

**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 will help you focus 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.

Learning to live with a long-term illness is a journey of many steps. A person in an earlier group called successful adaptation the 1% Solution. Rather than hoping for a silver-bullet cure, this woman focuses on a series of small changes, each of which produces a small but measurable improvement.

This workbook contains many ideas for reducing pain and discomfort, bringing greater stability, and improving quality of life. By completing its worksheets, you will take a step toward developing a comprehensive self-management plan that fits your unique circumstances, your own 1% Solution.

Chapter 1: Understanding Your Situation

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. Patterns of symptoms vary, too. The bottom line: each person's illness is different. 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. 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 35 (average for people in our program), your activity level would be about three hours a day

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.

My Self-Rating _____

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, diabetes, 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)
- Lupus
- Lyme disease
- Migraine headaches
- Myofascial pain syndrome (MPS)
- Orthostatic problems such as neurally mediated hypotension (NMH) or postural orthostatic tachycardia syndrome (POTS)
- 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	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Life Circumstances

Just as people with CFS and fibromyalgia differ in their symptoms, the severity of their illness and in the number of illnesses they have, so do they come from many different life

situations. Some 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. We suggest you think about your life situation in terms of your family situation (single or married, stage in life, finances), your responsibilities (who is dependent on you: often children, sometimes parents, spouse, grandchildren or others) and your sources of support (family, friends, church or other religious group, etc.).

My Life Circumstances

Family situation _____

Responsibilities _____

Support _____

Coping Skills & Attitude

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 through brief self-help classes such as this one. This program helps you build on the coping skills you already have.

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, see the Success Stories on our website (<http://www.cfidsselfhelp.org/library/topic/Success+Stories>).

Understanding CFS and FM

Another part of understanding your situation is understanding CFS and/or FM. For basic information about the two conditions, see “Basic Facts” on our website. For other resources, including patient organizations, websites, support groups and books, see the article “Educate Yourself” on our site, part of the series Eight Steps to a Better Life.

Chapter 2: Managing Your Symptoms

A central part of managing CFS and FM is managing symptoms. In this chapter, you identify your symptoms, read about a general approach to symptom management and review treatment options for fatigue, pain, poor sleep and cognitive problems (brain fog).

A) Identifying Your Symptoms

There are four major symptoms almost always present in CFS and FM: fatigue, pain, poor sleep and cognitive problems (“brain fog”). People usually experience additional symptoms as well. In the form below, note whether a symptom applies to you. If it does, rate it from 1 (mild) to 10 (severe). If you have additional symptoms, add them at the bottom of the form.

My Symptoms	Applies To Me	Rating: 1 to 10
Fatigue		
Pain		
Poor Sleep		
Cognitive Problems (“Fog”)		
Abdominal pain (bloating, diarrhea/constipation)		
Alcohol intolerance		
Allergies & rashes		
Anxiety		
Chills or night sweats		
Depression		
Dizziness		
Fever		
Headaches		
Jaw pain		
Loss of libido		
Lymph node tenderness		
Nausea		
Numbness/tingling in hands, arms, legs, feet, face		
Ringing in the ears		
Sensitivity to light, sound, smell or weather		
Sore throat		
Weight gain or loss		

B) Four Treatment Principles

Treating the symptoms of CFS and FM usually involves the following four principles:

1) Focus on Quality of Life

Because so far there is no cure for either CFS or fibromyalgia, the goal of treatment is not healing but rather controlling symptoms and improving quality of life. Treating symptoms can reduce pain and discomfort, bring greater stability, lessen suffering and may increase a person's functional level.

2) Use of Multiple Strategies

Because people with CFS and fibromyalgia have more than one symptom and because each symptom may have more than one cause, treatment plans usually involve multiple strategies. For example, treating pain often involves both the use of medications and lifestyle strategies such as exercise, pacing and relaxation. These lifestyle strategies have a multiplied effect, since each one also addresses fatigue and poor sleep.

3) Experimentation

There is no standard medical treatment for either illness, that is, no medication that is consistently effective. For this reason, symptom control is usually achieved by trial and error. Experimentation is also useful to find lifestyle adjustments that are effective. For example, you may have to try several exercise regimes to find one that helps you without intensifying your symptoms.

4) Central Place of Lifestyle Change

Your success in reducing symptoms and regaining control of your life will probably depend more upon your efforts and willingness to adapt to CFS/FM than on anything a doctor does for you. In the words of CFS/FM physician Dr. Charles Lapp, "Medical treatment does not treat the disease; it only palliates the symptoms." The key to recovery is "acceptance of the illness and adaptation to it by means of lifestyle changes, for which medical treatment is no substitute."

C) Treating Fatigue

Fatigue has many causes and can be addressed by using multiple strategies, each matched to a cause. The causes of fatigue, in addition to CFS/FM, include:

Overexertion	Being too active, living “outside energy envelope”
Pain	Produces muscle tension, which is tiring
Poor Sleep	Feel tired if sleep not restorative
Inactivity	Deconditioning from lowered activity level
Stress	Stress creates worry and muscle tension
Depression	Low spirits produce sense of listlessness
Poor Nutrition	Lack energy if don’t eat well
Medications	Side effects include fatigue

Here are ways to combat fatigue, matched to the causes above.

Pacing (For Overexertion)

Perhaps the single most important key to controlling fatigue, and other symptoms of CFS and FM, is to reduce your activity level to fit the limits imposed by illness. This is often called “living within the energy envelope” or pacing. Pacing includes many adaptations, such as priority setting, rest breaks, short activity periods, switching between high and low intensity tasks, living by a schedule, and managing special events. Pacing also includes mental adaptation: accepting that life has changed and one must lead a different kind of life. (See the next chapter for an in-depth discussion of pacing.)

Treating Pain and Sleep

Addressing pain and sleep using the strategies described in the next two sections produces the bonus of reducing fatigue at the same time.

Exercise (For Inactivity / Deconditioning)

Low-level aerobic activity produces a higher level of fitness, thus reducing the fatigue caused by inactivity. Exercise also helps combat pain, lessens stress and improves mood.

Stress Reduction & Addressing Emotions

You can combat the fatigue coming from stress by using relaxation and other stress management strategies, which are outlined in chapter 4. Like other self-management strategies, stress management techniques improve multiple symptoms, including pain and poor sleep. Emotions can be treated using a combination of self-management strategies, professional help and medications. For more, see chapter 5.

Improving Nutrition

People with CFS and fibromyalgia often have difficulty getting good nutrition. This problem can be addressed by improving the nutritional quality of food, by paying attention to portion size and timing of meals, and by dealing with food allergies and sensitivities.

Checking for Medication Side Effects

Many medications, including some anti-depressants and drugs prescribed for pain, create fatigue as a side effect. To combat this source of tiredness, ask your doctor about fatigue when reviewing medications. A change of medication or a lower dosage may help.

If fatigue is a problem for you, fill out the Managing Fatigue worksheet below. Check the treatments you have tried already and rate them from -5 (made me much worse), through 0 (no effect), to +5 (very helpful). Also, check those treatments you want to use in the future. There is space at the bottom for you to add other ideas to try.

Managing Fatigue	Tried Y/N	Rating -5/+5	Use in Future
Reduce activity level			
Take rest breaks			
Use short activity periods			
Switch between high and low intensity tasks			
Make daily and/or weekly plans			
Keep a health log			
Accept the illness			
Treat pain			
Improve sleep			
Exercise			
Use relaxation & other stress reduction strategies			
Address emotions			
Improve nutrition			
Check for medication side effects			

D) Treating Pain

Pain is usually the central symptom in fibromyalgia and is often a problem for CFS patients as well. Because pain in CFS and FM can have a variety of causes, it is usually managed with a variety of strategies. If pain is a problem for you, you can create a pain management plan from the following options.

Medications

People with FM and CFS who seek pain relief through medications usually begin with over-the-counter pain relievers, such as Tylenol, aspirin or ibuprofen. Some use prescription medications such as Ultram (Tramadol) or, in some cases, narcotics. Prescription drugs that improve sleep can have a beneficial effect on pain as well. Anti-depressants, such as Elavil (Amitriptyline), Prozac and Paxil are often tried. The FDA has approved three drugs for the treatment of FM: Lyrica (pregabalin), Cymbalta (duloxetine hydrochloride) and Savella (milnacipran HCl).

It is impossible to predict which treatment will be successful, so experimentation is usually required to find medications that are helpful. Usually, patients are started on dosages that are a small fraction of normal dosage levels. Sometimes a pain-reliever loses its effectiveness as the body becomes accustomed to it. In that case, a change to different medication may help.

Exercise, Posture & Movement

Exercise is one of the most-commonly prescribed treatments for FM and can be helpful for CFS as well. An exercise program done regularly can help reduce stiffness, counteract deconditioning and improve one's outlook. A program of gentle stretching can be helpful for both FM and CFS. In addition, people with FM can usually reduce stiffness by taking frequent breaks for stretching. Dr. Lapp stresses that it is important to start at a very low level, perhaps with just stretching. If that is tolerated, then range of motion exercises might be added gradually, then light weights, then perhaps a few minutes of aerobic exercise.

Pacing

Pacing, which can include some or all of the following strategies, is an effective antidote to overactivity. For much more on pacing, see chapter 3.

- Reducing overall activity level
- Setting priorities and delegating
- Taking scheduled rests
- Having short activity periods
- Switching between high and low intensity tasks
- Using best hours of day for most demanding activities
- Knowing mental and social limits
- Keeping records to see links between activity and symptoms

Relaxation

Being in pain often triggers muscle tension and anxiety, both of which can intensify the experience of pain. Muscle tension is directly painful, while anxiety contributes to the experience of pain indirectly by increasing stress and a sense of helplessness. Relaxation is an antidote to both tension and stress. Also, it offers a distraction from pain. Relaxing activities may include exercise, mindful breathing, baths and hot tubs, massage, rest and listening to tapes. You might also consider practicing a formal relaxation or meditation procedure on a regular basis. For more on stress management, see chapter 4.

Treating Worry, Frustration & Depression

The experience of pain is intensified by emotions like worry, frustration and depression. Worry and frustration create muscle tension, which makes pain more intense. Relaxation procedures can reduce pain both directly by easing muscle tension and indirectly through reducing stress. People who are depressed have a lower threshold for pain. Self-help strategies, sometimes in combination with medications, can help manage it.

Treating Fatigue & Poor Sleep

Pain, fatigue and poor sleep are tightly connected. Fatigue deepens the experience of pain. When we feel tired, we experience pain more intensely, thus reducing fatigue lessens pain. Similarly, poor sleep intensifies pain, so improving sleep can help control pain. Of the three symptoms, poor sleep is often the one addressed first.

Heat, Cold & Massage

Heat, cold and massage can be used for temporary relief of pain. Heat is best utilized for reducing the pain that results from muscle tension and inactivity. For localized pain, you might use a heating pad or hot packs. For overall relief, people often use warm baths, soaks in a hot tub or lying on an electric mattress pad. Cold treatments decrease inflammation by reducing blood flow to an area. They also may numb the areas that are sending pain signals. You might use gel packs, ice packs or bags of frozen vegetables. With both heat and cold, you should not use the treatment for more than 15 or 20 minutes at a time. Massage of painful areas can also provide temporary relief from pain. Like heat, massage increases blood flow and can also relieve spasms.

Pleasurable Thoughts and Activities (Distraction)

Experiencing ongoing pain can lead to becoming preoccupied with pain. Immersing yourself in pleasant thoughts and activities can lessen pain symptoms by providing distraction. Imagery can be especially helpful, such as visualizing a pleasant scene. Engaging in activities that bring pleasure can also provide distraction from pain. Examples include reading a book, watching a movie, listening to or playing music and spending time with people or in nature.

Healthy Self-Talk

Our internal thoughts about ourselves can have a dramatic effect on our moods, which, in turn, affect our perceptions of pain. This can be a vicious cycle. An increase in symptoms may trigger negative thoughts like “I’m not getting anywhere,” “I’ll never get better,” or “It’s hopeless.” Such thoughts can then make us feel anxious, sad, angry and helpless,

intensifying pain and triggering another round of negative thoughts and more muscle tension. You can break this cycle by changing your “self-talk.” See the article on our website titled “Taming Stressful Thoughts.”

Managing Pain	Tried Y/N	Rating -5/+5	Use in Future
Use pain medications			
Exercise			
Use good posture & body mechanics			
Reduce activity level			
Take rest breaks			
Use short activity periods			
Switch between high and low intensity tasks			
Make daily and/or weekly plans			
Keep a health log			
Use relaxation & other stress reduction strategies			
Treat worry, frustration & depression			
Reduce fatigue			
Improve sleep			
Use heat, cold & massage			
Use pleasurable thoughts & activities (distraction)			
Practice healthy self-talk			

My pain medications:
(Name / Dosage)

E) Treating Poor Sleep

Poor sleep is an almost universal problem with CFS and FM. Sleep problems include difficulty getting to sleep, waking in the middle of the night or early in the morning, and over sleeping. In addition to sleep problems due to CFS and FM, a majority of people with the two conditions experience sleep disorders such as sleep apnea and restless legs syndrome.

Addressing sleep problems can be good initial focus for symptom management because treating sleep can both improve quality of life and reduce other symptoms. If you are troubled by poor sleep, consider creating a sleep management plan using a combination of strategies selected from the three approaches described below: improved sleep hygiene, use of medications and treatment of sleep disorders.

Sleep Hygiene: Sleep Environment and Habits

Sleep can be disturbed by such things as irregular hours, a noisy environment, tension and worry, an uncomfortable bed or a noisy sleeping partner. A starting point for better sleep is to address these and other aspects of your sleep hygiene.

- *Have a Comfortable Environment:* Provide yourself with an environment conducive to good sleep by using a good mattress, and by exercising control over light, noise and temperature. (Note: Noise includes snoring by your sleep partner.)
- *Establish a Routine:* Go through the same routine each night and have a consistent bedtime. Prepare for sleep by gradually reducing your activity level in the several hours before bedtime and by having “going-to-bed” rituals you do consistently at the same time each night. It often helps to limit computer and TV usage in the last hour or so before bedtime.
- *Use Relaxation and Distraction:* It may be easier to fall asleep if you listen to soothing music or distract yourself in some other way, such as by counting or watching your breath. (For instructions on relaxation procedures, see chapter 13 in the introductory course textbook.)
- *Control Stress and Worry:* Stress often leads to muscle tension, which makes falling asleep more difficult. Practicing relaxation methods can help you ease tense muscles. Try relaxation procedures or soak in a hot tub or bath before going to bed. If being preoccupied with problems makes it difficult to fall asleep, consider setting aside a “worry time” each night before going to bed. Write your worries and what you’ll do about them. If worries come up as you are trying to go to sleep, tell yourself “I’ve dealt with that. I don’t have to worry because I know what I’m going to do.”
- *Get Up at the Same Time:* Setting an alarm so that you get up at the same time each day can help you adjust gradually back to more normal hours.

- *Use Pacing:* Being too active during the day or early evening can create a sense of restlessness called “tired but wired.” Keeping activity within limits and having a winding down period before going to bed are antidotes.
- *Limit Daytime Napping:* If you nap during the day and find that you have trouble falling asleep at night, or your sleep is worse than usual when you nap, consider sleeping only at night. Use your bed only for sleeping and intimacy.
- *Avoid Caffeine, Alcohol & Tobacco:* Consuming too much caffeine, drinking alcohol and smoking can make getting good rest more difficult. Avoid products containing caffeine, like coffee, tea, soft drinks and chocolate, for several hours before going to bed. Avoid alcohol before bedtime; it can create restless and uneven sleep. The nicotine in tobacco is a stimulant, thus smoking is a barrier to falling asleep.

Medications

Treating sleep with drugs is challenging because there is no single medication that has proven helpful in solving sleep problems for people with CFS and fibromyalgia. Also, many patients develop drug tolerance, so that a medication becomes less effective over time. For both these reasons, sleep problems can benefit from a flexible, experimental approach that utilizes a variety of strategies.

If you think medications might improve your sleep, you might start with non-prescription substances. These include over the counter products like melatonin and valerian, antihistamines such as Benadryl and Tylenol PM. If you prefer prescription medications, a reasonable approach is to find a physician willing to work with you to find what helps in your unique situation. Often a combination of two drugs is prescribed, one to initiate sleep and another to maintain sleep. Medications commonly prescribed to treat sleep problems include zaleplon (Sonata) and eszopiclone (Lunesta) to help you fall asleep and drugs such as cyclobenzaprine (Flexeril), tizanidine (Zanaflex), doxepin elixir, amitriptyline (Elavil) or trazadone (Desyrel) to help you stay asleep.

While medications can improve sleep, they can also make it worse. Some sleep medications that are effective when used occasionally can produce poor sleep if used frequently. Also, some drugs produce side effects, like a feeling of grogginess in the morning. Medications taken for other problems may interfere with sleep if they contain substances like antihistamines or caffeine.

Sleep Disorders

A majority of people with CFS and FM have one or more sleep disorders. Treating them can have a dramatic effect on symptoms. If improving sleep hygiene and using medications don't produce an improvement in your sleep, consider asking your doctor for a referral to a sleep specialist, who can examine you for sleep disorders. Two of the most common disorders are sleep apnea and restless legs syndrome.

Managing Sleep	Tried Y/N	Rating -5/+5	Use in Future
Sleep Hygiene			
Control sleep environment: mattress, light, noise			
Use a going to bed routine			
Use relaxation			
Use distraction			
Use a “worry time”			
Get up at consistent time			
Use pacing to avoid “tired but wired” feeling			
Limit daytime napping			
Avoid caffeine, alcohol & tobacco			
Medications			
Try drugs to aid sleep			
Check other meds for side effects on sleep			
Sleep Disorders			
Treat apnea & restless legs syndrome			

My sleep medications:
(Name / Dosage)

F) Treating Cognitive Problems

Cognitive problems, such as being forgetful, feeling confused and having difficulty concentrating, are common in CFS and FM. They have a variety of causes, including:

Overexertion	Being too active, living “outside energy envelope”
Fatigue	Tiredness makes it hard to be mentally alert
Overstimulation	Too much sensory information
Multi-tasking	Doing more than one task at the same time
Stress	Stress increases CFS/FM symptoms generally
Poor Sleep	Side effect is foginess
Medications	Side effects include grogginess and confusion

Like the other symptoms discussed in this chapter, brain fog is best addressed by using a combination of strategies and by developing new habits. Your efforts to control fatigue and poor sleep, and your success at pacing will help you control fog. Here are 13 additional strategies for addressing cognitive problems.

Switch to Easier Task (Take a Break)

Cognitive difficulties can be caused by overactivity. If you’re not thinking clearly, take a break. A brief rest may be enough to end the fog.

Avoid Over-Stimulation

If you are sensitive to noise, to light or to sensory input coming from more than one source at the same time, limit sensory input by avoiding situations of over-stimulation.

Do One Thing at a Time (No Multi-tasking)

Many people with CFS and FM experience fog when they try to do more than one thing at a time, such as reading while watching TV or talking while fixing dinner. The solution: instead of multi-tasking, do only one thing at a time. Teach family members to wait by saying things like “I’m working on X right now, but I’ll help you as soon as I’m done.”

Control Stress

Stress can trigger or intensify brain fog. You can reduce fog by avoiding stressful situations and by learning how to relax in response to stress. Reduce the effects of a stressful situation by resting ahead of time or limiting how long you participate.

Do a Medication Check

Some drugs create confusion as a side effect. If you have this problem, talk to your doctor about adjusting dosage levels or changing to other drugs. Also, consider medications to increase attention and concentration.

Use Lists and Other Reminders

Write out tasks for the day on a To Do list. If you don’t complete the list, congratulate yourself for what you have done and move other tasks to the next day’s list. Use Post-It

notes in prominent places to jog your memory. Write a note to yourself about what to do if brain fog hits, e.g. I will take a rest break or I will switch activities.

Organize and De-Clutter

If you find your physical environment overwhelming, organize your house and remove clutter. (For a success story, see the article “Illness and Housekeeping.”)

Use Routine

Reduce fog by living a predictable life with routines. For example, always put your keys in your purse when you arrive home. If your fog is thickest in the morning, put out your clothes the night before.

Pick Your Best Time of Day

Use the hours when you’re sharpest to do jobs that require concentration and mental clarity.

Postpone, Switch Tasks or Cancel Activities.

If you're not thinking clearly, postpone jobs that are mentally challenging, switch to a simpler task or opt out.

Do Something Physical

Physical activities like exercise, laughing, singing or deep breathing can increase energy and clear your mind. Also, eating counteracts mental fuzziness.

Reframe

Brain fog can be frightening and embarrassing. Many students have told us that they have learned to speak reassuringly or lightheartedly to themselves and to others at times when they lack mental clarity.

Plan Your Response

Deal with the fact that brain fog is confusing by planning your response ahead of time. Develop rules to guide you when you're feeling lost, so you have standard, habitual responses you can fall back on.

Managing Cognitive Problems	Tried Y/N	Rating -5/+5	Use in Future
Reduce fatigue			
Improve sleep			
Practice pacing			
Switch to easier task (take a break)			
Avoid over-stimulation			
Do one thing at a time			
Control stress			

Check medications			
Use lists and other reminders			
Organize and de-clutter			
Use routine			
Pick your best time of day			
Postpone, switch or cancel activities			
Do something physical			
Reframe			
Plan your response			

Chapter 3: Managing Activity Through Pacing

Many people with CFS and FM find themselves caught in repeating cycles of push and crash, swinging between overactivity, which intensifies symptoms, and forced rest. Pacing offers an alternative, a way to live a more stable and predictable life by knowing and honoring your limits. 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.

This chapter walks you through the nuts and bolts of pacing, beginning with how to define your limits and continuing on through how to adapt your life so you can live in harmony with your body's needs.

For examples of how people use pacing in their lives, see the stories in two sections of our online Library (www.cfidsselfhelp.org/library): Energy Envelope and Pacing, and Success Stories. Here are five places to start:

- 25 Reasons Why I've Improved
- Acceptance, Discipline and Hope: A Story of Recovery from CFIDS
- How I Use Pacing to Manage CFS
- Living Within My Envelope: A How-To Story
- Third Time's a Charm: How I Learned to Pace Myself

A) Finding Your Limits

Pacing involves discovering and adjusting to the limits imposed by CFS and FM. You started the process of finding limits by placing yourself on the Rating Scale in chapter 1. Your rating gave you an idea of how many hours a day you can be active without intensifying your symptoms.

In this section, you will gain a deeper understanding by defining your limits in different parts of your life. First, you will examine different types of physical activity. By zeroing in on each type of activity and asking yourself a few questions, you can begin to build a detailed profile of your activity limits. You will learn that just as activities come in many forms—from bathing to walking to house cleaning— so, too, does your tolerance for each. Then, you will learn how to discover your limits for mental and social activity, and also for sleep and rest. Finally, you will assess the effects that stress has on you. The purpose of the exercises in this section is to help you understand in detail where your energy goes.

Developing a detailed description of your limits is a gradual process that may take months, a year or even longer. But every discovery you make can be useful; any insight you have can help you feel better. It's fine to begin by estimating. Over time, you can replace estimates with more accurate figures. Keeping a health log is very useful for that purpose. (See chapter 7 in the introductory course textbook for ideas on record keeping and sample logs.)

Activity Limits

Begin to define your limits by looking at how much activity you can do without making yourself more symptomatic. Assess yourself for each of three types of activity: physical, mental and social.

Physical activity

Physical activity is any activity involving physical exertion. It includes things like personal care (e.g. bathing and dressing), housework, shopping, standing, driving and exercise. To define your limits in this area, estimate how many hours a day in total you can spend in physical activity without intensifying your symptoms. Because the effects of exertion can be cumulative, also ask yourself how many hours a day you could sustain over a week without worsening symptoms. Note what are your best hours of the day. Then, estimate how long you can do various specific activities such as housework, personal care, shopping, standing up, driving and exercise.

Over time, you can replace your estimates with firm limits by focusing on one activity at a time, keeping a simple record of time spent and symptoms. For example, you may believe you can stand in the kitchen for 10 minutes while fixing meals. To test this idea, note your starting and ending time while preparing food, and how you feel during and after. (Often the effects of activity are delayed.) You can also think about ways to adjust your activities. For example, you might sit down to prepare meals or to shower.

Physical Activity	
Hours per day (overall)	
Best time of day	
Personal care	
Housework	
Shopping	
Standing	
Driving	
Exercise	

Mental activity

Mental activity is activity that requires concentration, like reading or working on the computer. Four questions to ask in this area are: How many hours per day can I spend on mental activity without intensifying my symptoms? How long can I spend in a single session? Does the setting make a difference? (Reading in quiet environment vs. with TV in background.) And what is my best time of day for mental work? You may be more productive at mental tasks if you have two or more brief sessions a day rather than one long one or if you do mental tasks only during your good hours.

Mental Activity	
Total time per day	
Time per session	
Setting	
Best time of day	

Social activity

This is the time you spend interacting with other people, either in person or on the phone. Questions to ask about in-person meetings include: How much time can I spend with people without intensifying symptoms? Also, does the setting make a difference? Meeting in a public place or with a large group may be stressful, but meeting privately or with a small group may be OK. Is the amount of time dependent on the specific people involved and the situation? (You may tolerate only a short time with some people, but feel fine spending longer periods with others.) For phone calls, ask how much time is safe in a day and for each call. Also, does the particular person make a difference?

Social Activity	
In person time limit	
Limits on setting	
Limits on size of group	
People I find difficult	

Phone limit per day	
Phone limit per call	
Phone limit by person	

Sleep and Rest

This factor refers to the quantity and quality of both sleep at night and rest during the day. To understand your sleep limitations, ask: How many hours of sleep do I need? What is the best time for me to go to bed and to get up? How refreshing is my sleep? Ask yourself how much time you spend resting, how many rest periods you have and the effects of rest. Reminder: we define rest as lying down with eyes closed in a quiet environment. Integrating rest periods into your day is a good way to control symptoms.

Sleep and Rest	
Hours of sleep/night	
Bed & Rise time; Hrs slept	
Sleep quality	
Rests (number & length)	

Stress & Physical Sensitivities

CFS and FM add new stresses to life and make people more sensitive to stress. This last area asks you to rate your overall stress level from 1 (no stress) to 10 (high stress) and your vulnerability in three areas: money, relationships and physical sensitivities. Questions in the last area are: Do I have allergic reactions to food? Am I chemically sensitive? Am I sensitive 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? (If you're employed, you may want to add "Work" to the list.) For more on stress and how to reduce it, see Chapter 4.

Stress / Physical Sensitivity	Rating (1-10)
Overall stress level	
Money	
Relationships	
Sensitivities:	
Food	
Chemicals	
Noise & Light	
Weather	

B) Learning 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 years and involving the use of multiple strategies. Here are ten often used by people in our program.

1) Reduce Activity Level

The primary strategy for adjusting to 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 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. Finally, you may decide to *eliminate* some activities or relationships.

Problem solving is a useful tool for finding the appropriate activity level. This skill involves considering a variety of solutions and experimenting to find those that work. You can find a three-step process for problem solving in chapter 4 of the introductory course textbook.

2) Take Scheduled Rests

Taking planned rests can help you reduce your symptoms, gain stability 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 many people, this means one or two rests of 15 minutes to half an hour each. People with severe CFS or FM may benefit from taking many brief rests a day, for example a 10 to 15 minute rest every hour or two. In any case, you will gain maximum benefit if you are consistent, making rest a part of your daily routine regardless of how you feel.

The length of the rest period, the number of rests and the way rest is done vary from person to person. Many find it most effective if they rest by lying down with their eyes closed in a quiet place, but others listen to music and/or rest in an easy chair. To quiet the mind, some people do a relaxation procedure, listen to a CD or, sometimes, read a book.

We suggest that you start with lying down in a quiet place. If that doesn't work for you, experiment with other ways of resting. If you fall asleep while resting, it may be a sign that your body requires more rest. You can determine your body's need for rest by keeping a sleep log.

3) Set Limits for Individual Activities

Another strategy is to set limits on particular activities. This can mean that you stop doing some things entirely or that you reduce the amount of time you spend doing something so 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). You can find your limits by experimenting and then enforce your limits by using a timer. For some further examples of limit setting, see the article “25 Reasons Why I’ve Improved,” in the Success Stories section of our website.

4) Use 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. 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.

5) Practice 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.

6) Use 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.

7) Pay Attention to 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, 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. One person found 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 understanding.

8) Control 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.

9) Sit When Possible & Use Devices

If you tire 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). You may be able to get more done, avoid symptoms or both by using devices to help you. 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.

10) Keep Pleasure in Life

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. For all these reasons, enjoyable experiences make it easier to live within your limits.

A Note on Accepting Your Limits

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 our 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.

In the worksheet called “My Pacing Strategies,” check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

My Pacing Strategies	Tried Y/N	Rating -5/+5	Use in Future
Reduce activity level			
Delegate & simplify			
Take scheduled rest breaks (pre-emptive rest)			
Set limits for individual activities			
Use short activity periods			
Switch between light, moderate & heavy tasks			
Use rule of substitution (pigs at a trough)			
Pay attention to time of day			
Control sensory input			
Sit when possible			
Use devices			
Have pleasurable activities			
Accept your limits			
Use daily and/or weekly schedules			
Stay within mental limits			
Stay within social limits			
Reduce activity level for special events			

C) Creating Daily and Weekly Plans

In addition to the strategies described in the previous section, you can use planning to pace yourself, beginning with daily plans and then going on to weekly planning.

Daily Plans

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. Here's how one student described her planning.

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.

Rest should be integrated into your day as a regular part of your schedule. You will smooth out your life if you make rest consistent, setting aside certain times of day for rests of certain lengths of time. The idea is to rest by plan, rather than in response to symptoms.

When you plan your day and live your plan, your symptoms are likely to come under better control and you may be tempted to do more. This temptation is part of the push and crash cycle that you are trying to break. Remember that the goal is to have a consistent level of activity, rather than to push hard when feeling well, then crash when symptoms intensify.

You can find a form for setting up a daily schedule on page 84 of the introductory course textbook and online at <http://www.cfidsselfhelp.org/library/daily-schedule> .

Weekly Plans

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 determine the amount of activity you can sustain over a period of time without worsening symptoms. Consistency in activity level brings control. You can find your sustainable level of activity by trying different amounts of activity and noting the results. For more, see the Weekly Schedule section of chapter 7 in the introductory textbook.

Keeping written records is crucial. A health diary can reveal the connections between what you do and your symptoms. It also helps you hold yourself accountable for your actions, by showing you the effects of your decisions. And it can motivate you by showing you that staying inside your limits pays off in lower symptoms and a more stable life. (Logging is discussed in detail in chapter 7.)

You can find a form for setting up a weekly schedule on page 83 of the introductory course textbook and online at <http://www.cfidsselfhelp.org/library/weekly-schedule> .

D) Achieving Consistency

Pacing begins with the use of strategies like those described in the last two sections. You can maximize the benefits of pacing by using these strategies consistently, doing a similar amount of activity each day and also taking similar amounts of rest. The reward: to the extent you can live consistently according to your plans, rather than in response to symptoms, you will have a more predictable life, an increased sense of control and may be able to expand your activity level.

Here are nine strategies for increasing consistency.

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.”

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.

Stop & Choose

One way that people get pulled outside their limits is by giving in to the temptation of doing something that seems appealing at 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 based on 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!!”

Develop Personal Rules

Some people with CFS and FM have had success using very detailed and individualized rules to protect them from doing too much. Living by a set of personal rules means not having to think and also reduces the power of spontaneity to overwhelm good judgment. 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.

These may be general rules. For example, one person with a severe case of CFS has three rules for herself: 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.

In addition, some people develop rules for specific circumstances. For example, they might set a limit on how long they stay on the computer, how long they spend with people in social situations and how long they will stand before taking a rest. If you develop specific rules for yourself, 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?

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 chapter 7 in our introductory course textbook.

Heed Your Body’s Messages

You can gradually retrain yourself to respond differently 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.’”

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 on our website titled “Taming Stressful Thoughts” or “Changing Your Thinking” in chapter 13 of the introductory course text.

Value Yourself

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.”

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 on the next page, check and rate the strategies you have used in the past. Also, check those strategies you want to use in the future.

My Strategies for Consistency	Tried Y/N	Rating -5/+5	Use in Future
Make changes gradually			
Use routine			
Stop and choose			
Adjust expectations			
Use reminders of how pacing helpful			
Develop personal rules			
Keep records			
Listen to your body			
Forgive yourself			
Use assertiveness			
Value yourself			

E) Handling Special Events

Anything out of the ordinary --a vacation, a holiday celebration or even having people over for dinner-- creates a double challenge if you have CFS and/or FM. Non-routine events require more energy than you normally use. For that reason, they can pull you outside your energy envelope, intensifying your symptoms. At the same time, you may want to be more active than usual or feel pressured by others to be more active, a second potential cause for a relapse.

How can you balance your desire to enjoy a special event with your body's limits? Here are four strategies, plus an example from someone in an earlier group.

Take Extra Rest: Before, During and After

Perhaps the most widely-used strategy for making special events more successful is to get more rest than usual before, during and after the event. Store up energy by taking extra rest before the event; limit symptoms by taking extra rest during; and take whatever extra rest is needed afterwards. The amount of extra rest will vary; twice as much as usual would be typical.

Plan in Detail

Another strategy is to plan in great detail. If you are traveling, this may include planning your activities for each day of the trip, including alternate activities you can do if your energy level is not what you expect. Depending on the severity of your condition, you might also arrange for a wheelchair or motorized cart in airports. If you are going to a family event, it might mean finding out the schedule ahead of time and deciding how much activity you will have.

Discuss Your Plans with Others

After deciding on your level of participation, discuss your plans with the other people involved in the event, so they know what to expect from you. You might also alert them to the possibility that you may need to cancel out of some events if your symptoms are high. If you discuss your limits and the unpredictability of symptoms with others ahead of time, you can reduce the chances for surprise or disappointment and create a climate of flexibility.

Change Your Role

Another strategy for minimizing the cost of a special event is to change your role and level of involvement. For example, instead of doing all the cooking for a holiday celebration, ask family members to each bring a dish. Or you might go to an event, but stay two hours, rather than the whole day or take periodic rest breaks. Travel can be made more doable by being less active than you used to be and by spending extra time resting.

These adjustments to activity are based on accepting a lower activity level and appreciating what you can do. By changing your expectations, you can focus on what you *can* do, rather than resenting all you are not able to.

An Example

A bedbound person with CFS used these ideas to handle a ten-day visit from her daughter and seven year old granddaughter. The patient was motivated to try something different because past visits had led to significant relapses. 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 daughter, who accepted it. She spent time with her granddaughter every other day, but in a quiet way that did not overwhelm her. After her visitors left, she spent two days resting.

The result: no setback but rather a sense of triumph. Instead of a family visit leading to a months-long relapse, it was an experience of control through pacing. About her time with her granddaughter, she wrote, “I had never even come close to surviving a visit from my granddaughter since developing CFS/FMS. It absolutely thrilled me that we were able to make some special memories together without it being damaging for me.”

Special Event Worksheet

A planning tool that allows you to use many of the strategies mentioned above is the Special Event Worksheet. (To print a blank form, see the Logs and Forms page: http://www.cfidselfhelp.org/library/type/log_forms_worksheets .) This form helps you to decide how you will use your time during the event and also the actions you can take in the period leading up to the event and the time after the event.

In the section of your Plan called “My Special Event Strategies,” check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

My Special Events Strategies	Tried Y/N	Rating -5/+5	Use in Future
Extra rest: before, during and after			
Detailed planning			
Discuss plans with others			
Be flexible			
Delegate & simplify			
Reduce activity level			
Reduce expectations			
Focus on what can do			
Use Special Event Worksheet			

F) Minimizing Relapses

Times of intense symptoms, often called flares, setbacks or relapses, are a common and often demoralizing part of CFS and fibromyalgia. In addition to creating additional pain and discomfort, they can be deeply troubling, creating the worry that you will never gain control over your illness or have a chance at lasting improvement. But there are things you can do to reduce their frequency and severity.

1) Limiting the Severity of Relapses

There are many things you can do to limit relapses. Some are actions to take; others are mental adjustments to make the situation more understandable or bring consolation.

Learn to Identify and Respond to Warning Signs

You may be able to reduce the length of a setback, or even prevent it, by training yourself to spot relapse warning signs and to take quick action. Relapse warning signs include feeling especially weak, dizzy or tired; having more pain than usual; feeling more confused than usual; and feeling cranky. Depending on the severity of the warning signs, countermeasures include lying down, reducing your activity level, limiting sensory input and/or limit your time with other people.

Go to Bed ...and Stay There

The most common strategy for overcoming setbacks is to take extra rest, continuing until the flare subsides. As one student in our program said, “When relapses occur, for whatever reason, I tell myself just to go with what my body is telling me to do: rest!”

Postpone, Delegate or Eliminate Tasks

Reducing activity by postponing tasks, asking for help or deciding not to do something can help speed the end of a setback. One student said, “Asking for help if I cannot do it all or just letting go of the less important things that I am unable to do at the time helps me reduce stress and my setbacks.”

Use Positive Self-Talk

People in our program report being helped by saying consoling words to themselves. Because relapses can be deeply discouraging, it can help to say soothing words to yourself, such as “this flare will end, just like all the others.” Self-reassurance can help you relax and quiet the inner voices that insist you’ll never get better.

Stay Connected

Connecting with someone you trust via a phone call or email can be helpful because of the suggestions you receive, because of the reassurance you get or just from feeling connected to another person.

Prepare

Having things handy and in place can help reduce the anxiety of a crash and make it easier to weather. Several students have described how they plan for flare-ups. One keeps

a large supply of food in the house, including food that her husband and children can cook. Also, she has rearranged her bedroom to have things she needs close to her bed. “It gives me a lot of peace of mind knowing I’m ready when one hits,” she says.

Take Extra Rest, Even If Flare Seems Over

Long periods of rest can create frustration as you think about all the things you want to do, but can’t because of your symptoms. This frustration can lead to resuming a normal activity level before the body is ready, leading, in turn, to another relapse. The final strategy for limiting the impact of relapses is to return gradually to a normal activity level. For many people, this means taking extra rest for two or three days after a relapse seems to be over.

Fill in the “Limiting Relapses” worksheet. Check and rate the strategies you have used in the past. Also, check those strategies you would like to try in the future.

Limiting Relapses	Tried Y/N	Rating -5/+5	Use in Future
Learn to spot warning signs			
Take quick action, e.g. lie down			
Go to bed until flare subsides			
Postpone, delegate and eliminate			
Use positive self-talk			
Call or email friends (stay connected)			
Prepare (e.g. food on hand)			
Take extra rest even if flare seems over			

2) Identifying Relapse Triggers

Some relapses are due to the waxing and waning of your illness, but other setbacks are caused by factors over which you have some control. These factors could be actions you take or events that you can learn to manage or avoid. You can begin to gain control over relapses by identifying relapse triggers, those things that predictably cause an intensification of your symptoms. (Keeping a health log can help you identify your triggers.) Items often mentioned in our groups include:

Overactivity

No surprise: living “outside the energy envelope” is a common cause of intensified symptoms via the cycle of push and crash. The antidote: pacing. Living consistently within limits reduces the frequency and severity of relapses.

Poor Sleep

Non-restorative sleep can intensify symptoms and precipitate a vicious cycle in which symptoms and poor sleep reinforce one another. The solution: address sleep problems using good sleep habits (sleep hygiene), medications or both.

Other Illnesses

Coming down with an acute illness or having multiple chronic illnesses can reduce energy and worsen symptoms. By treating other conditions and acknowledging that they intensify symptoms, you can reduce flares.

Stress

CFS and fibromyalgia are very stress-sensitive, so minimizing stress can prevent relapses. Stressors may include emotionally-charged events, such as financial problems, a disability review or a move, or can be long-term, such as family conflict. Also, we may intensify setbacks by our expectations for ourselves or by our reactions to stress. For ideas on reducing stress, see the next chapter.

Stressful Relationships (Particular People)

Some people with CFS and FM find interactions with particular people to be a source of disabling stress. Responses include talking with the person to redefine the relationship, limiting contact, getting professional help and ending the relation.

Travel and Other Special Events

Special events, like a vacation, a wedding, family visits or the holidays, can trigger a relapse. Events like these are often associated with expectations (both internal and from others) about our level of participation, leaving us feeling pressured toward a higher-than-usual activity level. For ideas on how to handle special events, see the next section.

Sensory Overload

If you are sensitive to light, noise or crowds, you may experience intensified symptoms in situations of sensory overload. One common solution is avoidance. For example, get together with one or a few people rather than a large group or visit stores and restaurants when there are not busy.

Fill in the worksheet below, rating triggers by how much they affect you, from 0 (not at all) to 10 (very much).

My Relapse Triggers	Rating 0 - 10
Overactivity	
Poor sleep	
Other illnesses	
Stress in general	
Stressful relationships (particular people)	

Travel and other special events	
Sensory overload (light, noise, crowds, etc.)	

3) Preventing Relapses

The last step in controlling flares is preventive: your personalized list of lifestyle habits you can use to avoid flares. Ideas often suggested in our groups include the following.

- Stay within my energy envelope
- Take daily pre-emptive rests
- Get to bed at the same time & get up at the same time
- Keep a health log
- Have realistic expectations
- Ask others for help
- Listen to my body's signals: stop rather than "pushing through"
- Stretch regularly
- Take pain and sleep medications faithfully
- Reduce activity when traveling
- Avoid noisy places (sensory overload)
- Have at least two pleasurable activities every day
- Practice relaxation and stress reduction every day

My Relapse Prevention Strategies	Tried Y/N	Rating -5/+5	Use in Future
Pace myself: stay within envelope			
Take daily pre-emptive rests			
Regular times to go to bed & get up			
Keep a health log			
Have realistic expectations			
Ask others for help			
Be assertive			
Heed body's signals rather than "pushing thru"			
Stretch regularly			
Take pain and sleep meds			
Reduce activity when traveling			
Avoid noisy places (sensory overload)			
Have pleasurable activities daily			
Do stress reduction practice daily			

Chapter 4: Controlling Stress

Stress is a double challenge to people with Chronic Fatigue Syndrome and fibromyalgia. First, illness adds new sources of stress, such as the ongoing discomfort of symptoms, uncertainty about the future and financial pressure. Second, CFS and FM are very stress-sensitive illnesses, so a given level of stress takes a greater toll than on healthy people. Thus, you face a double stress challenge: your stresses are multiplied at a time when you are more vulnerable to the effects of stress. This combination makes stress management a high priority.

Sources and Signs of Stress

Stress can come from many different sources. Check those that apply to you and rate them from 1 (minor source of stress) to 10 (major source of stress).

Sources of Stress in My Life	Applies to Me	Rating 1-10
Symptoms: ongoing discomfort is tiring and worrisome		
Limits: frustration from living within strict limits		
Loss: loss of control, income, friends and dreams for future		
Isolation: stress from spending time alone or feeling different		
Money: financial pressure		
Relationships: often strained; may lose some relationships		
Thoughts: unrealistic expectations or excessive pessimism		
Uncertainty: worry about the future		
Sound & light: sensitivity to sensory information		
Allergies to food & chemicals		

Any of the following can be signs of stress. Check those that apply to you.

Signs of Stress	Y/N
Muscle tension (especially in head, neck & shoulders)	
Grinding teeth or clenching jaw	
Feeling anxious or nervous	
Moodiness	
Nervous movement (e.g. tapping fingers or feet)	
Feeling depressed	
Irritability	
Sleep problems (trouble falling asleep or staying asleep)	

Approaches for Managing Stress

Because stress is so common and so debilitating, we recommend that people use multiple techniques to manage it. For many people in our program, pacing is an important stress management technique. Some other often-used 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 outdated expectations). The overall point: because there are so many causes of stress, most people use a variety of approaches to manage it. Our discussion of stress management is divided into two categories: stress avoidance and stress reduction.

Stress Avoidance

Stress avoidance is preventive, using self-observation to identify stressful situations and then taking measures to avoid them.

Avoiding Stress Triggers

Common stressors include substances that create allergic reactions, situations that produce sensory overload and some 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 those situations can help you control symptoms. Many patients are selective about their exposure to television and movies, avoiding material that is emotionally arousing or has rapid scene changes.

Some people with CFS and FM find interactions with people who are anxious, negative or demanding are the cause of disabling stress. Responses they have made include talking with the person, limiting contact, getting professional help, and ending the relationship.

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 and taking regular rests, and taking time for meditation or prayer all help control stress. Another way to reduce stress is through routine: doing things in familiar ways and living your life according to a schedule reduces stress by reducing decision making. 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.

Stress Reduction

In addition to avoiding stress, you can manage it by taking steps to reduce stress. Here are eight approaches to consider.

Relaxation

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.) Examples of relaxing activities include prayer and meditation, deep breathing, exercise, yoga, imagery, taking a bath and playing with a pet.

Mental Adjustments

Your thoughts can be a source of stress. For example, you may have unrealistic expectations for yourself. You may think that as a “good mother” or “good wife,” you should keep the house as you did before becoming ill. Adjusting your standards to fit your new limits reduces stress and helps you avoid overdoing. There is no need to strive for perfection.

Another way in which thoughts can increase stress is through “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 generate feelings of anxiety, sadness, anger and helplessness. You can learn how to recognize and change habitual negative thoughts to be more realistic and more positive. Replacing overly pessimistic thoughts reduces anxiety, sadness and feelings of helplessness. There are many self-help manuals for doing this or you can get professional help.

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. 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.

Information

Educating yourself about CFS and FM can be a great stress reducer. Two places to start: the Basic Facts link on our homepage or the article “Educate Yourself.”

Pleasurable Activities

Enjoyable activities lessen frustration while distracting you from your symptoms. Examples include reading, exercise, watching TV, journaling, listening to music, playing games, doing art projects, pursuing a hobby, and talking to a supportive person.

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.

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.

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 (Taking Control)

By speaking up for yourself, setting limits, and saying "No," you protect yourself and avoid doing things that intensify symptoms. By having a "voice," you reduce the stress that results from keeping things inside.

Medications

Prescription medications can be helpful as part of a stress management program.

Your Strategies

In the worksheet below, check the stress management strategies you have tried and rate their helpfulness from -5 to +5. Also, check those you would like to use in the future.

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

Chapter 5: Addressing Feelings

Feelings such as worry, frustration, sadness and grief are common and understandable responses to long-term illness. They are a reaction to the changes, limitations and uncertainty brought by illness. Because emotions are so common in long-term illness, managing them deserves a place in your self-management plan.

There are two additional reasons to include managing emotions in your plan. First, CFS and fibromyalgia tend to make emotional reactions stronger than they were before and harder to control. People often say they cry more frequently, get upset more easily or have more angry outbursts than before they were ill. The intensification of feelings applies to positive events as well as negative. Any experience that triggers the production of adrenaline intensifies emotions and often makes symptoms worse as well.

Second, emotions can intensify symptoms. For example, being in constant pain can trigger worries about the future. Worry leads to muscle tension, which, in turn, increases pain. You can interrupt this cycle in several ways, such as by using relaxation to reduce muscle tension and by changing your “self-talk” to reduce worry.

Self-help strategies may be useful for managing feelings. Professional help can play a role as well. Emotions such as depression and anxiety can be caused or intensified by changes in brain chemistry. In those cases, emotions may be treated using prescription anti-depressants or anti-anxiety medications. Also, counseling can be helpful.

Talking with a professional about the problems triggered by CFS or FM does not imply that “it’s all in your head.” Rather, counseling offers help dealing with a difficult situation. The help may include support, coping strategies, perspective on your situation. If you think talking with a counselor might be helpful, you might seek out one who specializes in treating people with long-term illness.

Depression

Depression is common in people with CFS and fibromyalgia. Some of the depression is situational, a reaction to the limits, disruption, losses and uncertainty brought by long-term illness. Self-management strategies are usually helpful in response to this type of depression. Depression may be biochemical, as well, created by changes in the functioning of the brain. Self-management strategies may be useful for this type of depression, but treatment normally includes medication, too.

Depression may be triggered by a sense of helplessness, by fear, frustration and anxiety, by loss, or by uncertainty about the future. Signs of depression include feelings of unhappiness or sadness, lack of interest in friends or activities, isolation, suicidal thoughts, and loss of self-esteem. Serious or long-term depression or thoughts of suicide call for immediate help from a doctor, therapist or suicide-prevention service.

Everyone has times when they feel unhappy or sad. We can recognize that these feelings are likely to occur from time to time and plan how to respond. Here are a dozen strategies.

Get help

If you are seriously depressed, suicidal or have been depressed for some time, get help now. Phone a suicide prevention center, talk to your doctor, see a psychologist or call a friend. If your situation is not urgent but depression reduces your ability to do your normal daily activities, you should consider professional help: counseling, medications or both. A therapist can provide an outside view of your situation, help you to accept your illness and support you in your efforts to improve. If you have family tension because of illness, couples or family counseling can be helpful.

Get active

Depression produces hopelessness, an attitude that becomes a self-fulfilling prophecy. Counteract those feelings by taking actions, such as those listed below, that have a good chance of helping. Being active changes mood; also, successes promote hope.

Establish good daily habits

Keeping to a daily routine regardless of how you feel can help counteract depression. Forcing yourself to do things, even if you don't want to, counteracts the inertia of depression.

Exercise

Exercise is a natural anti-depressant. For ideas on how to exercise safely with CFS/FM, see chapter 12 in the introductory course textbook.

Use problem solving

Taking action to solve a problem replaces helplessness with a sense of accomplishment.

Rest

Some depression is associated with physical symptoms, such as fatigue and pain. Resting to reduce these symptoms can also improve mood.

Change your thinking

If you have a tendency to think of the worst that might happen, you can retrain yourself to speak soothingly and realistically when you're worried or depressed. For example, remind yourself when you're feeling low that periods of bad feelings end. Change your mental climate by noticing what's going well and congratulating yourself on your accomplishments.

Do something pleasant

Pleasurable activities offer a distraction from symptoms and help create a good mood. The key is to find things that will absorb your attention. Such activities might include reading, listening to music, sitting in the sun, taking a walk, doing crafts, solving puzzles, watching a movie and spending time with friends.

Stay connected

Supportive human contact is very soothing. Time with positive people counteracts isolation and preoccupation with problems. Contact can be as easy as a phone call or an exchange of emails.

Consider medications

If your depression is biochemical in origin, you may be helped by an anti-depressant medication. On the other hand, tranquilizers and narcotic painkillers intensify depression, so if you are depressed, it may be due partially to a medication side effect.

Help others

Get involved with something larger than yourself to counteract the isolation and preoccupation that often accompany illness and to rebuild self-esteem. Helping others might involve a regular commitment, like doing volunteer work, something as simple as a phone call to a friend or trading favors (for example, baking for grocery shopping).

Manage stress

Controlling stress can help you manage your emotions, because stress tends to make emotions more intense. Living within your energy envelope and managing the stresses in your life will make emotions more manageable.

In the worksheet below, check the strategies you have used and rate their helpfulness from -5 to +5. Also, check those you would like to use in the future.

Managing Depression	Tried Y/N	Rating -5/+5	Use in Future
Counseling / therapy			
Anti-depressant medications			
Keeping active			
Keeping daily routines			
Exercise			
Problem solving			
Resting			
Change negative thinking			
Pleasurable activities			
Staying connected			
Check medication side effects			
Help others			
Manage stress			

Anxiety and Worry

Given the vulnerability we feel and uncertainty about the future, it's not surprising that anxiety and worry would be common reactions to CFS and FM. Here are eight strategies that are often helpful. Many of them also counteract depression.

Use Relaxation & Other Stress-Busting Tools

Controlling stress can help you manage your anxiety and other emotions, because stress tends to make emotions more intense. Learning relaxation and other stress reduction techniques helps reduce the intensity of your emotional reactions and, by doing so, reduces the echo effect in which emotions and symptoms amplify one another. A regular stress reduction practice can also lower background worry, the ongoing anxiety that results from long-term stress.

Use Problem Solving

Taking action to solve a problem counteracts helplessness and worry, replacing them with a sense of control and power.

Change Your Thinking

If you have a tendency to think of the worst that might happen, you can take steps to short-circuit the process in which your thoughts increase your anxiety. One antidote is to retrain yourself to speak soothingly when worried, saying things like "I've been here before and survived" or "this is probably not as bad as it seems." Also, you can do "reality checks" by testing your fears against facts and by asking for feedback from others.

Stay Connected

Simple human contact is often very soothing. Calling a friend or getting together to talk, share a meal or see a movie counteracts isolation, preoccupation with problems and the low mood often associated with chronic illness.

Exercise

Exercise is a natural anti-anxiety agent. It relieves tension, lessens stress and improves mood.

Pursue Pleasure

Pleasurable activities offer a distraction from symptoms, counter anxiety, and help create a good mood. Such activities might include reading, music, games or spending time with friends.

Don't Worry Alone

The act of sharing a worry almost always reduces its size and emotional weight. Discussion may help you find solutions and almost always makes the worry feel less threatening. Putting a worry into words translates it from the realm of imagination into something concrete and manageable. Seek out people who can offer support and reassurance.

Consider Professional Help and Medications

Counseling and therapy can make worries more manageable. Also, like depression, anxiety can have a physical basis in the biochemistry of the brain. If so, medication may help.

In the grid below, check the strategies you have used and rate their helpfulness. Also, check those you want to use in the future.

Managing Anxiety & Worry	Tried Y/N	Rating -5/+5	Use in Future
Use relaxation & other stress management tools			
Practice problem solving			
Change negative thinking			
Stay connected			
Exercise			
Pursue pleasure			
Don't worry alone			
Consider counseling / therapy			
Consider medications			

Frustration and Anger

Frustration and anger are two other understandable reaction to the uncertainty and loss of control brought by chronic illness. Further, irritability seems to be a symptom of CFS and fibromyalgia. Many people with CFS and FM see crankiness as a sign that they are outside their energy envelope.

Feeling angry is normal and can have positive effects if it motivates you to work to regain control of your life, but it can be destructive if it is expressed in a way that drives away people who want to help or on whom you depend. Self-management can make anger more manageable by reducing the sources of frustration. For example, pacing replaces helplessness with predictability and reduces the occurrence of irritability. Stress reduction practices can help you relax, reducing your susceptibility to frustration. Here are other strategies used by people in our program to address anger.

Get Professional Help

If your anger is making your relationships more stressful, you might consider getting professional help. Talking with a counselor can ease the pressures created by having a long-term illness. Consider one who specializes in helping people with chronic illness.

Talk It Out in Safe Environment

Expressing anger by talking it out with someone who is not the target of your frustration can release the feeling and provide insight.

Write

Putting experience in words can be helpful. Psychologist James Pennebaker has found that people have fewer health problems if they write about traumatic events in a way that combines factual description and emotional reactions. A related technique is to write a letter to the person you are mad at, and then tear it up instead of sending it.

See Things from a Fresh Perspective

The amount of anger you experience may be related to your thoughts, to how you see your situation. You can reduce anger by changing your self-talk. One person who did this reported, "I find that a lot of anger has disappeared and this is a most wonderful feeling. I have now reached the stage where most of this new thinking is automatic."

Plan Your Response

If you are irritated by comments like "I'm sure you would feel better if you would try this new remedy," you can prepare a response so that such comments don't bother you. In this case, you might say something like "Thanks for your suggestion, but I'm under my doctor's care and I'm following his treatment plan."

Acceptance

You may lesson anger by accepting that some people will not understand CFS/FM. Also, you may reduce anger by naming it: "I'm feeling angry now." The exercise produces a detachment from the feeling.

If anger is an issue for you, fill out the worksheet below.

Managing Frustration & Anger	Tried Y/N	Rating -5/+5	Use in Future
Pacing activity			
Pre-emptive rests			
Stress reduction practices			
Counseling			
Talking to a friend			
Writing (journaling)			
Change perspective			
Plan response			
Acknowledge feeling			

Guilt

Guilt is another frequent companion of people with CFS and FM. Sometimes its origin is a person's looking back and blaming themselves for becoming sick. Other times, its roots are in the sense of not contributing to the family or to society. If you experience guilt, what can you do to ease the burden it imposes? Here are seven strategies to consider.

Adjust Expectations

Guilt is often triggered by a difference between a person's expectations and their capabilities. You can reduce guilt by adjusting your expectations downward to match your new level of functioning. As one person said, "If I were caring for an injured loved one, in distress, how would I take care of her? I should treat myself the same way."

Reframe (Change Self-Talk)

Part of the process of adjustment is changing our internal dialogue or self-talk, so that it supports our efforts to live well with illness rather than generating guilt. One person says that when she takes a nap, instead of telling herself she is lazy, she says, "I am helping myself to be healthy. I am saving energy to spend time with my husband or to baby sit my grandchildren." Similarly, when feeling tired, you can say "This fatigue is not my fault; it came with CFS. So I don't need to feel guilty about not being able to do everything I used to." Or: "I didn't ask for FM, so why should I feel shame when it prevents me from doing things."

Shift Attention

Feeling guilty is inevitable, but we can control how we respond when feelings of guilt arise. One person said that she asks herself "Is this feeling productive?" In some cases, the answer will be "Yes." Guilt can draw our attention to ways in which we have failed to live up to our standards and can motivate us to act differently. (See next strategy.)

If the feeling is not productive, however, it may be better to respond to guilt by turning our attention elsewhere. As another person wrote, "It's better not to go some places in your head, so I've learned how to control my own thoughts."

Apologize and Make Amends

Guilt can be helpful if it motivates you to take better care of yourself in the future and to treat those around you with more care. One person said that if she does something to hurt her husband or her children, like lashing out at them verbally, she apologizes. Others say that they have used guilt over canceling out on commitments as an impetus to be more consistent in their pacing, making themselves more dependable.

Educate Others

In addition to adjusting your expectations for yourself, others expectations of you will have to change as well. This involves educating the people in your life, emphasizing that CFS and FM are long-term conditions that impose significant limits and require adjustments of the person who is ill and those around her.

Learn Assertiveness

Another strategy for reducing guilt is to be assertive, standing up for yourself by stating what you will and won't do.

Practice Relationship Triage

A final strategy is to reevaluate your relationships, practicing what we call *relationship triage*: making explicit decisions about whom to include in your life, concentrating on the more valuable or necessary relationships and letting others go.

If guilt is an issue for you, fill out the section below.

Managing Guilt	Tried Y/N	Rating -5/+5	Use in Future
Adjust expectations			
Change self-talk			
Shift attention			
Apologize and make amends			
Educate others			
Learn assertiveness			
Practice relationship triage			

A Note on Positive Emotions

Even positive emotions like joy can create problems, as suggested by one person in our program, who said: "I cried at one of the classes, because I was so happy to be around people who understood me. Almost immediately, I had an attack of brain fog." It seems that any experience that triggers adrenaline, whether positive or negative, intensifies symptoms.

Chapter 6: Recasting Relationships

Serious illness creates stresses for most relationships. Relations with family, friends, coworkers and bosses, and even doctors are altered in ways that create new challenges for both people with CFS or FM and for those around them. This chapter describes eight general strategies for improving relationships. Our website contains additional material directed toward families and couples. (See Family & Friends section of the Library.)

Assess & Triage

If you have CFS or FM, it is likely that many relationships will be redefined and some will end. One response is to make this transition a conscious and deliberate process by using *relationship triage*.

You might think of your relationships as a series of concentric rings. In this scheme, the inner ring contains the most important people in your life, typically family and closest friends. People on the outer ring are casual acquaintances. In between there may be one or two other rings of people with varying levels of importance. You may develop different approaches to people in various rings, concentrating on those in the inner ring.

The general idea is to concentrate on the more valuable or necessary relationships. In the words of Dr. David Spiegel of Stanford: “Save your energy and use the illness as an excuse to disengage from unwanted social obligations. Simplify the relationships that are necessary but unrewarding, and eliminate the ones that are unnecessary *and* unrewarding.”

Adapt How You Socialize

You may be able to preserve a good number of relationships by adapting how you socialize. For example, if you have severe limits and cannot often get out of the house, you may be able to stay in touch with people using phone calls and emails, plus having them make occasional visits.

Another adaptation is to limit the length of socializing, for example by limiting how long you talk on the phone or the amount of time you spend face-to-face with others. A third adaptation is to alter the settings in which you socialize. You may be able to tolerate time in a restaurant if you go either before or after the busiest hours.

Other adjustments include limiting the number of people you socialize with and taking rest breaks. One woman with a large family told her married adult children that she would not host more than one couple at a time.

Do Your Part

One step toward easing strains in your relationships is to acknowledge that your illness creates problems for others. Your symptoms and moods, for example, may make you unpredictable, and your limits may force others to take on additional responsibilities. Express your appreciation for their efforts. Acknowledge that the illness can make you unreliable. Out of respect for other people, warn them that you might have to cancel on short notice. To help maintain the relationship, tell them that you value them and that canceling a get together does not mean you don't like them.

Take responsibility for the problems your illness creates for others. For example, if your illness makes you moody, make a list of things you can do to help yourself feel better so that you avoid inflicting your moods on others. When you are feeling irritable, you might listen to music, take a walk or have a brief rest.

Change Expectations and Use Assertiveness

Because of guilt or pressure from others, you may do more than your body can tolerate. A solution is the combination of changing your expectations and being more assertive. Changing expectations is a gradual process by which we come to accept that we have limits and need to adapt to a "new normal." For more, see the discussion on coming to terms with loss in the next chapter.

Learning assertiveness can also be a gradual process, as you educate others about your limits. Here are four ideas to consider. First, be very specific in the requests you make or limits you set. Second, show that you understand the other person's situation. You might say something like, "I know my illness makes your life more difficult and that some things I say and do may be frustrating."

Third, preface your request with a statement of appreciation, such as "I appreciate all you do for me." Fourth, if you find it difficult to be assertive, practice saying your request to yourself or someone you trust before making it to the person whose help you want.

Educate Others (Selectively)

Perhaps the most common relationship frustration among people with CFS and FM is not feeling understood and not being believed when we say we are ill. People in our program report that attempts to educate others often require patience and are not always successful.

A woman in our program was successful in educating her family using a creative approach. She gave a pamphlet about CFS to her husband and adult children, asking that they read it as their birthday present to her. Over a period of time, her family members came to accept her CFS. (The pamphlet was "For Those Who Care" and is available from the CFIDS Association of America: www.cfids.org. The Arthritis Foundation has a

similar brochure for fibromyalgia. We have materials in the Family and Friends section of our website.)

Most people with CFS and FM eventually put limits on their efforts to educate others, focusing on the relationships that are most important and recognizing that some people may never understand or be sympathetic.

Build New Sources of Support

Creating new relationships can be a powerful antidote to frustration in relationships and can also counteract some of the losses and the isolation brought by illness. One good place to meet new friends is through support groups. Similar experiences are available now on the Internet, at online chat rooms and message boards.

In thinking about how to meet your practical and emotional needs, consider putting together a group of people who can help. Some may offer practical help, such as grocery shopping, housecleaning or driving. Others may be companions for outings, such as a visit to a restaurant or a night at the movies. Still others may offer emotional support by listening and offering reassurance. In any case, it's wise to have several people to fill these various needs, so that one or two people don't feel overburdened and burn out.

Professional support helps some people with CFS and fibromyalgia. A sympathetic therapist can provide support and offer an outsider's view of your situation. If you're interested, you might look for one who specializes in working with people who have chronic illness. A local support group is often a good source of leads. Therapy can also be helpful for couples. It can offer a place in which the strains created by living with long-term illness can be addressed.

Accept Help and Help Others

Other people often feel helpless about our illness. By giving them something specific to do, you can do them a service while helping yourself. As one person in our program said, "People are often thrilled when I ask for help in clear, practical ways." A caution: asking to much of others in total or of one person in particular can risk caregiver burnout.

Helping others aids self-esteem and also gives others an incentive to stay in the relationship. As someone in our groups said, "I ask myself what I am doing to make a relationship valuable to the other person."

Embrace Solitude

A final strategy for responding to limits and the loss of relationships is to embrace solitude. Serious illness often forces people to spend much more time alone than before. Solitude can provide an opportunity to develop new solitary interests. Some patients, recognizing that they will be spending less time with people, have seen the situation as a

chance to do things like reading and art work that they didn't have enough time for earlier in their lives. See, for example, JoWynn Johns' article "In Praise of Solitude."

Your Strategies

Check the strategies you have used and rate their helpfulness. Also, check those you want to use in the future.

Strategies for Relationships	Tried Y/N	Rating -5/+5	Use in Future
Reduce contact with some people			
Drop some relationships			
Change type of contact (in-person => phone)			
Set limits on time, setting or number of people			
Recognize problems created by illness			
Take responsibility for your share of problems			
Practice assertiveness			
Educate others about CFS/FM (within limits)			
Meet others with CFS/FM			
Get professional support (counseling)			
Accept help			
Help others			
Nurture self with solitude			

Chapter 7: Creating a New Life

CFS and fibromyalgia usually bring many serious losses. We often experience loss of control over our bodies, loss of friends and loss of valued activities. We may be forced to give up our job and thereby lose income, companionship, status and identity. And often we have to abandon dreams, thus losing the future we had envisioned for ourselves. In sum, we experience the loss of the person we used to be and the person we hoped to become. The pervasiveness of loss presents us with some of our biggest challenges: keeping hope alive and bringing new meaning to life in the face of loss.

The emotional reaction to loss is grief. While grief is usually associated with the death of a loved one, it can occur after any loss. Responses to loss are sometimes discussed in terms of the well-known stages of death described by Elizabeth Kubler-Ross in her book *On Death and Dying*. For most people, however, there is not a neat, orderly progression implied by the term stages. Rather, grief is a more individual process in which a person may experience some, but not necessarily all, of the emotions described by Kubler-Ross. Also, a person may experience some emotions more than once or may feel two or more at the same time.

Working through loss is often a several year process, normally ending in acceptance. Acceptance involves acknowledging that life has changed, perhaps permanently and certainly for an extended period of time. Acceptance includes letting go of your past life and also of the future as you had envisioned it.

Acceptance also includes a realization of the need to live differently than before and a willingness to build a new life. This attitude was summarized by recovered PWC (person with CFS) Dean Anderson, who said that acceptance was a key to his recovery. He described acceptance not as 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.” In his words, acceptance also means finding ways “to be productive and [to] find fulfillment under unfamiliar and difficult circumstances.”

Working Through Loss

Managing grief is a two-step process, first working through loss to acceptance and second moving beyond loss to create a new life.

Developing and implementing a self-management plan offers one way to work through grief. The use of pacing can increase control, thereby replacing uncertainty with predictability. Pacing strategies, such as taking regular rests, help to stabilize life with chronic illness, reducing the swings between high symptoms and times of remission. Resting ahead of an event can make it more likely you can attend, thus counteracting the sense of not being dependable. A health log can enable you to see patterns in your symptoms, showing you what makes your symptoms worse.

In addition to pacing, here are some other ways to move through grief.

Keep structure in your life

Having daily and weekly routines provides a sense of stability and familiarity. Routine also offers a distraction from loss.

Use problem solving

Respond to the emotions of chronic illness by problem solving. By adopting self-management strategies, you remedy the circumstances that triggered the emotions.

Avoid stress

Having to adjust to the many changes brought by illness is traumatic. In a situation in which you are already overloaded emotionally, it's best to avoid people and situations that add more stress, to the extent possible.

Seek support

Seek support from family, friends and beyond. Other people with CFS and FM can provide support and models of successful coping. Professional counseling can also help.

Respond to grief triggers

If your emotions intensify around the anniversary of your becoming ill or on other special dates, plan something positive for those times. If comparison with some people or situations make you feel anxious and uncomfortable, consider limiting your exposure to them.

Acknowledge loss

Some people report they found it useful to make a public declaration of loss. One person in our program, who wrote Christmas letter to friends to explain why they hadn't heard from him, found that writing the letter helped him accept his limits.

Recognize grief as a long-term process

You may experience grief more than once as you move through the stages of life, for example if you remain single while friends marry or you remain childless while others become parents or if you can't be the parent you had hoped to be or can't have the career you trained for.

Address self-pity

Self-pity often accompanies long-term illness. Counteract it by staying connected to others and by shifting your attention off yourself through helping others.

In the worksheet on the next page, check and rate the strategies you have used. Also, check ones you want to try in the future.

Working Through Loss	Tried Y/N	Rating -5/+5	Use in Future
Pacing			
Structure: daily & weekly routines			
Problem solving			
Stress avoidance			
Support			
Acknowledging grief triggers			
Acknowledging loss			
Recognizing grief as cyclic & long-term			
Addressing self-pity			

Creating a New Life

While some people with CFS and fibromyalgia recover, most experience long-term limitations. The losses brought by long-term illness create a challenge: who are you if you can't be your old self or live the life you had planned? Long-term illness forces us to reevaluate our lives and recast them in a new way. Here are some strategies used by people in our program to build a new life.

Focus on gains and improvement

One way to give positive meaning to life is to focus on gains that have occurred because of being ill. Some people in our program say they prefer the person they are today to the one before their illness, saying things like “the new me is a kinder, gentler and more caring person.” Others say that in some respects they have a better life today than before they were ill, with the ability to focus on what is important and more time for relationships.

Develop new interests

A powerful antidote to loss is to develop new interests and, from that, a new sense of purpose and meaning. Some people with CFS and FM have taken the opportunity to return to art, crafts or other hobbies that had languished when they were busy with career and family. Others see their illness as a challenge and find a sense of purpose in trying to understand their illness and to expand their area of control. Still others have found meaning in helping others. Whatever path they chose, these people found new ways to bring meaning to their life.

Adjust your goals to your abilities

Focus on those things you can do, rather than on those you can't, and congratulate yourself on your accomplishments. This is sometimes called adjusting expectations to a “new normal” and applies to all family members, not just the person who is ill.

Practice gratitude

Some people find it helpful to look at their illness through the lens of gratitude, seeing their illness as a gift. For more, see two articles on our website. One is a personal essay titled “The Healing Power of Gratitude”. The other summarizes research on the subject: “Counting Your Blessings: How Gratitude Improves Your Health.”

Nourish Yourself

Between what you feel you have to do and the suffering imposed by illness, it is easy to let positive things slip out of your life. Anticipation and enjoyment of positive experiences reduces stress, replacing it with pleasure and building a positive sense of self-esteem. Enjoyable experiences may include the physical pleasure that comes from exercise, laughing, taking a bath, listening to or playing music or from intimacy. Or it may be the enjoyment and satisfaction from keeping a garden, painting a picture or completing a crafts project. Or it may be the mental pleasure that comes from enjoying the beauty of nature or from reading a book or the spiritual satisfaction of meditation or prayer.

Find positive models

People in our program report that their adjustment was improved once they found other people with CFS and FM who had made positive adjustments to life with long-term illness. Such people provide inspiration and practical ideas for successful adaptation. Also, comparing yourself to other people with CFS and FM is more appropriate than comparisons with healthy people.

Promote Family Acceptance

Building a new life is difficult if family and friends have outdated and unrealistic expectations of your abilities. Educating them about your illness and limitations is one foundation for positive adaptation. As described in the “For Family and Friends” articles on our website, all members of the family have to accept a “new normal.”

Creating a New Life	Tried Y/N	Rating -5/+5	Use in Future
Reframe life to focus on gains			
Develop new interests & goals			
Adjust expectations to “new normal”			
Practice gratitude			
Nurture self (pleasurable experiences)			
Find models of successful adjustment			
Promote family acceptance			