You can protect yourself against intensified symptoms by reducing your activity level and using the other strategies described the article “[Strategies for Special Events](#).”

In the worksheet below, check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

Pacing Strategies	Tried Y/N	Rating -5/+5	Use in Future
Lower overall activity level			
Delegate			
Simplify			
Eliminate			
Scheduled rests			
Limits for individual activities			
Physical activity			
Mental activity			
Social activity			
Short activity periods			
Activity switching (light, moderate & heavy)			
Rule of substitution			
Time of day			
Control of Sensory input			
Devices			
Chairs & stools			
Scooters			
Step counters & heart rate monitors			
Pleasure			
Accept your limits			
Use daily and/or weekly schedules			
Reduce activity level for special events			

Chapter 4: Consistency in Pacing

While many people with CFS and FM believe that their life would be improved if they paced themselves, they find it difficult to do so consistently and the benefits of a more predictable life, a lower level of symptoms and an increased sense of control remain beyond reach.

But it is possible to pace consistently, by replacing one set of habits and routines with a new set. Doing so takes patience, discipline and effort, but you can make it doable if you focus on one thing at a time from the strategies and techniques described in this chapter.

Suggested Places to Start

Here are two consistency strategies that many people find especially helpful. We recommend you start here, but feel free to try whatever strategy appeals to you.

Listen to Your Body

You can gradually retrain yourself to listen and respond to the signals sent by your body. Instead of ignoring your body, you can learn to hear and respond to the body's warning signs. In the words of one person, "Getting well requires a shift from trying to override your body's signals (in order to continue what you were doing) to paying attention when your body tells you to stop or slow down." Another person said, "I've had to learn to replace 'work until done' with 'stop when tired.'"

Here's an example the benefits of listening to the body. A person in our program was cooking a chili one day 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, a 10 to 1 payoff.

Personal Rules

Pacing may seem daunting at first, but you can think of the process as replacing a set of habits and routines that no longer fit your life with a new, more appropriate set. Over time, the new set can become second nature.

One bridge from old to new habits is to use detailed and individualized rules. Rules are planned responses to various situations. Living by a set of rules reduces the power of spontaneity to overwhelm good judgment. Rules show you how to substitute new ways of doing things for old habitual behaviors. Over time, the new behavior becomes a habit.

Rules can take several forms. First, you might begin by stating a few rules crucial to controlling symptoms. For example, one person who rated herself at 25 on our scale had three rules: no more than two trips outside the house per week, no driving beyond 12 miles from home, and no phone conversations longer than 20 minutes. If you are bothered by brain fog, you might consider

taping rules in some prominent place, like the refrigerator, the bathroom mirror or your computer.

A second approach is to create a set of rules covering specific circumstances. For example, you might establish rules for how long you stay on the computer, how long you talk on the phone, how much exercise you do, when you go to bed at night and get up in the morning, when and how long you rest during the day, how long you spend in social situations and so on.

If you develop specific rules, you can simplify your illness management program into asking yourself two questions: What situation am I in right now? What is my rule for this situation? Personal rules have an if/then structure. For example:

- If I've been on the computer for 20 minutes, then it's time to take a 10-minute break
- If it's 11 am, then it's time for my morning rest.
- If it's 9 pm, then it's time to start getting ready for bed

Third, you might write down your strategies for symptom management and carry them with you on a card or post them on the refrigerator or bathroom mirror. For example, for managing fatigue, people in our program often mention taking daily rests, getting enough sleep, limiting the number of times they leave the house each week, breaking up tasks into small chunks and limiting the time spent standing up. For managing pain, common strategies include pain medications, exercise, adequate sleep, daily rests, massage and heat and/or cold.

Other Strategies for Consistency

Over time, you will also probably use some, or perhaps all, of the following strategies.

Make Changes Gradually

You may feel overwhelmed at times when you think of all the adjustments you have to make to live well with CFS or FM. The solution: focus on one thing at a time. One person described how she changed by saying, "The transformation into a more disciplined person was a long-term process. The changes have been introduced gradually over time. And I make sure I find the right one before I move on to adding the next."

Use Routine and Reminders

Having a regular daily schedule eliminates a lot of decision-making. One person in our program said, "Instead of having to ask whether something is or is not within my envelope, I have tried to stick to a schedule I know is safe." Another says, "Except in special circumstances like Christmas day, I do roughly the same stuff at roughly the same time of day....[I've done it for so long that] it's not a mental battle to do it - it's just the way my day is." For a success story describing the use of routines, see the article [Getting the Most from Limited Energy](#).

While pacing may seem daunting at first, it can become second nature over time as one's daily habits are altered. Reminders can be helpful, for example, a timer to limit the length of computer sessions.

Planning: Daily & Weekly Plans

Pacing often begins with putting limits on individual activities or taking scheduled rests, but over time it can become a lifestyle as you learn to live according to a plan rather than in response to symptoms. To the extent you can live according to your plans, you will achieve a more predictable life, gain an increased sense of control over your illness, and may be able to expand your energy envelope.

A beginning point for planning is something like setting aside several times each day for rest breaks or having a wind down time before going to bed. Then you can go on to planning a day at a time. In the morning or the night before, list possible activities for the day. Then evaluate your list, asking whether you will be able to do everything on it without intensifying your symptoms. If not, identify items that can be postponed, delegated or eliminated. One person in our program described her planning as follows: “Every evening I list my appointments and possible other activities for the following day. By doing this, I can recognize activities that I really don’t have to do, but that can be postponed. This frees up my days for my targeted rest time.”

When you feel comfortable planning one day at a time, try moving on to planning longer periods, such as a week. The challenge here is to estimate what level of activity you can sustain over a period of time without worsening symptoms. Consistency in activity level brings control. You can find your sustainable activity level through experimentation. Maybe you can be active for two hours a day, four hours or even fourteen. The way to determine your limit is by trying different amounts of activity and noting the results.

Stop & Choose

One way that people get pulled outside their limits is by giving in to the temptation of doing something that seems appealing in the moment. A way to avoid such lapses is to stop before you act and realize you have a choice.

One person in our program carries a card in her purse to remind her of the consequences of overactivity. On one side, it says “What’s the Trade-Off?” The other side reads “Just Say No.” (An alternative to the second part is to ask: Am I willing to accept the consequences?)

Another person visualizes how she would feel if she went outside her envelope. She says, “Imagining the fatigue and brain fog provides a counterweight to the immediate pleasure I anticipate from doing something that takes me beyond my limit.” A third person has sayings she uses to remind her of alternatives. One is “I can finish this task and crash or listen to my body and stop.”

Alternatively, you can focus on the positive and give yourself reminders of what you gain through pacing. For example, you might post notes to yourself in prominent places in your house, saying things such as “Staying within my limits gives me a sense of control,” “Pacing reduces my symptoms,” and “Pacing makes my life more stable.”

Adjust Your Expectations

Many strategies for succeeding at pacing require the development of new habits and routines, which in turn are based on reduced expectations. The ability to develop new expectations is rooted in adopting a different attitude, a particular kind of acceptance.

As explained by recovered CFS patient Dean Anderson, this acceptance is not resignation, but rather “an acceptance of the reality of the illness and of the need to lead a different kind of life, perhaps for the rest of my life.”

Some people find it helpful to compare themselves to other people with CFS and FM rather than to healthy people. Coming to acceptance is a process that often takes several years, but it has significant benefits. In the words of one person, “I’ve discovered that I can now be perfectly at peace with lowering my expectations as I know too well what happens when I try to push the envelope and then relapse!!”

Keep Records

Keeping a health log, which should take no more than a few minutes a day, can help you gain consistency in pacing in at least three ways.

First, records can help you get a clearer picture of your limits and reveal the connections between what you do and your symptoms. With records of your activity level and your symptoms, you can see how much activity you can do safely in a day and a week, and whether there are delayed effects. Also, a log can show the effects of mental and emotional events, as well as physical activity.

Second, a log can help you hold yourself accountable for your actions by documenting the effects of your actions. Reviewing your records can be like looking at yourself in a mirror. As one person in our program said, “Logging brings home to me the reality of my illness. Before logging, I didn’t realize that most of my time is spent on or below about 35% functionality. This false perception that I was better than I am led me to overdo things, but now I am less ambitious.”

Third, records can motivate you by showing you that staying inside your limits pays off in lower symptoms and a more stable life. Records of progress can provide hope. For more on record keeping, see [Logs, Worksheets and Rules](#) in our introductory course textbook.

Forgive Yourself

No one stays in their envelope all of the time. Life has its ups and downs; some times are more stressful than others. Instead of beating yourself up when you slip or circumstances overwhelm you, it’s better just to ask, “What can I learn from this experience?” and move on.

For more on how to change your “self-talk” (internal monologue of thoughts about yourself) to be more supportive, see the article [Taming Stressful Thoughts](#) or [chapter 31](#) in the introductory course text.

Learn Assertiveness

Some people with CFS and FM have difficulty acting in their own interest. In some cases, the answer is to learn assertiveness. Assertiveness means finding your limits and then communicating them to others. One person in our program reported that she was able to avoid setbacks when she learned to speak up for herself. She wrote, “Communicating clearly when I need medicine, rest or quiet time and taking time for these things when I need them all help me to prevent a relapse.”

Consider Counseling

Other people have a habit of putting others’ needs ahead of their own. Sometimes called “people pleasers,” these individuals with CFS and FM have difficulty setting limits or saying “no” to others. Because of this view, people pleasers may not take care of themselves. This trait can be deeply ingrained and may require counseling to change.

In the worksheet below, check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

Strategies for Consistency	Tried Y/N	Rating -5/+5	Use in Future
Listening to body			
Personal rules			
Gradual change			
Routine & reminders			
Daily & weekly plans			
Stop and choose			
Adjusting expectations			
Keeping records			
Forgiving yourself			
Using assertiveness			
Counseling			

Chapter 5: Managing Stress

If you have CFS or FM, you face a double challenge because of stress. First, CFS and FM bring new stresses to your life, such as ongoing symptoms, isolation, financial pressure and uncertainty about the future. Second, CFS and FM make people more stress sensitive, so a given level of stress takes a greater toll than it would on a healthy person.

Because of this combination, people with CFS and FM often feel under chronic stress, with their fight-or-flight mechanism stuck in the “on” position. For all these reasons, address stressing is a high priority.

Sources

One reason that stress is such a big challenge in CFS and FM is that it can come from many different sources. They include:

Symptoms	Ongoing discomfort is debilitating and worrisome
Limits	Frustration due to smaller energy envelope
Loss	Many losses: health, income, friends, etc.
Isolation	Stress from time alone and from feeling different
Money	Financial pressure
Relationships	Often strained; some may end
Thoughts	Unrealistic expectations or feeling helpless
Uncertainty	Worry about the future
Sound/Light	Sensitivity to sense data
Allergies	Sensitivity to foods and/or chemicals

Approaches to Managing Stress

Because stress is so common and so debilitating, we recommend you use multiple techniques to manage it.

Some pacing strategies also help with stress. These include reducing overall activity level, learning to be assertive (saying “no”), taking daily rests and using routine. For some people, a changing jobs can be a stress reduction measure. Work changes include switching from full-time to part-time work, moving to a less demanding job, working from home, adopting a flexible schedule, and taking early retirement.

Other frequently-used stress management approaches include doing a daily relaxation procedure, de-cluttering (e.g. reorganizing the kitchen or discarding unused possessions), limiting exposure to the media, limiting contact with some people, avoiding crowds, getting help with household chores and making mental adjustments (such as letting go of unrealistic expectations).

A typical stress management plan might include a daily relaxation procedure, daily exercise, regular rest breaks, having pleasurable activities every day, living by a schedule and avoiding noisy environments and negative people.

Here are a couple of examples from people in our program. One person in our program says, “I do a variety of things to manage stress, such as deep breathing, listening to relaxation tapes, getting regular massages, walking with my dog, and writing in my journal.” Another writes, “The ways I try to handle stress are: meditating daily, scheduling a regular time [to go to] bed each night, keeping our home an emotionally welcoming place for my husband, engaging in pleasurable activities, and avoiding unwanted situations [that] drain my energy.”

Suggested Place to Start

We especially recommend two stress management strategies: a daily relaxation period and modifying self-talk. These two will be described in detail, followed by more than a dozen additional strategies. As with pacing strategies, these are only suggestions. Feel free to try another strategy if you prefer.

Relaxation

When we become stressed in the face of challenge, we often respond with a fight-or-flight reaction. Adrenaline flows, and we feel charged up. If the challenge is brief, the initial reaction is followed by relaxation. If, however, you feel yourself to be under constant threat, as you may if you are always in pain, your body stays in a state of tension.

Physically relaxing activities counteract both the physical and the emotional aspects of stress. Through relaxation, you can reduce muscle tension and anxiety. Relaxation is also very helpful for pain control. Combining rest with a relaxation procedure or meditation can be an even more effective means of stress reduction and, over time, can help you turn off the fight-or-flight response and enter deep relaxation.

Examples of relaxation procedures include focusing on your breathing, the body scan, progressive relaxation, the relaxation response and guided imagery. (You can find step-by-step instructions for these and other relaxation procedures the [Controlling Stress](#) chapter 13 of the 2006 edition of our introductory course text.) Because everyone is different, some techniques work well for one person and other techniques work better for another. In particular, techniques using imagery seem very helpful to some people, but not useful to others. Try several techniques to see what works for you. Also, you may find that a particular technique works for a while, and then becomes ineffective. If that happens, try something else.

It usually takes several weeks or more of practice to develop skill in using a technique, so allow some time before expecting results. To be fair, you should practice four or five times a week, setting aside ten to 20 minutes for each session and choosing a time when you won't be disturbed. Learning concentration is a common problem when doing a relaxation practice. The mind tends to wander, so having patience is necessary.

We recommend combining a relaxation procedure with daily scheduled rests. Doing the two together provides a way to quiet the mind and turns off the fight-or-flight response, producing deep relaxation.

There are many good relaxation and meditation tapes available today. Some have step-by-step instructions to lead you through a relaxation procedure, while others have music or relaxing sounds from nature. You may want to use such tapes or record your own from the techniques you find on our website or elsewhere. If relaxation makes you anxious or seems unpleasant, try other stress reduction techniques.

Formal relaxation procedures work for many people, but other, less formal approaches can help, too. These include exercise, baths, massage, acupuncture, rest and listening to relaxation tapes or music.

Mental Adjustments

Your thoughts can be another source of stress. For example, you may have unrealistic expectations. You may think that as a “good mother” or “good wife,” you should keep the house as you did before becoming ill. If that’s the case, you can reduce suffering by changing your expectations, so they better match your current abilities. Becoming aware of and changing the standards you have for yourself reduces stress and helps you avoid overdoing.

It may also help to change your expectations about how others view you. As one person said, “I let go of expecting people to respond to me the way I think they ‘should’. For example, I let go of expecting that people will understand my disease. So with no expectations, I [feel] less resentment, which leads to less stress in life.”

Thoughts can increase stress through our “self talk,” the internal dialogue we have with ourselves, especially about negative events. For some people, an increase in symptoms may trigger thoughts like “I’m not getting anywhere,” “I’ll never get better” or “It’s hopeless.” Negative thoughts like these can then make you feel anxious, sad and helpless. The thoughts and the stress they create may make your symptoms worse and trigger another round of negative thoughts. The cycle can be very demoralizing, leading to an overly pessimistic view of your situation and making it difficult to motivate yourself to do things to feel better.

But you can learn how to recognize and change habitual negative thoughts so that your self-talk is more realistic and more positive. There are many self-help manuals for doing this. Our favorite is *Mind Over Mood* by Greenberger and Padesky. Others include *Feeling Good* by Burns and *Learned Optimism* by Seligman. Also, you can get professional help; look for a counselor who specializes in Cognitive Therapy, also called Cognitive Behavioral Therapy (CBT). For an introduction to Cognitive Therapy, see the article [Taming Stressful Thoughts](#).

Other Stress Reduction Strategies

Here are 11 more stress reduction strategies:

Supportive Relationships: Family, Friends and Professionals

Good relations are a buffer against stress. Feeling connected to people who understand and respect you reduces anxiety and counteracts depression. Beyond that, talking to another person may help you clarify your situation or the response you receive may enable you to see your life in a different, more constructive way. You may receive such support from family members, friends, other people with CFS and FM or therapists. Support also means practical assistance, which might include such things as shopping, cooking, bill paying or housecleaning. For more on this topic, see the section on relationships.

Problem Solving

Taking practical steps to improve your situation can also help reduce anxiety and worry. A member of one of our groups, who suffers from severe brain fog, reported that she had gone to the emergency room after taking her medications three times in one day. Worried that brain fog might lead her to make the same mistake again, she asked her group for suggestions and adopted one of them: a pill box with compartments for each day of the week. Using the pill box greatly reduced her fear of repeating her mistake, and thus was a stress reducer for her.

Another person in our program reported, “I have spent quite a bit of time analyzing my activities, everything from how long I stayed somewhere to ways to minimize pain in doing chores. From this analysis, I have tried many different ideas that have proved to be very helpful.”

Information

Educating yourself about CFS and FM can be a great stress reducer, as you replace fears with facts. Two places to start, on our website, are [Basic Facts About CFS and FM](#) and the article [Educate Yourself](#), part of the series “Eight Steps to a Better Life.”

Pleasurable Activities

Doing things that bring you pleasure can distract you from stress and reduce preoccupation with problems. Listening to or playing music or engaging in other artistic pursuits are good stress reducers. The same can be said of reading a good book, seeing an engrossing movie, spending time in nature and talking with a friend. The key is to find an activity in which you can become absorbed. By immersing yourself, you interrupt the worry cycle, distract yourself from symptoms and experience some relaxing pleasure.

Exercise and Movement

Exercise is a natural stress reducer, since it causes your body to produce endorphins and other soothing body chemicals. A similar effect can be obtained through other forms of movement. If you are worried, just getting up and moving around can help break the spell.

Journaling

Writing may be useful as a stress reducer. You might find it helpful to write out what’s bothering you as a way of venting frustration and lessening worry. Another use of journaling is to help you change perspective on your life. Some people have told us they found it very helpful to keep a journal in which they note positive events every day. Over time, they found that their mental attitude toward their illness and their life changed in a positive direction. See Joan Buchman’s

article [The Healing Power of Gratitude](#). For a model of a gratitude journal, see Sarah Ban Breathnach's book *Simple Abundance Journal of Gratitude*.

Talking and Being Listened To

It is not surprising that, in a survey, talking to a friend was rated as the number one way to combat worry. Talking to someone you trust provides reassurance and connectedness to dispel worry. According to Edward Hallowell, studies have shown that talking to another person changes what is happening in your brain at a physical level.

Laughter and Humor

This is another good stress reducer. Watching a funny movie, reading a humorous book, looking at favorite cartoons or laughing with friends can be a great release. Like exercise, laughter promotes the production of endorphins, brain chemicals that produce good feelings and reduce pain. Research suggests that it can strengthen the immune system, counteract depression and even provide a substitute for aerobic exercise. Short periods of laughter can double your heart rate for three to five minutes. A natural tension reducer, laughter produces relaxation for up to 45 minutes.

Solitude

For some people, just having time alone can be helpful. One person wrote, "I spend much of my time in quiet, relaxing activities such as reading, needlework, etc. If I have a day that does not allow me to participate in these activities to some minimal extent, I find myself extremely tense, stressed out and emotional."

Assertiveness

By speaking up for yourself, setting limits and saying "No," you protect yourself and avoid doing things that intensify symptoms. For example, you can teach your family and friends to respect your need for rest times and can make your limits clear by telling others how long you'll talk on the phone or how much time you will spend at a party. By having a "voice," you reduce the stress that results from keeping things inside.

Learning to delegate and ask for help are also stress reducers. Others often feel as helpless as you about your illness; asking them to help you in some specific way replaces the sense of helplessness with a feeling of accomplishment.

Medications

Prescription medications can be helpful as part of a stress management program. As one person in our program wrote, "I resisted the idea [of medications] for a long time, and now kick myself for having done so. [Zoloft] has helped level off my reactions to everyday stress and evened out my mood."

Stress Avoidance

In addition to stress reduction, there is a second major approach to stress management: stress avoidance. This other approach is preventive, using self-observation to learn how stress affects you and then taking measures to avoid stressful circumstances.

For example, you may notice that when you hit a limit, any further activity will intensify your symptoms. In such circumstances, rest can reduce the stress on your body. Having good relationships are a buffer against stress. People with supportive relationships have lower anxiety and depression, so support is a strategy for stress avoidance as well as being a way to reduce stress.

Overall, the idea of prevention is to avoid generating a stress response by avoiding stressful situations. Fewer stress hormones means more time for your body to repair itself. The main ways to prevent stress are by avoiding stress triggers and by using pacing, order and routine.

Avoiding Stress Triggers

There are three types of stress triggers: a) substances that create allergic reactions, b) situations that produce sensory overload and c) particular people. You can reduce symptoms by avoiding foods and other substances to which you are allergic or sensitive, minimizing situations that create sensory overload and limiting contact with anxious, negative or overly-demanding people.

If you are particularly sensitive to light, noise or crowds, or experience sensory overload in other ways, avoiding or limiting your exposure to those situations can help you control symptoms. For example, if you are susceptible to sensory overload, you may socialize mostly at home or in small groups, limit your time in crowded stores or go to restaurants at off-peak times. Also, many people with CFS and FM are selective about their exposure to television and movies, avoiding material that is emotionally arousing or has rapid scene changes. Some people have “media fasts,” periods in which they watch no television, listen to no radio and ignore newspapers.

Some people with CFS and FM experience high levels of stress when they interact with people who are anxious, negative or demanding. Responses they have made include talking with the person, limiting contact, getting professional help, and ending the relationship. As one person wrote, “I have cut people out of my life that only irritate or don’t support me. It was a hard thing to do but has made a big difference in how I feel.”

Pacing, Order and Routine

Pacing strategies reduce stress. Reducing activity level, scheduling activity based on priorities, having short activity periods, scheduling important tasks for your best time of day, taking regular rests, and taking time for meditation or prayer all help control stress. As one person wrote, “I found that I could avoid much stress by knowing my limits. Planning too many activities in one day or scheduling them too close together are big stress triggers, so I try to prevent their activation by limiting the number of activities in a day and by giving myself plenty of time in between activities.”

Another way to avoid stress is through order. If you’re bothered by clutter and disorder, you may benefit from working to bring order to your house. For some tips and a success story, see the article [Illness and Housekeeping](#).

And a third stress avoidance strategy is routine: doing things in familiar ways and living your life according to a schedule reduces stress by reducing decision making and increasing predictability. It takes more energy to respond to a new situation than it does to something familiar, so by reducing the surprises and novelty in life, you reduce your stress.

In the worksheet below, check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

Strategies for Stress Management	Tried Y/N	Rating -5/+5	Use in Future
Stress Reduction			
Relaxation (e.g. meditation, prayer, imagery)			
Mental adjustments			
Changing expectations			
Changing “self-talk”			
Supportive relationships			
Problem solving			
Information			
Pleasurable activity (e.g. reading, music,			
Exercise and movement			
Journaling			
Talking and being listened to			
Laughter and humor			
Solitude			
Assertiveness			
Medications			
Stress Avoidance			
Avoiding certain foods and/or chemicals			
Avoiding noise & crowds			
Limiting exposure to media			
Avoiding some people			
Pacing: less activity, short activity periods			
switching activities, taking rests			
minding time of day, delegating			
Routine			
Reducing clutter			